

**Inflammatory Bowel Disease and Young People: The Lived
Experience and Review of Psychosocial Outcomes for
Cognitive Behavioural Interventions.**

Hannah Crook

Doctorate in Clinical Psychology

2019

Inflammatory Bowel Disease and Young People: The Lived Experience and Review of Psychosocial Outcomes for Cognitive Behavioural Interventions.

Hannah Crook

Thesis submitted in partial fulfilment of the degree of Doctor of Clinical
Psychology

Doctorate in Clinical Psychology
Faculty of Medicine and Health Sciences
University of East Anglia

Submission date: 5th March 2019

Thesis portfolio word count (excluding appendices): 26,030

This copy of the thesis has been supplied on condition that anyone who consults it is understood to recognise that its copyright rests with the author and that use of any information derived therefrom must be in accordance with current UK Copyright Law. In addition, any quotation or extract must include full attribution.

Thesis Portfolio Abstract

Purpose: The overall aim of this thesis portfolio is to add to a small, but increasing, body of research regarding young people with Inflammatory Bowel Disease (IBD). This focusses on establishing the psychosocial outcomes of cognitive behavioural based intervention for children and adolescents with IBD and investigating the lived experience of adolescents with IBD.

Design: This project is presented as a portfolio which includes a brief introduction, followed by a systematic review of psychosocial outcomes of cognitive behavioural based psychological intervention for children and adolescents with IBD. A bridging chapter outlines the connection of this review to the qualitative paper on the lived experience of adolescents with IBD, which is presented in chapter three. Extended methodology of this empirical paper is offered and the portfolio is concluded with an overall discussion and critical evaluation.

Results: A systematic review identified ten studies that reported on the psychosocial outcomes of cognitive behavioural based interventions for children and adolescents with IBD. This demonstrated a trend for improvements in depression, anxiety and general functioning for these young people. The empirical study used an Interpretative Phenomenological Analysis (IPA) to understand the lived experience of eight adolescents with IBD. This produced three superordinate themes: The Turning Point for Health, Resilience and Acceptance and Fragility of Health Position.

Conclusion: The findings from the systematic review demonstrate the importance, and helpfulness, of psychological interventions for children and young people with IBD and support the need to integrate physical and mental health care. Further

research is necessary to establish whether cognitive behavioural elements are necessary for effective intervention in addition to the therapeutic relationship. The findings from the empirical paper provide an insight into the lived experience for adolescents with IBD and identifies clinical implications, such as the importance of those in the young person's wider system having some understanding of IBD. Potential areas of future research are suggested.

Contents

Acknowledgments.....	7
Introduction to Thesis Portfolio.....	8
1. Systematic Review.....	10
1.1 Abstract.....	12
1.2 Introduction.....	13
1.3 Method.....	16
1.4 Results.....	20
1.5 Discussion.....	35
1.6 References.....	41
2. Bridging Chapter.....	51
2.1 References.....	55
3. Empirical Paper.....	58
3.1 Abstract.....	60
3.2 Introduction.....	61
3.3 Method.....	66
3.4 Results.....	71
3.5 Discussion.....	88
3.6 References.....	95
4. Extended Methodology.....	103
4.1 Interpretative Phenomenological Analysis.....	104
4.2 Reflexivity.....	108
4.3 Method: Data Analysis.....	109

4.4 Quality and Rigour.....	115
4.5 References.....	117
5. Discussion and Critical Evaluation.....	119
5.1 Summary of Research.....	120
5.2 Strengths and Limitations.....	122
5.3 Clinical Implications and Future Research.....	125
5.4 Personal Reflections.....	127
5.5 Overall Conclusion.....	128
5.6 References.....	129
Appendices	133

Acknowledgements

I would like to thank my research supervisor, Judith Young, for all her help, guidance and support in this project. Thank you for your patience in helping me navigate the world of research. Thanks to my secondary supervisor, Imogen Rushworth, for her valuable input and support with the correct use of apostrophes! I would like to thank the clinical team for all their specialist knowledge in the field of Inflammatory Bowel Disease and their efforts in recruiting participants. I feel privileged to have met with eight excellent adolescents, and supportive parents, who shared their stories with me. Thank you so much for taking the time. Thanks to all my family (Le Serves and Crooks!) for the support and providing plenty of opportunities to take my mind off studying. A big thank you to my husband for all his support and sacrifice in helping me get to this point. To my Mum for the constant availability to sound things out and a big thanks to Mum and Dad for being so helpful and excellent with looking after Harry! Finally, a special thanks goes to my little boy, who keeps everything in perspective and always provides the most welcomed distraction anyone could wish for.

Introduction to Thesis Portfolio

This thesis portfolio was completed as part of the researchers Doctorate in Clinical Psychology at the University of East Anglia. The work focuses on children and adolescents with Inflammatory Bowel Disease (IBD). IBD encompasses two conditions, Crohns Disease and Ulcerative Colitis. The disease has a remitting and relapsing course and common symptoms include abdominal pain, frequent diarrhoea, fatigue and delayed puberty (Greenley et al., 2010). Peak age for onset is between 15 and 35 years of age (Bishop, Lemberg & Day, 2014) and it is suggested that the prevalence of IBD in children and young people has increased in recent years. Adolescents with IBD is an under researched area, with much study being targeted at an adult population. This thesis portfolio aims to improve this by researching the lived experience of adolescents with IBD and reviewing the psychosocial outcomes of cognitive behavioural based psychological interventions for children and adolescents with IBD. The portfolio consists of five chapters with the main body of work being presented within the systematic review (chapter one) and the empirical paper (chapter three).

Chapter One: This chapter presents a systematic review using a narrative synthesis method. The aim of the review is to establish the psychosocial outcomes of cognitive behavioural based intervention for children and adolescents with IBD.

Chapter Two: A concise bridging chapter outlines the link between the systematic review and empirical paper. In line with recent government initiatives, and the

changing priorities of the National Health Service, this chapter focuses on the importance of the integration of physical and mental health care.

Chapter Three: The empirical study is presented. Due to a gap in the literature, the lived experience of adolescents with IBD was further explored through the use of semi-structured interviews. An Interpretative Phenomenological Analysis (IPA) was conducted to make sense of this data and nine subordinate themes were established under three overall superordinate themes.

Chapter Four: This chapter presents an extended methodology which explores the analysis from the empirical paper in more detail and considers the theoretical underpinnings of IPA.

Chapter Five: The discussion and critical evaluation chapter summaries the thesis portfolio content and discusses the findings in the wider context. Clinical implications are considered and personal reflection on the thesis process are offered.

Chapter 1.

**Systematic review paper prepared for submission to: Journal of Pediatric
Psychology**

Author Guidelines available in Appendix A.

The research reported is original work which was carried out under the supervision of Judith Young (Primary Supervisor) and Imogen Rushworth (Secondary Supervisor). I am the lead author of this paper which is prepared for journal submission.

Psychosocial outcomes of cognitive behavioural interventions for children and adolescents with Inflammatory Bowel Disease (IBD): A systematic review

Hannah Crook^a, BSc. (Hons)., PGCert., PGDip.

Judith Young^{ab} BSc.(Hons), MSc., PGDip., C.Psychol.,

Dr Imogen Rushworth^a BSc (Spec Hons), PhD, ClinPsyD

^a *Department of Clinical Psychology, University of East Anglia, United Kingdom*

^b *Psychological Medicine Service for Children, Young People and Families,
Addenbrookes Hospital, Cambridge, United Kingdom*

Correspondence should be addressed to Hannah Crook, Department of Clinical Psychology, Norwich Medical School, University of East Anglia, Norwich, NR4 7TJ.

E-mail: Hannah.crook@uea.ac.uk

Word count: 6514

Abstract

Objective: To conduct a systematic review that considers the psychosocial outcomes of cognitive behavioural informed interventions for children and adolescents with Inflammatory Bowel Disease (IBD).

Methods: A comprehensive search of electronic databases was conducted to identify studies that used psychosocial outcomes to assess the effectiveness of a cognitive behavioural approach with children and adolescents with IBD. Outcomes reporting on anxiety, depression and general functioning were extracted. A risk of bias assessment was conducted and the quality of the evidence was assessed.

Results: 9 studies were identified and a narrative synthesis framework was used to report the findings. The evidence suggests that children and adolescents with IBD experience a trend towards improvements in depression, anxiety and general functioning following cognitive behavioural informed psychological intervention.

Conclusions: This review supports the use of psychological intervention in improving anxiety, depression and general functioning in adolescents with IBD. Features of interventions that appear to produce more positive outcomes (such as programme length) are explored. Recommendations for clinical practice, and further research, are discussed.

Key words: Cognitive therapy; inflammatory bowel diseases; adolescent; child; systematic review.

Introduction

Inflammatory Bowel Disease (IBD), encompassing Crohn's Disease (CD) and Ulcerative Colitis (UC), is a remitting and relapsing disease that is characterised by abdominal pain, diarrhoea and fatigue (Greenley et al, 2010). Peak age for onset is in adolescence and young adulthood years (Bishop, Lemberg & Day, 2014) and it is suggested that adolescent patients with IBD are more likely to experience emotional and behavioural difficulties than healthy peers (Mackner, Sisson & Crandall, 2004; Greenley et al., 2010). This trend can also be found for young people with other long-term health conditions, such as diabetes and epilepsy (Lavigne & Gaier-Routman, 1992; LeBlanc, Goldsmith & Patel, 2003).

The role of psychological support in the context of having a long-term health condition is receiving increasing recognition. The No Health Without Mental Health (2011) cross government strategy highlights the importance of psychological support for individuals with long term health conditions. In addition, health-related quality of life for people with long term health conditions is part of the National Health Service (NHS) Outcome Framework Indicators (2018), and the importance of integrating physical and mental health is part of the NHS Five Year Forward View (2014). There is growing evidence that effective support for the psychological and mental health needs of people with long-term conditions can lead to improvements in both mental and physical health (Naylor et al., 2012). Psychological interventions in hospitals have been shown to reduce hospital stays by 2.5 days and reduce health costs per patient by 20% (Chiles et al., 1999). Specifically, cognitive behavioural therapy (CBT) based interventions have been shown to improve quality of life, coping skills and adjustment for adult, adolescent

and child patients with co-morbid mental health and long-term health conditions (Thompson et al., 2011 & Spurgeon et al., 2005).

Research into the effectiveness of psychological interventions, such as CBT, for young people with chronic health conditions is promising. Review studies have shown CBT, or CBT-based intervention, has a positive effect on symptoms of depression and anxiety in young people with a range of chronic health conditions, such as diabetes, epilepsy, asthma and chronic pain (Bennett, Shafran, Coughtrey, Walker & Heyman, 2015; Kibby, Tyc & Mulhern, 1998; Palermo, Wilson, Peters, Lewandowski & Somhegyi 2009). However, guidelines for evidence-based interventions for mental health difficulties in children and adolescents with chronic health problems are limited, and, given the higher rate of psychological difficulties in this population, this may mean that psychological needs are not being met. Limitations in the evidence base are illustrated in National Institute for Health and Care Excellence (NICE) guidelines for Crohn's Disease (2016), which highlights that multidisciplinary support should be offered to patients to help them deal with disease and treatment concerns, such as body image and living with a chronic health problem, but little direction is offered about how this would be done.

Research into the effectiveness of psychological interventions for patients with IBD has been the focus of a number of systematic reviews. Timmer et al. (2011) concluded that psychological therapy, including psychodynamic therapy, CBT, systemic therapy, brief therapy and supportive therapy, could not be

recommended due to inconclusive findings from the review, although it was acknowledged that an adolescent population may benefit from these interventions. Similar outcomes were observed in a review by McCombie, Mulder and Gearry (2013) who found that a skills based psychological intervention had a minimal effect on psychosocial outcomes. Tarricone et al. (2017) reported that one third of studies included in their review found psychological therapy, including mindfulness-based therapy, hypnotherapy, CBT, solution focussed therapy and other psychological interventions, to be effective in improving psychosocial outcomes. These review papers focus, primarily, on an adult population and, with the exception of Timmer et al. (2011), do not include a youth population.

Increased understanding of the psychosocial outcomes of psychological intervention for children and adolescents with IBD will be of value to clinical teams to ensure a patient's psychological needs are catered for as well as their physical needs. As mentioned, previous reviews have considered the effectiveness of psychological interventions for patients with IBD (Timmer et al., 2011; Tarricone et al., 2017; McCombie et al., 2013) but, to date, the evidence into a child and adolescent population has not been reviewed. Consequently, this systematic review will aim to establish the psychosocial outcomes of cognitive behavioural informed interventions for children and adolescents with IBD. Specifically, this review will answer the following question:

- What are the psychosocial outcomes of cognitive behavioural informed interventions for children and adolescents with Inflammatory Bowel Disease (IBD)?

Methods

Overview of methodological approach

To understand the psychosocial outcomes of cognitive behavioural informed interventions for children and adolescents with IBD, a systematic review was undertaken. The protocol for this review was listed on PROSPERO (the international prospective register of systematic reviews) in March 2018. Refinements were made to the protocol to focus on cognitive behavioural informed psychological interventions and a child and adolescent age range (under 19 years of age). These refinements allowed the review to reflect the age range seen within paediatric services within the NHS and mirror the World Health Organisation (WHO, 2018) definition of children. Furthermore, a focus on an evidence based psychological intervention, namely CBT, allowed for more clinically relevant conclusions. The Cochrane Handbook for Systematic Reviews of Interventions (2018) and Popay et al's. (2006) guidance on narrative synthesis were consulted and utilised to provide a systematic and transparent approach to the synthesis of the included studies. The PRISMA (Preferred Reporting Items for Systematic Reviews and Meta-Analyses) checklist can be found in Appendix B which pertains to the content of this review.

Criteria for inclusion and exclusion

Types of studies. All designs of study were included in this review due to the absence of a previous review and the limited amount of available research. Included studies were required to present empirical research which had been published in English in a peer review journal. Reviews, abstract only and

conference papers were excluded. Any papers that included duplicate data from another paper already included in the review were omitted.

Types of participants. No minimum number of participants within a study was specified to ensure wide reaching inclusion of relevant research. Participants were children or adolescents, under the age of 19, who had a diagnosis of Inflammatory Bowel Disease, either Crohn's Disease or Ulcerative Colitis. This wide-reaching age range is reflective of the age range presented in the included papers and mirrors the age of children seen within NHS paediatric services. In addition, a broad age range was necessary to ensure an appropriate number of papers were included in this review.

Types of intervention. Any psychological intervention that demonstrated cognitive and behavioural approaches was included. The intervention content may include cognitive restructuring, exposure techniques, behavioural activation, IBD specific psycho-education. Studies with interventions that did not demonstrate elements of cognitive behavioural principles, such as hypnotherapy, psychotherapy and psychoanalysis, were excluded from the review. Interventions could be individual, within a group or delivered to parent and young person dyads. These interventions could be delivered face to face or over the phone, to help increase access to the intervention.

Types of outcome measures. Papers were screened for psychosocial outcomes measures that assessed mental health and general functioning. These

outcome measures could be self, parent or clinician report. Pain outcomes were explored in some papers however, after much discussion, it was decided that the inclusion of pain outcomes did not align with the mental health focussed outcomes of the current review and the evaluation of pain outcomes could be a review study in its own right. Furthermore, as pain was not included in the search criteria, we could not be sure that papers that did report on pain outcomes were included in the final papers. Therefore, studies that reported on pain outcomes, or physical symptoms, only were excluded from the review and these outcomes were not extracted from the included papers.

Study Identification and Search Strategy

Searches of electronic databases, namely PsychArticles, Cinahl Complete, Psychinfo and Medline Complete, were created and run individually in May 2018. Databases had been chosen based on the search strategy identified by similar reviews (Timmer et al., 2011; Tarricone et al., 2017). Searches were conducted in all text and were filtered for peer reviewed journals in English. No time frame was specified due to no previous review into children and adolescents with IBD being conducted. Search terms were categorised into 3 topic areas 1) Cognitive Behavioural Psychological Intervention, 2) Inflammatory Bowel Disease and 3) Child or Adolescent. Medical Subject Headings (MeSH terms) were used for each topic area to ensure a wide-reaching search. Further details of search terms can be found in Appendix C. Any relevant reviews were scanned for additional articles that may be appropriate for the current review (the ancestry method), however, no additional articles were found during this process. Initial screening, based on

abstract and title, was conducted by the first author. A second screening of full text articles for inclusion was independently carried out by another author (JY). There was unanimous agreement between both authors on the final included articles.

Data Extraction

A data extraction form was developed which detailed the study characteristics. This included demographic information, details of intervention and recorded outcomes. Three domains of outcome were extracted to allow a focus on psychosocial outcomes of interventions. These were broadly identified as anxiety, depression and general functioning outcomes. Outcomes in included papers that reported on pain, perceived control and disease severity were not extracted for the purpose of this review.

Assessment of Risk of Bias in included studies

The Cochrane Collaboration Risk of Bias Tool was utilised to assess the risk of bias in the included studies (Higgins, Altman & Stern, 2011). This tool assesses six categories of bias: selection bias, performance bias, detection bias, attrition bias, reporting bias, and other bias. A slightly adapted version of the tool, as suggested by Lukens and Silverman (2014), was used to evaluate non-randomised studies that did not use a comparison group. The first author independently evaluated the risk for each study, with a second reviewer (RP) evaluating a third of included studies to substantiate quality. Any inconsistencies, although small, were discussed between both parties, original articles were consulted and agreement was established.

Methodological Quality Assessment

The QualSyst tool (Kmet, Lee & Cook, 2004) was used by the first author to independently assess study quality. An example of this tool can be found in Appendix D. This tool was developed to assess primary research from a variety of fields and, due to the high heterogeneity in the studies in this review, it was selected as an appropriate rating tool. Around a third of the included papers were reviewed by a second reviewer (KR) to substantiate quality. High agreement was found between ratings and any discrepancies (although small) were discussed to agree a final summary score. Studies are rated on a number of areas such as, study design, blinding, selection bias, sample size, confounders, and given a summary score, a higher score indicating higher quality research.

Data Synthesis

A narrative synthesis was undertaken to allow for a meaningful review of the current literature which comes from a small number of studies with considerable heterogeneity. This approach aims to provide clinically relevant and meaningful synthesis of the available data. Due to the small number of RCTs, and heterogeneity between studies in terms of study design, participants, intervention and outcome measures, a meta-analysis was not carried out.

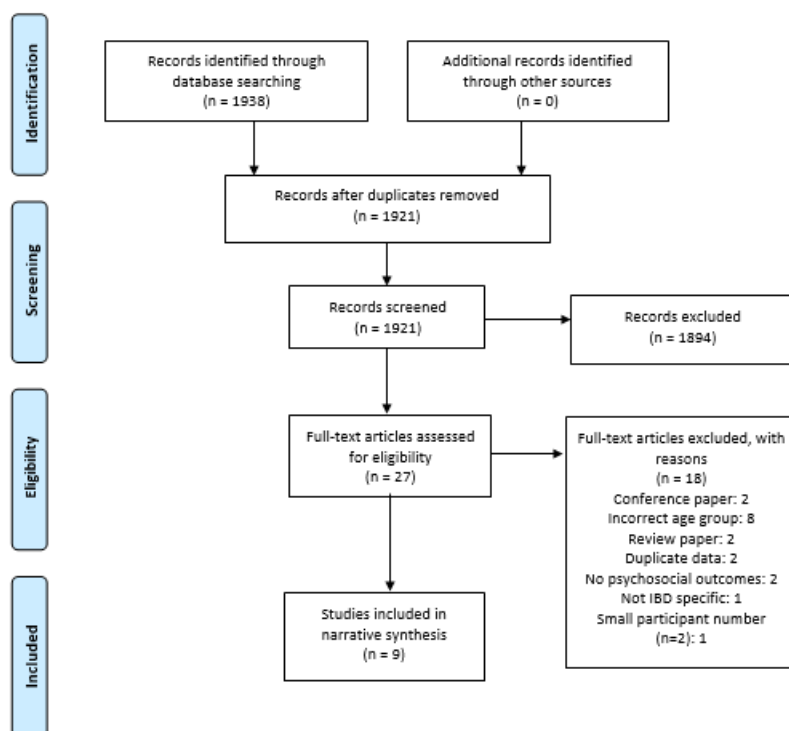
Results

Outcome of Search Process

The initial search, in May 2018, identified 1938 articles. Once duplicates were removed (n= 17), 1921 titles were screened and, where the title indicated any relevance to the review question, the abstract was read. Of these, 1894 articles were

deemed not to reach inclusion criteria and the remaining 27 papers were read in full. Of the 27 full text articles, 13 papers were omitted, five were discussed in more detail with the last author and a joint conclusion was reached that they should also be omitted. One of these studies (Reigada et al. 2014), a case study with two participants, fitted the specified inclusion criteria, however, post hoc, it was decided that as the review found sufficient papers for a narrative synthesis, and the quality of this study was low, it would be omitted from the final review. A total of seven studies, and two follow up longitudinal studies, were deemed to fit the criteria of the review. PRISMA flowchart can be found in Figure 1 below.

Figure 1. Flowchart following PRISMA guidelines. Adapted from Moher, Liberati, Tetzlaff and Altam; The PRISMA Group (2009)



Study characteristics

In total, four Randomised Controlled Trials (RCTs) (Table 1), three non-randomised studies (Table 2) and two longitudinal studies (Table 3) were selected for inclusion. The non-randomised studies provided pre and post measures from the treatment group, with one study utilising a waiting list control group. The total number of participants (excluding duplicated participants in longitudinal studies) was 525. Gender representation was fairly equal, with 54.2% female participants, and the average age of participants entering a trial was 14.3 years (with a range of 8-18 years.) All but one of the studies were conducted in the United States of America (USA). Three studies provided follow up data and two longitudinal studies were included that analysed longitudinal data from other studies included in this review.

Table 1. Characteristics of included randomised studies

Study identifier, year, Country	n	Age range (mean)	% female	Intervention (duration)	Study Design	Comparator Group	Measures	Outcomes	Quality rating
Levy et al. 2016 USA	185	8-17 (13.5)	47%	Social Learning and Cognitive Behavioural Therapy (3 sessions)	RCT and follow up data Baseline 1-week post treatment 3, 6- and 12-month post treatment	Education Support Comparison Condition (3 sessions)	IMPACT-III CDI-C MASC FDI	Significant improvement for IBD quality of life in both groups. Significant for treatment group at one-week post treatment. * Less depression in both conditions but not significant No significant change in anxiety in both conditions No Significant difference for FDI in both conditions	.96
Reigada et al. 2015 USA	22	9-17 (13.2)	59%	Treatment of Anxiety and Physical Symptoms related to IBD (TAPS + IBD) (15 sessions)	RCT and follow up Pre Post 3 months post	Supportive Non-Directive Therapy	IBD-SAS	Significant differences in both groups at both time points. Greater reduction in treatment group *	.88
Szigethy et al. 2014 USA	217	9-17 (14.3)	51%	Primary and Secondary Control Enhancement Training – Physical Illness (PASCET-PI) (12 sessions + 4 optional + 3 parent sessions)	RCT Pre Post	Supportive Non-Directive Therapy	CDSR IMPACT-III	Significant reduction in CDSR-R but no significant differences between groups. IMPACT-III and CGAS improved for both group with no significant difference.	.96
Szigethy et al. 2007 USA	41	11-17 (14.9)	51%	PASCET-PI (12 sessions + 4 optional + 3 parent sessions)	RCT Pre Post	Treatment As Usual (TAU)	CGAS CDI-C and CDI-P CGAS	Significant improvement in CDI-CP scores in treatment group** Significant improvement in CGAS scores in treatment group.**	.88

Note. IMPACT III = Child report quality of life; CDI-C = Child Depression Inventory Child; CDI-P = Child Depression Inventory Parent; MASC = Multidimensional Anxiety Scale for Children; FDI = Functional Disability Inventory; IBD-SAS = IBD Specific Anxiety Scale; CDSR = Childs Depression Rating Scale; CGAS = Children's Global Assessment Scale.
* p < .05; ** p < .01; *** p < .001

Table 2. Characteristics of included non-randomised studies

Study identifier, year	n	Age range (mean)	% female	Intervention (duration)	Study Design	Control Group	Measures	Outcome	Quality Rating
Reigada et al. 2013	9	11-17 (13.8)	56%	TAPS + IBD (15 sessions)	Single group, pre-post	None	SCARED IBD-SAS	Some improvement in anxiety symptoms however this finding was not significant.	.70
USA									
Szigethy et al. 2004	11	12-17 (14.8)	63%	PASCET-PI (12 sessions + 4 optional + 3 parent sessions)	Single group, pre-post	None	CDI-C CDI-P CGAS Social adjustment scale-self report	Significant reduction in depression symptoms (CDI-C*** & CDI-P**). Significant improvement in CGAS scores *** Significant improvement on social adjustment scale. **	.87
USA									
Grootenhuis et al. 2009	40	12-18 (15.6)	53%	OK Program (6 sessions)	Independent groups, pre-post and 6m follow up	Waiting list control group	State-trait inventory for children Dutch Quality of life questionnaire	No significant effect on anxiety levels in either group No significant change in overall quality of life scores in either group. Significant difference between pre and post scores in the treatment group on a body image sub scale of the quality of life measure *	.70
Netherlands									

Note. SCARED = Self Report for Childhood Anxiety Related Disorders; IBD-SAS = IBD Specific Anxiety Scale; CDI-C = Child Depression Inventory Child; CDI-P = Child Depression Inventory Parent; CGAS = Children's Global Assessment Scale.

* $p < .05$; ** $p < .01$; *** $p < .001$

Table 3. Characteristics of included longitudinal studies

Study identifier, year	n	Age range (mean)	% female	Intervention (duration)	Study Design	Comparator Group	Measures	Outcome	Quality Rating
Thompson et al. 2012 USA	41	11-17 (14.9)	51%	PASCET-PI (12 sessions + 4 optional + 3 parent sessions)	Longitudinal follow up data from Szigethy et al. 2007.	TAU	CDI-C CDI-P CGAS	Improvement in depression in treatment group compared to TAU. CGAS scores significantly improved at nine-month follow up in treatment group. *	.84
Szigethy et al. 2006 USA	11	12-17 (14.8)	63%	PASCET-PI (12 sessions + 4 optional + 3 parent sessions)	Longitudinal follow up data from Szigethy et al. 2004.	None	CDI-C CDI-P CGAS Social adjustment scale-self report	Improvements in all measures were maintained at 12-month follow up for treatment group, CDI-C***, CDI-P*, CGAS***, CSTAS***. Not reported in paper	.83

Note. CDI-C = Child Depression Inventory Child; CDI-P = Child Depression Inventory Parent; CGAS = Children's Global Assessment Scale;

* $p < .05$; ** $p < .01$; *** $p < .001$

Types of Intervention

Each included study utilised a CBT or CBT-informed intervention. Four different types of intervention were being evaluated. All interventions were identified as CBT or CBT-informed by the authors and this was evidenced in the descriptions of the programmes content, such as the use of cognitive approaches e.g. cognitive restructuring, relaxation strategies and homework tasks. Details of the interventions are outlined below.

Social Learning and Cognitive Behavioural Therapy (SLCBT; Levy et al. 2016). A three-session programme for parents and the young person which encourages participants to think about, and cope with, symptoms in a way that encourages wellness rather than illness behaviour. This included CBT techniques such as relaxation, stress management and cognitive strategies. In addition, parents were trained in how to reinforce wellness behaviours. Between session work was set in order to practice the skills acquired during the session.

OK Program (Grootenhuis, Maurice-Stam, Derkx & Last, 2009). This six-session program aims to build participants knowledge of IBD by asking participants to tell their own story. Relaxation techniques are taught to help in stressful situations, social competence is enhanced through discussions about the impact of IBD on activities and self. Cognitive restructuring helps challenge unhelpful thinking. Between session work is set to practice learned techniques.

Primary and Secondary Control Enhancement Therapy-Physical Illness (PASCET-PI; Szigethy, 2003). This approach offers 12 core 50-minute sessions which cover psychoeducation about depression and illness, problem solving as applied to illness coping, cognitive restructuring, relaxation techniques and behavioural activation approaches. A further four sessions are available if necessary. Participants receive workbooks to facilitate their learning and help homework tasks. In addition, three 60-minute family sessions are offered at the beginning, middle and end of treatment. These sessions compliment the core sessions by reviewing the role of the family within the illness and using the techniques learnt on the programme, within the home. Through the development of this programme, small variations in the amount of sessions offered, and duration, can be found in the included papers.

Treatment of Anxiety and Physical Symptoms related to IBD (TAPS + IBD; Reigada et al. 2013). This programme is based on a treatment for anxiety disorders in youth which was adapted to target physical symptoms of anxiety in youth who seek medical care (Treatment of Anxiety and Physical Symptoms, TAPS). Development of this programme added focus to IBD-related anxiety and subsequent intervention (TAPS + IBD). Thirteen 50-minute weekly individual sessions are offered to young people with two monthly booster sessions post treatment. The individual sessions focus on psychoeducation around disease management, monitoring symptoms to allow for differentiating between anxiety and IBD, cognitive strategies and illness-related exposure work. Three independent parent sessions are also provided at the beginning, middle and end to allow for work from sessions to be mirrored at home.

Psychosocial outcomes of interventions

Anxiety. Four of the included studies measured anxiety symptoms, pre and post intervention. RCT results show conflicting outcomes. Reigada et al. (2015) demonstrated a significant reduction in anxiety as measured by the IBD-Specific Anxiety Scale (IBD-SAS; Reigada et al. 2011), with a large effect size reported post treatment ($d = 1.21$), which was maintained at three-month follow up ($d = .75$). The IBD-SAS has the benefit of differentiating IBD related anxiety from DSM-IV (The Diagnostic and Statistical Manual of Mental Disorders, American Psychiatric Association, 2005) anxiety symptoms and therefore, it may be better placed to capture improvement from an IBD anxiety related intervention such as TAPS + IBD. This 15-session intervention focusses primarily on interventions to help manage IBD related anxiety. In contrast, Levy et al. (2016), demonstrated no significant change in anxiety symptoms following SLCBT treatment, although the brief nature of this treatment (3 sessions), and lack of focus on anxiety symptoms specifically, may indicate why little change was observed.

Results from non-randomised studies demonstrate mixed results. One study showed some improvement in anxiety symptoms in the treatment groups (Reigada et al. 2013), although no statistical significance was established. This study had no comparison group, increasing the risk for bias and the quality of this evidence is judged to be moderate. Grootenhuis et al. (2009) found no change in scores on the State -Trait-Anxiety Inventory for Children (STAI-C, Bakker, van Wieringen, van der Ploeg & Spielberger, 1989) in either the treatment group or waiting list control group.

The findings of these studies present conflicting results for the effect of a CBT based intervention on anxiety symptoms in children and adolescents with IBD, although it appears that there is a trend towards an improvement in anxiety symptoms following intervention. It may be that this improvement is noticeable when an anxiety specific CBT intervention is evaluated by an IBD specific outcome measure (as seen in the two studies by Reigada et al. 2013 & 2015) but more general approaches and measures do not show improvement. In addition, significant improvement, or a trend towards intervention, is observed in longer duration treatment approaches (15 sessions compared to 3 and 6 sessions), as this presumably provides more in-depth intervention to attendees.

Depression. Depression outcomes were measured in four of the included studies with the Child Depression Inventory (CDI; Kovacs, 1985) being used in the majority of papers. Szigethy et al. (2007) RCT demonstrated significant pre to post treatment changes in the treatment group on the CDI, Child and Parent version (CDI-CP), in comparison to the treatment as usual (TAU) group with a large effect size ($d = 1.01$). However, there was no significant difference in the amount of depression symptoms as measured by the Schedule for Affective Disorders and Schizophrenia for School Age Children- Present and Lifetime Version (K-SADS-PL; Kaufman et al., 1997) between groups. A later RCT (Szigethy et al. 2014) used a larger sample size ($n = 178$) to evaluate the same intervention. Results from the Children Depression Rating Scale-Revised (CDSR; Poznanski & Mokros, 1996) showed significant reductions for all participants from pre to post intervention. However, no significant difference was found between the CBT treatment group and a supportive non-directive therapy approach (SNDT). 65% of participants had

complete remission of depression at 3 months but, again, there was no differences between CBT treatment group and SNTD group. Levy et al. (2016) reported less depression, as measured by the CDI, following intervention but these findings were not significant.

A non-randomised study (Szigethy, Whitton, Levy-Warren, Ray, Weisz & Beardslee, 2004) demonstrated significant reductions in depression diagnosis and depressive symptoms following intervention and reported that these trends were irrespective of reporter (parent or child) or method (clinical interview or self-report).

All these studies demonstrated high quality as assessed by the Quallsyst tool and there appears to be a trend suggesting that a CBT based intervention may reduce depression symptomology. Szigethy et al. (2014) illustrated that both a CBT informed approach and a SNTD approach resulted in a reduction in symptoms of depression. It may be that factors common to both therapies, such as the therapeutic relationship and social support, contribute to this improvement.

General functioning. Three RCT's measured general functioning pre and post intervention. Szigethy et al. (2007) demonstrated significant improvement at a $p < .05$ level on the Children Global Assessment Scale (CGAS; Schaffer et al., 1983) for the treatment group in comparison to the TAU group with a large effect size ($d = .86$). Improvements in IBD-related quality of life (IMPACT-III; Otley et al. 2002) and CGAS following treatment were further observed in Szigethy et al. (2014).

However, there were no significant difference between groups, suggesting that a SNTD has similar impact to CBT approaches for improving general functioning in children and adolescents with IBD. IMPACT-III was also used in Levy et al. (2016) and, again, participants in both conditions reported improvement in their IBD related quality of life. However, those in the CBT condition demonstrated a significantly greater improvement at one-week post treatment compared to the control group. This study also utilised the Functional Disability Inventory (FDI; Walker & Greene, 1991) to assess difficulty in physical and psychosocial functioning as related to an individual's physical health. No significant difference was found between or within groups for this measure and this was observed both from parent and young person report.

A non-randomised study (Grootenhuis et al., 2009) found no general improvement following intervention in participant quality of life, however a positive significant change was observed for participants' perception of body image. Szigethy et al. (2004) found significant improvements in the 11 participants on the CGAS measure following intervention ($p < .005$) with a large effect size ($d = .81$). This study was the only one within the review to use the Social Adjustment Scale-Self Report (Weissman, 1999) to measure social functioning. Again, all participants demonstrated significant improvement ($p < .01$) on this measure following treatment, with a moderate effect size ($d = .54$).

These studies demonstrated high quality as measured by the Quallsyst tool and there appears to be a trend towards CBT interventions for participants with IBD

being beneficial for general functioning. However, it should be noted that in two studies improvement was also observed for the control group (education support comparison condition and supportive non-directive therapy) which raises questions about the necessity of CBT specific elements in the treatment approach.

Longitudinal data. Two of the included studies reported on longitudinal data from earlier papers included in the review. Thompson et al. (2012) conducted follow up research on participants from Szigethy et al. (2007). Six participants were lost to follow in the intervention group and five in the TAU group. Attrition analyses showed no significant differences between those who did and did not complete follow up. Improvements were detected in the CDI-CP and K-SADS-PL measure of depressive symptoms at a trend level at six month and 12-month follow up in the PACET-PI group in comparison to the TAU group. Individuals in the PASCET-PI group showed significantly improved CGAS scores at six months follow up although this was not continued for data collected at 12-month follow up. Group attendees were offered booster sessions in the follow up period with each participant attending, on average, two booster sessions.

Szigethy et al. (2006) collected six- and 12-month data from all participants in the Szigethy et al. (2004) study. Improvements in depression and general functioning observed post treatment were maintained at 12-month follow up. Booster CBT sessions and psychopharmacology were available to participants, and utilised, during the follow up period.

This longitudinal data suggests that gains at post treatment are maintained at follow up for the CBT intervention used in the initial studies (PASCET-PI).

However, it is not clear if the additional sessions offered in the follow up period account for this maintenance.

Risk of Bias in included studies

Risk of bias was assessed for the nine included papers within this review as informed by the Cochrane Collaboration (Higgins, Altman & Stern, 2011). Details can be found in Appendix E. The risk of bias was judged to be low for the four RCT studies and longitudinal studies included in this review but higher for the non-randomised studies, including the non-randomised study that utilised a comparison group. Typically, higher bias was detected in the non-randomised studies due to a lack of comparison group and no blinding in outcome assessment. A number of studies were assessed to demonstrate ‘other bias’ due to the authors evaluating a psychological intervention that they had developed as this may bias evaluation and reporting within the article. Figures 2, 3 and 4 summarise the risk of bias detected within each study.

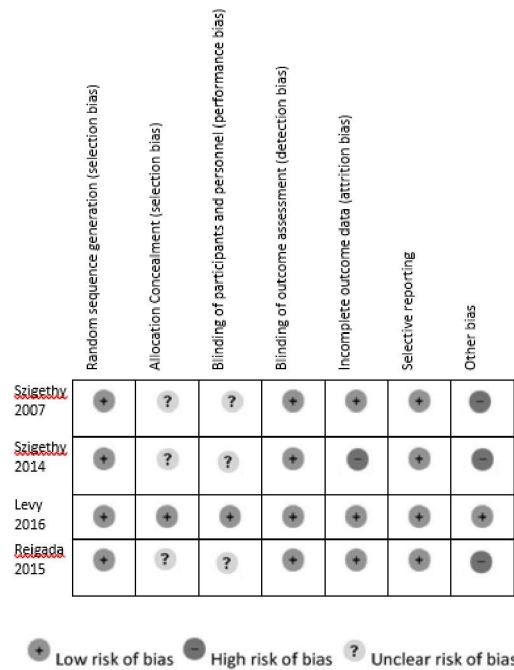


Figure 2: Risk of bias summary for RCT's

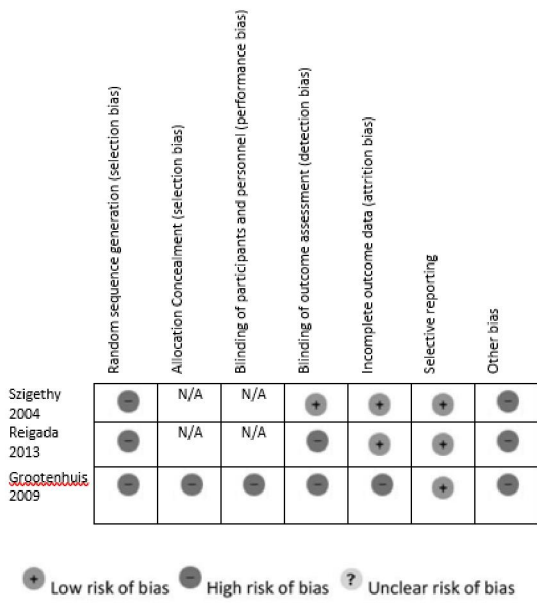


Figure 3: Risk of bias summary
for non-randomised studies

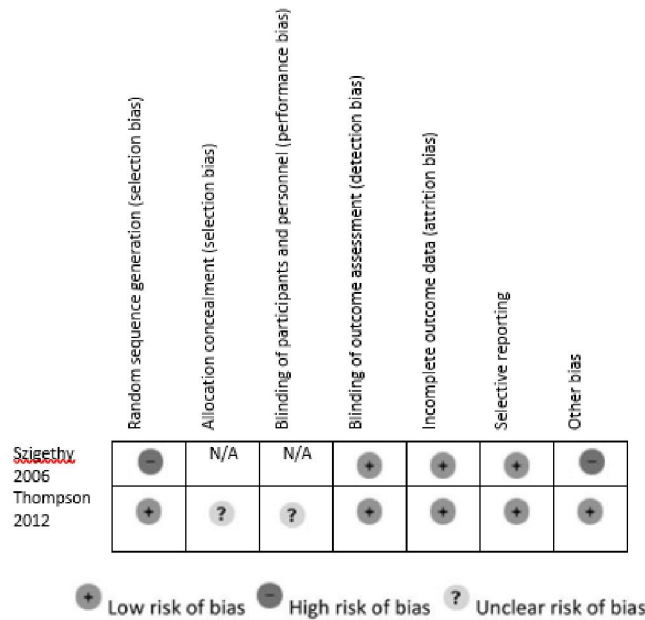


Figure 4: Risk of bias summary for longitudinal studies

Summary of quality assessment

The QualSyst tool (Kmet, Lee & Cook, 2004) was used to assess the methodological quality of the included studies. Details of this can be found in Appendix F. Each study was given a summary score, ranging from 0-1, to indicate the quality of criteria such as design, blinding, sample size, control for confounding variables. Criteria not appropriate to a particular study was deemed ‘not applicable’ and was excluded from the calculation of the summary score. Summary scores for RCTs demonstrated high quality studies with scores ranging from .88 – .96 with a mean of .92. Non-randomised studies demonstrated a moderate level of quality with scores ranging from .70 to .87, with a mean score of .75. Longitudinal studies demonstrated a similar summary score of quality to the primary research paper. Quality scores can be found in the included tables.

Discussion

The purpose of this systematic review is to provide a narrative synthesis of the psychosocial outcomes of cognitive behaviour informed interventions for child and adolescents with IBD. In the absence of any previous similar reviews, all appropriate studies were included to summarise the available research. This review considered the quality and bias of the included studies, outlined any methodological limitations of the research and synthesised the findings to consider the implications for clinical practice.

Following a systematic review of the literature, nine studies were identified that met inclusion criteria to help establish the psychosocial outcomes of cognitive behaviour informed intervention for children and adolescents with IBD. Although a relatively small number of studies, this presented the opportunity to synthesise emergent findings in the area of clinical health psychology which is continuing to receive increasing recognition in the nation's health agenda. It was encouraging that over 50% of the included primary studies were RCTs. This gold standard methodology can allow us to draw more meaningful conclusions about the psychosocial outcomes from the included studies.

Overall there appears to be a trend towards psychological interventions having a positive effect on scores of anxiety, depression and general functioning in children and adolescents with IBD. This trend towards improvement, or significant change, is observed in 80% of studies that reported on depression, 50% that reported on anxiety and 80% that reported on measures of general functioning. When only the highest quality studies with the least bias are considered (namely the included RCT's), 100% of studies reported improvement in scores of depression and general functioning (with two thirds demonstrating significant improvement) and one of the two studies measuring anxiety reported significant improvement.

Within the included studies, four different types of intervention were being evaluated. All interventions were identified as CBT or CBT-informed by the authors and this was evidenced by descriptions of the programmes content. Results from the six-session OK Programme (Grootenhuis, Maurice-Stam, Derkx & Last,

2009) found no significant change in measures of general functioning and anxiety. More positive results were reported by Levy et al. (2016), who found that three-session of SLCBT had a significant impact on general functioning and improved symptoms of depression. This programme included parents throughout and they were trained to reinforce wellness behaviours. This element may have contributed to improving the young person's general functioning.

Most articles included in this review evaluated TAPS+IBD programme (Reigada et al., 2013) and PASCET-PI (Szigethy, 2003). These programmes run for longer (15 sessions and up to 19 sessions respectively) and focus on either anxiety or depression and they repeatedly demonstrate significant change, or at the least improvement, in this domain. It is acknowledged that there is more data evaluating these programmes which may allow for more meaningful conclusions to be drawn. However, these findings may show that better mental health outcomes can be expected if the programme has more sessions and is focussed on a specific mental health problem. Longitudinal studies only evaluated the PASCET-PI programme and showed that improvement in scores were maintained at 12-month follow up. This programme offers booster sessions following completion of the intervention and this may be key in maintaining improvement. It should be noted that two RCTs that evaluated these programmes utilised a 'supportive non-directive therapy' as the comparison group and in both studies improvements were observed in this group as well as the treatment group. This does raise a question about whether the content of the CBT intervention is necessary for improvement or whether the common factors of therapy, such as the therapeutic relationship, empathy and supportive environment, are providing the mechanism for improvement. It also contests the

earlier point about whether better psychosocial outcomes can be expected if the programme focusses on a specific mental health problem, supportive non-directive therapy did not have this focus.

It is important to acknowledge that grey, or unpublished, literature was not included as part of this systematic review, and searches for relevant articles were limited to peer reviewed material. This may bias the pool of articles from which this sample was taken and therefore a positive effect from psychological intervention was more likely to be found. In addition, nearly half of the primary research papers were non-randomised studies with small participant numbers and, in most cases, a lack of comparison or control group. This research design is judged to be lower in quality and have higher risk of bias. Furthermore, within the included studies there was a number of papers written by the same authors who were assessing a CBT based intervention for IBD that they had developed. This may present a potential for bias to overestimate the findings in favour of the developed treatment, although no evidence of this was found in the included articles. Due to time and resources, quality ratings and risk of bias judgement were completed by the primary author with second authors reviewing a third of included articles. Although no large discrepancies were found in ratings, it would be more robust to have two authors rating all articles to minimise interpretation bias. Despite this, these studies do present the best available peer reviewed evidence in this field and they provide support for the helpfulness of psychological intervention in improving psychosocial outcomes for children and adolescents with IBD.

As previously mentioned, there is increasing recognition about the importance of mental health support for individuals in the context of a chronic health problem and psychological approaches, such as CBT, are being increasingly used in a health setting to help patients cope with long term health conditions (Magidson & Weisberg, 2014). Consequently, the current review provides some timely and clinically relevant findings about how the psychological and mental health needs of children and adolescents with IBD can be best met. It seems reasonable to suggest that psychological intervention for this cohort has a positive impact on anxiety, depression and general functioning. However, it is not clear whether this intervention needs to include specific CBT elements or whether the common factors of therapy (active listening, empathy, warmth etc), as seen in SNTD, are responsible for this positive effect. This mirrors the ongoing debate about the 'active ingredient' of therapy (Messer & Wampold, 2002). It appears that a more intensive programme (15-19 sessions) has a more positive impact on psychosocial outcomes than less intensive approaches (six sessions) and a specific focus on anxiety or depression, rather than general mental health, appears to be more beneficial for improving outcomes in these areas. The offer, and use, of booster sessions following the completion of a programme appears to help maintain improvements one year on. Clinicians are likely to be aware of the importance and helpfulness of systemic approaches when working with young people (Carr, 2009) and this is echoed within this review. Interventions that involved the individual's family within the therapy reported more positive outcomes.

Conclusions

In sum, the available evidence suggests that psychological intervention, particularly those that are longer term (e.g. around 15 sessions), can benefit psychosocial outcomes for children and adolescents with IBD. This aligns with NICE guidelines for Crohn's disease (2016) which highlights the importance of continued multidisciplinary support to help patients deal with the disease and living with a chronic health problem. Although it should be highlighted that no equivalent psychosocial based recommendation is made in the NICE guidelines for UC (2013). However, it is not clear whether the inclusion of CBT specific skills is necessary for improvement in outcomes. Future research would benefit from exploring this further, particularly as a CBT informed approach may be costlier to deliver than non-directive approaches due to its specialist nature. This suggestion is echoed in NICE guidelines for Crohn's disease (2016), although a similar recommendation cannot be found in NICE guidance for UC (2013), where it is recommended that further research is necessary to establish information needs of Crohn's patients and consider whether support based on these needs leads to better psychological, social and physical outcomes.

Acknowledgements

The author thanks Kate Roberts and Rose Papadopoulos for their work in reviewing the quality and risk of bias of included studies.

Conflict of interest: none declared. This research was supported by the University of East Anglia as fulfilment of the Doctoral Programme in Clinical Psychology.

References

- American Psychiatric Association. (2000). *Diagnostic and statistical manual of mental disorders* (4th ed). Washington, DC: Author.
- Bakker, F.C., van Wieringen, P.C.W., van der Ploeg, H. M. & Spielberger, C.D. (1989). *Dutch translation and manual of the State-Trait-Anxiety Inventory for Children (STAI-C) from Spielberger et al.* (In Dutch). Lisse: Swets Test Services.
- Bennett, S., Shafran, R., Coughtrey, A., Walker, S. & Heyman, I. (2015). Psychological interventions for mental health disorders in children with chronic physical illness: A systematic review. *Archives of Disease in Childhood*, 100, 308-316. doi:10.1136/archdischild-2014-307474
- Bishop, J., Lemberg, D.A. & Day, A. (2014). Managing inflammatory bowel disease in adolescent patients. *Journal of Adolescent Health, Medicine and Therapeutics*, 6, 1-13. doi:10.2147/AHMT.S37956
- Carr, A. (2009). The effectiveness of family therapy and systemic interventions for child focused problems. *Journal of Family Therapy*, 31, 3-45. doi: 10.1111/j.1467-6427.2008.00451.x

Chiles, J.A., Lambert, M.J. & Hatch, A.L. (1999). The impact of psychological interventions on medical cost offset: A meta-analytic review. *Clinical Psychology Science and Practice*, 6, 204-220. doi: 10.1093/clipsy.6.2.204

Greenley, R.N., Hommel, K.A., Nebel, J., Raboin, T., Li, S., Simpson, P. & Mackner, L. (2010). A meta-analytic review of the psychosocial adjustment of youth with inflammatory bowel disease. *Journal of Paediatric Psychology*, 35, 857-869. doi: 10.1093/jpepsy/jsp120]

Grootenhuis, M.A., Maurice-Stama, H., Derkxb, B.H. & Lasta, B.F. (2009). Evaluation of a psychoeducational intervention for adolescents with inflammatory bowel disease. *European Journal of Gastroenterology & Hepatology*, 21, 340–345. doi: 10.1097/MEG.0b013e328315a215

Her Majesty's Government (2011). No Health Without Mental Health: A cross-government mental health outcomes strategy for people of all ages. Available from: https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/213761/dh_124058.pdf

Higgins, J.P.T., Altman, D.G., Gøtzsche, P.C., Jüni, P., Moher, D., Oxman, A.D., Savović, J., . . . Cochrane Statistical Methods Group (2011). The Cochrane

Collaboration's tool for assessing risk of bias in randomised trial. *Research Methods and Reporting*, 343. doi: 10.1136/bmj.d5928.

Higgins J.P.T., & Green S. (2018). *Cochrane Handbook for Systematic Reviews of Interventions* Version 6 [updated September 2018]. The Cochrane Collaboration. Available from <http://handbook.cochrane.org>.

Kaufman J., Birmaher B., Brent D., & Rao U. (1997). Schedule for affective disorders and schizophrenia for school-age children-present and lifetime version (K-SADS-PL): Initial reliability and validity data. *Journal of the American Academy of Child and Adolescent Psychiatry*, 36, 980-988.
doi:10.1097/00004583-199707000-00021

Kibby, M.Y., Tyc, V.L., & Mulhern, R.K. (1998). Effectiveness of psychological intervention for children and adolescents with chronic medical illness: A meta-analysis. *Clinical Psychology Review*, 18, 1, 103-17. doi:10.1016/S0272-7358(97)00049-4

Kmet, L.M., Lee, R.C. & Cook, L.S. (2004). Standard Quality Assessment Criteria for evaluation primary research papers from a variety of fields. Edmonton: Alberta Heritage Foundation for Medical Research (AHFMR). Available from <https://www.ihe.ca/advanced-search/standard-quality-assessment-criteria-for-evaluating-primary-research-papers-from-a-variety-of-fields>

Kovacs, M. (1985). The Children's Depression Inventory. *Psychopharmacology Bulletin*, 21, 995-998.

Lavigne J., & Gaier-Routman J. (1992). Psychological adjustment to pediatric physical disorders: A meta-analytic review. *Journal of Pediatric Psychology*, 17, 133–57. doi: 10.1093/jpepsy/17.2.133

LeBlanc L., Goldsmith T., & Patel D. (2003). Behavioral aspects of chronic illness in children and adolescents. *Pediatric Clinics of North America*, 50, 859–878. doi: 10.1016/S0031-3955(03)00072-5

Levy, R.L., van Tilburg, M.A.L., Langer, S.L., Romano, J.M., Walker, L.S., Mancil, L.A. ... Whitehead, W.E. (2016). Effects of a cognitive behavioral therapy intervention trial to improve disease outcomes in children with Inflammatory Bowel Disease. *Inflammatory Bowel Disease*, 22, 2134-2148. doi:10.1097/MIB.0000000000000881

Lukens, C.T. & Silverman, A.H. (2014). Systematic review of psychological interventions for pediatric feeding problems. *Journal of Pediatric Psychology*. 39, 903-917. doi:10.1093/jpepsy/jsu040

- Mackner, L.M., Sisson, D.P. & Crandall, W.V. (2004). Review: Psychosocial issues in paediatric inflammatory bowel disease. *Journal of Paediatric Psychology*, 29, 243-257. doi: 10.1093/jpepsy/jsh027
- Magidson, J.F. & Weisberg, R.B. (2014). Implementing cognitive behavioural therapy in specialty medical settings. *Cognitive and Behavioural Practice*, 24, 367-371. doi: 10.1016/j.cbpra.2014.08.003
- McCombie, A.M., Mulder, R.T. & Gearry, R.B. (2013). Psychotherapy for inflammatory bowel disease: A review and update. *Journal of Crohn's and Colitis*, 7, 935-949. doi.org/10.1016/j.crohns.2013.02.004
- Messer, S.B. & Wampold, B.E. (2002). Let's face facts: Common factors are more potent than specific therapy ingredients. *Clinical Psychology: Science and Practice*, 9, 21-25. doi: 10.1093/clipsy.9.1.21
- National Institute for Health and Clinical Excellence (2013). Ulcerative Colitis: Management. Available from: <https://www.nice.org.uk/guidance/CG166>
- National Institute for Health and Clinical Excellence (2016). Crohn's Disease: Management. Available from: <https://www.nice.org.uk/guidance/CG152>

Naylor, C., Parsonage, M., McDaid, D., Knapp, M., Fossey, M., & Galea, A.

(2012). Long-term conditions and mental health: The cost of co-morbidities.

Kings Fund and Centre for Mental Health. Available from:

<https://www.kingsfund.org.uk/publications/long-term-conditions-and-mental-health>

NHS (2014). Five Year Forward View. Available from:

<https://www.england.nhs.uk/wp-content/uploads/2014/10/5yfv-web.pdf>

NHS Digital (2018). NHS Outcomes Framework Indicators. Available from:

<https://digital.nhs.uk/data-and-information/publications/clinical-indicators/nhs-outcomes-framework/current>

Otley A, Smith C, Nicholas D, Munk, M., Avolio, J., Sherman, P.M. & Griffiths,

A.M. (2002). The IMPACT questionnaire: A valid measure of health-related quality of life in pediatric inflammatory bowel disease. *Journal of Pediatric Gastroenterology and nutrition*. 3, 557-563.

Palermo T.M., Wilson A.C., Peters M., Lewandowski A. & Somhegyi H. (2009).

Randomized controlled trial of an Internet-delivered family cognitive-behavioral therapy intervention for children and adolescents with chronic pain. *Pain*, 146, 205–213. doi: 10.1016/j.pain.2009.07.034

Popay, J., Roberts, H., Sowden, A., Petticrew, M., Arai, L., Rodgers, M., & Britten

N. (2006). Guidance on the Conduct of Narrative Synthesis in Systematic Reviews. A product from the ESRS Methods Programme. Retrieved from: doi: 10.13140/2.1.1018.4643.

Poznanski E.O., & Mokros H.B. (1996). Children's Depression Rating Scale, Revised (CDRS-R) Manual. Los Angeles: Western Psychological Services.

Reigada, L.C., Benkov, K.J., Bruzzese, J-M., Hoogendoorn, C., Szigethy, E., Briggie, A., Walder, D.J., & MasiaWarner, C. (2013). Integrating illness concerns into cognitive behavioural therapy for children and adolescents with inflammatory bowel disease and co-occurring anxiety. *Journal for Specialists in Pediatric Nursing*, 18, 133-143. doi: 10.1111/jspn.12019

Reigada, L.C., McGovern, A., Tudor, M.E., Walder, D.J. MasiaWarner, C. (2014). Collaborating with pediatric gastroenterologists to treat co-occurring inflammatory bowel disease and anxiety in pediatric medical settings. *Cognitive and Behavioural Practice*, 21, 372-385. doi: 10.1016/j.cbpra.2014.03.004

Reigada, L.C., Polokowski, A.R., Walder, D.J., Szigethy, E.M., Benkow, K.J., Bruzzese, J-M. & Warner, C.M. (2015). Treatment for comorbid pediatric gastrointestinal and anxiety disorders: A pilot study of a flexible health

sensitive cognitive-behavioral therapy program. *Clinical Practice in Pediatric Psychology*, 3, 314-326. doi: 10.1037/cpp0000116

Shaffer, D., Gould, M.S., Brasic, J., Ambrosini, P., Fisher, P., Bird, H., & Aluwahlia, S. (1983). A Children's Global Assessment Scale (CGAS). *Archives of General Psychiatry*, 40, 1228-1231.

Spurgeon, P., Hicks, C., Barwell, F., Walton, I. & Spurgeon, T. (2005). Counselling in primary care: A study of the psychological impact and cost benefits for four chronic conditions. *European Journal of Psychotherapy and Counselling*, 7, 269–290. doi: 10.1080/13642530500367753

Szigethy, E., Whitton, S.W., Levy-Warren, A., DeMaso, D.R., Weisz, J. & Beardslee, W.R. (2004). Cognitive-behavioral therapy for depression in adolescents with inflammatory bowel disease: A pilot study. *Journal of American Academy of Child and Adolescent Psychiatry*, 43, 1469-1477. doi: 10.1097/01.chi.0000142284.10574.1f

Szigethy, E., Carpenter, J., Baum, E., Kenney, E., Baptista-Neto, L., Beardslee, W.R., & Demaso, D.R. (2006). Case study: Longitudinal treatment of adolescents with depression and inflammatory bowel disease. *Journal of American Academy of Child and Adolescent Psychiatry*, 45, 396-400. doi: 10.1097/01.chi.0000198591.45949.a4

Sziegthy, E., Kenney, E., Carpenter, B.A., Hardy, D.M. Fairclough, D., Bousvaros, A., ... DeMaso, D.R. (2007). Cognitive-Behavioral Therapy for Adolescents With Inflammatory Bowel Disease and Subsyndromal Depression. *Journal of American Academy of Child and Adolescent Psychiatry*, 46, 1290-1298. doi: 10.1097/chi.0b013e3180f6341f

Szigethy, E., Bujoreanu, S.L., Youk, A.O., Weisz, J., Benhayon, D., Fairclough, D., ... Newara, M. (2014). Randomized efficacy trial of two psychotherapies for depression in youth with Inflammatory Bowel Disease. *Journal of American Academy of Child and Adolescent Psychiatry*, 53, 726-735. doi: 10.1016/j.jaac.2014.04.014

Tarricone, I., Regazzi, M.G., Bonucci, G., Rizello, F., Carini, G., Muratori, R., Poggioli, G., & Campieri, M. (2017). Prevalence and effectiveness of psychiatric treatments for patients with IBD: A systematic literature review. *Journal of Psychosomatic Research*, 101, 68-95. doi: 10.1016/j.crohns.2012.05.021

Timmer, A., Preiss, J.C., Motschall, E., Rucker, G., Iantschek, G., & Moser, G. (2011). Psychological interventions for treatment of inflammatory bowel disease. *Cochrane Database of Systematic Reviews*. doi: 10.1002/14651858.CD006913.pub2.

Thompson R.D., Delaney P., Flores I., & Szigethy E. (2011). Cognitive-behavioral therapy for children with comorbid physical illness. *Child and Adolescent Psychiatric Clinics of North America*, 20, 329–48. doi: 10.1016/j.chc.2011.01.013

Thompson, R.D., Craig, A., Crawford, E.E., Fairclough, D., Gonzalez-Heyditch, J., Bousvaros, A., ... Szigethy, E. (2012). Longitudinal results of cognitive behavioral treatment for youths with Inflammatory Bowel Disease and depressive symptoms. *Journal of Clinical Psychology in Medical Settings*, 19, 329-337. doi: 10.1007/s10880-012-9301-8

Walker, L.S., & Greene, J. W. (1991). The functional disability inventory: Measuring a neglected dimension of child health status. *Journal of Pediatric Psychology*, 16, 39-58. doi: 10.1093/jpepsy/16.1.39

Weissman, M. (1999). *Social Adjustment Scale – Self Report (SAS-SR) User's Manual*. Toronto: Multi-Health Systems.

World Health Organisation (2018). Adolescent Health. Available from: https://www.who.int/topics/adolescent_health/en/

Chapter 2.

Bridging Chapter: Reflections on the integration of physical and mental health care for young people with Inflammatory Bowel Disease.

Word Count: 649

Chapter 2: Bridging Chapter

The integration of physical and mental health is receiving increased recognition throughout UK health services and with good reason. It is estimated that an individual with a chronic disease is three times more likely to experience depression than a healthy control (Egede, 2007) and similar prevalence has been reported from 29 countries in the World Health Organisation (WHO) Mental Health Survey (Von Korff et al., 2009). Recent government initiatives, such as the NHS (National Health Service) Five Year Forward View (2014), have highlighted the need for the NHS to move towards a more integrated system with physical and mental health. The Future in Mind (2015) report recommends that it should be easier for services to work together to ensure that children and young people have easy access to the right support from the right service.

Despite poor quality data, it is estimated that around 10-15% of adolescents live with a chronic disease (Michaud, Suris & Viner, 2007) and it is estimated that the risk of psychosocial adjustment difficulties in adolescents with a chronic disease is higher than healthy controls (Lavigne & Faier-Routman, 1992). Consequently, there appears to be a need for adolescents with chronic health problems to be offered psychological support. Interestingly, NICE (National Institute for Health and Care Excellence) offer clinical guidance for the management of depression in adults with a chronic health problem (NICE, 2009) but no comparable guideline is offered for children and adolescents. Therefore, clinical services are left with no evidence-based guidance to inform how psychological support is provided to children and adolescents with chronic health problems. There is a similar lack of

guidance within NICE guidelines for Ulcerative Colitis and Crohn's Disease. NICE guidelines for Crohn's Disease (2016) provide a psychosocial based recommendation that highlights that multi-disciplinary support should be offered to help patients deal with any concerns about the disease and living with a chronic illness, although this provides little direction for clinical staff. No equivalent psychosocial based recommendation is made in the NICE guidelines for Ulcerative Colitis (2013).

The systematic review in chapter 1 suggests that CBT-based intervention may improve depression, anxiety and general functioning in children and adolescents with Inflammatory Bowel Disease (IBD). These findings have been echoed in a number of review studies for young people with a range of other chronic health problems (Bennett, Shafran, Coughtrey, Walker & Heyman, 2015; Kibby, Tyc & Mulhern, 1998; Palermo, Wilson, Peters, Lewandowski & Somhegyi 2009). A review study has suggested that improvement following a psychological intervention is more likely to be observed in young people than in an adult population (Timmer et al., 2011). Due to this difference in outcomes, it may be that adult based clinical guidelines are not clinically relevant to children and young people. There is also a lack of research into psychological support for young people with IBD and this presents complications in developing clinical guidance which are based on high quality, extensive research.

The integration of physical and mental health is taking increasing priority in how health services are delivered. Research to date would suggest that young

people with chronic health problems, including Inflammatory Bowel Disease, benefit from this integrated approach and experience improvement in their psychological wellbeing from psychological intervention. However, the lack of NICE guidelines for the management of depression, and other internalised problems, for young people with chronic health conditions, leads to a lack of governance of this being delivered in front line services. NICE include qualitative research in their development of guidelines as it is deemed important to take into account patients' perspectives when making recommendations for provision of their care. Therefore, the opportunity has arisen to explore the lived experience of adolescents with Inflammatory Bowel Disease, a previously unstudied area with much of the research focussed on an adult population. It is hoped that this study will contribute to the evidence base and help shape patient care.

References

- Bennett, S., Shafran, R., Coughtrey, A., Walker, S. & Heyman, I. (2015). Psychological interventions for mental health disorders in children with chronic physical illness: a systematic review. *Archives of Disease in Childhood*, 100, 308-316. doi:10.1136/archdischild-2014-307474
- Egede, L. E. (2007) Major depression in individuals with chronic medical disorders. Prevalence, and correlates and association of health resource utilisation, lost productivity and functional disability. *General Hospital Psychiatry*, 29, 409–416. doi:10.1016/j.genhosppsych.2007.06.002
- Kibby, M.Y., Tyc, V.L., & Mulhern, R.K. (1998). Effectiveness of Psychological Intervention for Children and Adolescents with Chronic Medical Illness: A Meta-Analysis. *Clinical Psychology Review*, 18, 1, 103-17. doi:10.1016/S0272-7358(97)00049-4
- Lavigne, J., & Gaier-Routman, J. (1992). Psychological adjustment to pediatric physical disorders: A metaanalytic review. *Journal of Pediatric Psychology*, 17, 133–57. doi: 10.1093/jpepsy/17.2.133
- Michaud, P.A., Suris, J.C. & Viner, R. (2007) World Health Organisation. The adolescent with a chronic condition: Epidemiology, developmental issues and health care provision. Available from:

http://apps.who.int/iris/bitstream/handle/10665/43775/9789241595704_eng.pdf;jsessionid=03E4B1E0CBD0D6E1689DA1D6F21396CC?sequence=1

National Institute for Health and Clinical Excellence (2009). Depression in adults with a chronic physical health problem: recognition and management.

Available from: <https://www.nice.org.uk/Guidance/CG91>

National Institute for Health and Clinical Excellence (2013). Ulcerative Colitis:

Management. Available from: <https://www.nice.org.uk/guidance/CG166>

National Institute for Health and Clinical Excellence (2016). Crohn's Disease:

Management. Available from: <https://www.nice.org.uk/guidance/CG152>

NHS (2014). Five Year Forward View. Available from:

<https://www.england.nhs.uk/wp-content/uploads/2014/10/5yfv-web.pdf>

NHS England and Department of Health (2015). Future in Mind: Promoting,

protecting and improving our children and young people's mental health and wellbeing. Available from:

https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/414024/Childrens_Mental_Health.pdf

Palermo T.M., Wilson A.C., Peters M., Lewandowski A. & Somhegyi H. (2009).

Randomized controlled trial of an Internet-delivered family cognitive-behavioral therapy intervention for children and adolescents with chronic pain. *Pain*, 146, 205–213. doi: 10.1016/j.pain.2009.07.034

Timmer, A., Preiss, J.C., Motschall, E., Rucker, G., Iantschek, G., & Moser, G.

(2011). Psychological interventions for treatment of inflammatory bowel disease. *Cochrane Database of Systematic Reviews*. doi: 10.1002/14651858.CD006913.pub2.

von Korff,, M., Scott, K. & Gureje, O., (2009) *Global Perspectives on Mental–Physical Comorbidity in the WHO Mental Health Surveys*. Cambridge: Cambridge University Press.

Chapter 3.

Empirical paper prepared for submission to: Psychology and Health.

Author Guidelines available in Appendix G.

The research reported is original work which was carried out under the supervision of Judith Young (Primary Supervisor) and Imogen Rushworth (Secondary Supervisor). I am the lead author of this paper which is prepared for journal submission.

The Lived Experience of Adolescents with Inflammatory Bowel Disease.

Hannah Crook^a, BSc. (Hons)., PGCert., PGDip.

Judith Young^{ab} BSc.(Hons), MSc., PGDip., C.Psychol.,

Dr Imogen Rushworth^a BSc (Spec Hons), PhD, ClinPsyD

^a Department of Clinical Psychology, University of East Anglia, United Kingdom

*^b Psychological Medicine Service for Children, Young People and Families,
Addenbrookes Hospital, Cambridge, United Kingdom*

Correspondence should be addressed to Hannah Crook, Trainee Clinical
Psychologist, Department of Clinical Psychology, Norwich Medical School,
University of East Anglia, Norwich, NR4 7TJ.

E-mail: Hannah.crook@uea.ac.uk

Word count: 7997

Abstract

Objective: Inflammatory Bowel Disease (IBD), encompassing Crohn's Disease and Ulcerative Colitis, has its peak onset in adolescence. To date, literature has focussed on adults' experiences of living with IBD. The aim of this study is to explore the lived experience of adolescents with IBD and consider how they make sense of their disease.

Method: Eight adolescent participants, who had lived with IBD for at least six months, were recruited by a paediatric gastroenterology care team. Semi-structured interviews were conducted to gather data relating to the participants lived experience and sense making of their IBD. An Interpretative Phenomenological Analysis was used to study the participants' interviews.

Results: Three overarching themes were identified; The Turning Point for Health, Resilience and Acceptance, and Fragility of Health Position. Each theme included a number of subordinate themes which are discussed in more detail. Links between themes are considered.

Conclusion: This study provides insight into the lived experience of adolescents with IBD and how they make sense of their disease. Clinical implications are discussed, including the importance of others understanding of IBD in providing helpful support and sharing stories of building resilience and acceptance in the face of IBD.

Key Words: Inflammatory Bowel Disease; Adolescents; Lived Experience.

Introduction

Inflammatory Bowel Disease (IBD) encompasses two chronic conditions; Ulcerative Colitis (UC) (UC) and Crohn's Disease (CD) (CD) and affects 1 in every 250 people in the UK (Jordan, 2011) . The disease has a remitting and relapsing course and common symptoms include frequent diarrhoea, fatigue and delayed puberty (Greenley et al., 2010.) Pain is another common symptom of IBD (Bielefeldt, Davis & Binion, 2009) which is particularly evident during periods of severe inflammation. It has a wider systemic impact, causing IBD related arthralgia and arthritis, the most common extraintestinal manifestation of IBD (Arvikar & Fisher, 2011). Individuals with UC and CD experience similar symptoms, however the physiological condition differs. In UC there is continuous inflammation in the inner lining of the colon. In CD, inflammation can be in all layers of the bowel walls and anywhere in the digestive tract, with healthy areas in between (Sykes, Fletcher & Schneider, 2015). There is currently no cure for IBD and treatment can involve medication, mainly anti-inflammatory drugs, infusions, dietary treatment and surgery (Nicholas et al., 2007). These treatments can lead to visible difference, such as 'moon face' (facial swelling) caused by steroid use or the addition of a stoma bag (Dibley et al., 2018).

Bishop, Lemberg and Day (2014) highlighted the peak age for onset is between 15 and 35 years of age. It has been suggested that the prevalence of IBD in children and young people has increased, with 30% of patients being diagnosed before 21 (Karwowski, Kelijo & Szigethy, 2009). Consequently, many individuals

are diagnosed in their adolescent years. This is a critical developmental period, where identity, social skills and beliefs are shaped and developed (Karwowski et al., 2009). The presence of a chronic health condition, such as IBD, at this developmental stage can have important implications for disease outcomes through the life span (Williams, Holmbeck & Greenley, 2002). In addition, the characteristics of IBD, such as frequent visits to the bathroom and delayed puberty, can be a source of embarrassment and contribute to feeling different from peers at an age where adolescents strive for similarity (Greenley et al., 2010).

Existing research into the lived experience of IBD has been mostly within an adult population. For example, patients with UC highlighted they made important changes to their lifestyle as a result of the physical discomfort and emotional impact of this diagnosis (Sammut, Scerri & Borg Xuereb, 2015). Furthermore, interviews with female patients found an overarching theme of ‘balancing my disease’ which developed from the participants’ acknowledgement that they had to modify their lives to live with IBD (Sykes et al. 2015). Adjustment to living with IBD in an adult population was explored by Matini and Ogden (2015), who found the idea of the ‘new normal’ as central to adjustment. Patients would seek to recover a sense of normality by balancing life before and after diagnosis. However, recruitment for this latter study was through an online support group and participants highlighted shared experiences through social network as important in adjustment. Therefore, these ideas of adjustment may not be generalisable to all IBD patients.

Research into IBD in adolescence is more limited with a quantitative focus. A systematic review compared an IBD population to healthy controls, finding that children with IBD may be at greater risk for difficulties in emotional and behavioural functioning than their healthy peers. Although functioning in adolescents with IBD is similar to other paediatric chronic illness populations (Mackner, Sisson & Crandall, 2004). A meta-analysis of psychosocial adjustment of youths with IBD, albeit with a moderate number of studies, found that youth IBD patients had higher rates of depressive disorders, when assessed by clinicians, compared to youth with other chronic conditions (Greenley et al., 2010). However, in contrast, the patients self-report of symptoms of anxiety and depression did not differ from healthy peers and children with other chronic illness. This discrepancy may be because patients attribute symptoms to IBD rather than psychological difficulties. Other measures in the same study, such as social functioning and quality of life, showed discrepancies between patient and parent reporting, with parents often reporting more favourably than patients. This may be due to a lack of shared understanding between patients and parents about the difficult social challenges associated with IBD. This may highlight the lack of understanding from others about the challenges faced by young people living with IBD.

Qualitative research into youth experiences of IBD found that patients experience concerns and discomfort as a result of IBD symptoms, which can lead to a sense of vulnerability and a lack of control over their lives (Nicholas et al., 2007). Nicholas et al. (2007) reported that patients viewed themselves as different from their peers and highlighted that IBD negatively targets areas where adolescents may be most vulnerable, such as appearance and height. These IBD related worries

were more pronounced in adolescents than younger children. Although valuable, this study was conducted in Canada, which has the highest reported prevalence and incidence of IBD in the world (Crohn's and Colitis Foundation Canada, 2008). Therefore, patients have been treated in a different healthcare system and society context to the UK and findings may not be transferable to a UK population. Other research in Sweden (Brydolf & Segesten, 1996; Lindfred, Saalman, Nilsson, Sparud-Lundin & Lepp, 2012) has provided some valuable findings highlighting the importance of encouraging adolescents with IBD to communicate with healthcare professionals and stressing the value of social support for positive outcomes. However, again, this research was conducted within a different healthcare and social setting to the UK.

The research outlined above has contributed to understanding the biological, psychological and social components of IBD. This biopsychosocial approach (Engel, 1980), is used to understand the components of disease from a broader, more integrated perspective (Smith, 2002). However, with much of the research focussing on adults, the biopsychosocial understanding of adolescents with IBD is more limited. This is especially pertinent as adolescence is considered to be a crucial transitional period which is characterized by more biological, psychological and social changes than any other life stage, with the exception of infancy (Williams et al., 2002). An understanding of the biopsychosocial model of health conditions helps us to appreciate the factors that can influence the development, course and outcome of the disease (Havelka, Lucanin & Lucanin, 2009). When the biopsychosocial elements of adolescence intersect with the biopsychosocial components of a health condition, there can be unique challenges in the

management of the health concern (Christie & Viner, 2005). Therefore, it could be considered unhelpful to apply an adult based biopsychosocial understanding of IBD to adolescents and, consequently, there is a clinical need to further understand the biopsychosocial components of IBD for adolescents.

In summary, the current literature provides insight into an adults' experience of living with IBD. It also highlights some of the difficulties that paediatric patients with IBD may experience in comparison to healthy peers or children with other chronic health conditions. Quantitative studies have gone some way towards helping to understand the psychological and social components of IBD. However, there is more limited understanding of how IBD is experienced by the adolescent population. To the author's knowledge, this is the first study to explore the lived experience of adolescents with IBD, living in the UK and being cared for within the UK National Health Service (NHS). IBD is a diagnosis that is most common in adolescence (Bishop et al., 2014), and may negatively influence important aspects of adolescent development, such as puberty and social acceptance (Greenley et al., 2010). Therefore, a richer understanding of the psychosocial elements of IBD in adolescence would be valuable. This study will be exploratory in nature to gain an in-depth understanding of an adolescent lived experience of IBD so is most appropriately researched from a qualitative perspective. Therefore, the research questions are broad and open ended;

- What is the lived experience of an adolescent with IBD?
- How do adolescents understand and make sense of IBD?

Method

Participants

The identified age range for participants was between 12 and 16.

Adolescence is defined by the World Health Organisation (2018) as between 10 and 19, however a lower age limit of 12 is reflective of evidence that suggests from this age young people are capable of giving insightful answers, an important skill for the richness of data required for this research (Gibson & Possamai, 2002). The upper age limit is indicative of patients transferring to adult services at 16.

Purposeful sampling was used to allow the researcher to select participants based on their experience of living with IBD (Smith & Osborn, 2003). Eight participants, with a mean age of 14.6 (range 13-15 years) and 62% female participants ($n = 5$), were recruited from a NHS Paediatric Gastroenterology tertiary centre. This team provides medical and nursing input for young people with IBD with additional multi-disciplinary input available in the wider team, such as clinical psychology and dietetics. Participants had held a diagnosis of IBD for at least six months to allow for adjustment to the diagnosis and sufficient 'lived experience.' The mean length of time since diagnosis was 3 years (range 9 months to 6 years). All participants were in remission at the time of interview meaning that IBD symptoms were not currently experienced or, if experienced, at a lesser intensity. Participants were required to be fluent in English. Participants were excluded from the study if they might find the interview process difficult or distressing. Participants were assigned pseudonyms to protect their anonymity. Demographic information can be found in Table 1.

Table 1.
Demographic Information

Pseudonym	Gender	Age	Ethnic Group	Diagnosis	Length of diagnosis (years)
Harriet	Female	15	White British	CD	3.5
Gemma	Female	15	White British	CD	0.75
Louise	Female	13	White British	CD	1.5
Marie	Female	15	White British	Unclassified IBD	6
William	Male	15	White British	CD	6
James	Male	14	Mixed ethnic group	CD	3
Ella	Female	15	White British	UC	1.8
Toby	Male	15	White British	UC	3

Design

Qualitative semi-structured interview design (see Appendix H) allowed for an in-depth exploration of the adolescents lived experience. All interviews were conducted by the first author (HC). Two pilot interviews were conducted to establish the validity of the interview structure. The interview was deemed suitable and therefore not changed for future interviews. Due to this, interview data collected during the pilot interviews were included in the analysis. These data were analysed using an Interpretative Phenomenology Analysis (IPA) approach. The primary aim of this approach is to collect rich, detailed, first-person accounts of an individual experience of a particular phenomenon or to understand the participants' lifeworld (Larkin, Watts & Clifton, 2006). The consolidation criteria for reporting

qualitative studies (COREQ; Tong, Sainsbury & Craig, 2007, see Appendix I) were utilised to ensure complete and transparent reporting.

Setting

Interviews were conducted face-to-face at the participants home or parents place of work. One interview was conducted at the hospital during the participants routine clinical appointment. Interviews were offered at the hospital in all cases but were mostly declined due to the extensive geographical area covered by the hospital. Parents were present for five of the eight interviews.

Measure

The interview schedule was informed by literature and discussion with the clinical care team and research team. A young people's Patient and Public Involvement (PPI) board was consulted to ensure appropriate wording and accessibility for this age group. Adjustments to wording and images on participant material were changed following the board's recommendations. The interview schedule allowed for flexibility so participants could lead the direction of the interview and ensure important issues were discussed (Smith & Osborn, 2003). Interviews started with general open questions such as, 'What is your understanding of what IBD is?', followed by more specific questions, such as, 'What is your understanding of your diagnosis?', designed to elicit more in-depth detail (Smith & Osborn, 2003). Interview questions were grouped into five key areas: understanding of IBD, living with IBD, impact on personhood, impact on relationships and self-care.

Reflexivity

Interviews were conducted and analysed by the first author (a female post graduate clinical psychology student). Themes emerging from the transcripts were discussed with a second author (clinical psychologist) to ensure themes were representative of, and situated in, the data. Both authors, particularly the second author, had experience of working with young people in a health setting. The first author is a parent to a child with a long-term health condition and these experiences and personal narratives contribute to the interpretative process and the credibility of the research (Horsburgh, 2003). A critical realism stance was taken as there is an interest in seeking a truth but an acknowledgement that context is important and the truth could never be fully understood.

Procedure

Potential participants were approached by a member of the clinical care team and invited to take part in the study. If consent to contact (see Appendix J) was given, the researcher telephoned those interested to discuss the study further. As all participants were under 16 years of age, both parents and participants were spoken to during this telephone call. All parents and participants contacted agreed to take part and an interview date and time was booked for at least 7 days after this contact. This allowed time for age appropriate information sheets (Appendix K) and consent forms (Appendix L) to be received and read prior to the interview.

Prior to each interview the participants and parents were provided with a recap of the purpose of the study and given an opportunity to ask any questions.

Informed consent was taken from parents and assent was taken from participants. Interviews started with the collection of demographic information (Appendix M) which helped with rapport building, an important aspect of IPA, particularly when participants are being asked to talk about sensitive subjects (Smith, Flowers & Larkin, 2009).

Interviews were conducted between June 2018 and August 2018 and lasted between 30 and 75 minutes. Interviews were audio recorded and, later, transcribed. The first author transcribed six of the eight interviews, two were sent for transcribing through a reputable company and a confidentiality agreement was signed. Participants were given a £10 voucher in acknowledgement of their time. The clinical team were sent a letter to advise of an individual's involvement in the research project (Appendix N).

Ethical Issues

Ethical approval was gained through HRA assessment and REC committee and capacity and capability of the participating NHS trust to support the research was established (see Appendix O). All participants were under the age of 16 years so in addition to written assent from participants, parental consent was sought and gained. Interviews were transcribed and any potential identifiable information was changed or removed. Pseudonyms were used throughout to protect confidentiality. Participants were fully debriefed and informed that they could withdraw from the study up until the point of data analysis, which was 7 days after the interview.

Data Analysis

Transcribed interviews were analysed following IPA recommendations (Smith & Osborn, 2003) by the first author. The main aim of IPA research is to capture elements of an individual's lived experience and investigate how sense is made of these experiences (Pietkiewicz & Smith, 2014). Further details of the analysis process can be found in the extended methodology. The sample size of the current project is slightly larger than recommended for an IPA study (six participants is suggested by Smith, Flowers & Larkin, 2009). Due to this, the focus of the analysis inevitably shifts to assessing emergent themes for the whole group. However, in staying true to an IPA approach, these group level themes are illustrated by particular examples from participants. The overall themes discussed below were chosen based on their data richness and relatedness to understanding the lived experience. Qualitative research software, Nvivo 12, was used to aid the data management process.

Results

The experiences shared by the adolescents within this study highlighted three overarching superordinate themes: The Turning Point for Health, Resilience and Acceptance, and Fragility of Health Position. These overarching superordinate themes comprise of between two to four subordinate themes. The subordinate themes were drawn from the superordinate themes in individuals' transcripts and patterns were then looked for across transcripts. The structure of these themes can be found in Table 2. Further details about the emergent themes and superordinate themes for each participant, and the subordinate themes and overarching superordinate themes drawn from across participants, are presented in Appendix P

and Q. A diagrammatic representation of these themes, as informed by Wright et al. (2015), is detailed in Appendix R.

Table 2.
Superordinate and subordinate themes

Superordinate themes	Subordinate themes
The Turning Point for Health	i) The journey to diagnosis ii) Relief in diagnosis iii) The treatment journey
Resilience and Acceptance	i) Normality resumes vs. different normal ii) Responsibility for self
Fragility of Health Position	i) Invisible unpredictability ii) Different to peers iii) Impact of others iv) Physical vs. psychological

The researcher observes links across these superordinate themes whereby the Turning Point for Health appears to be a position that all participants experience before moving into Resilience and Acceptance. This movement has a sense of being unidirectional, and, even in the face of relapse, is not reversed. The theme of Resilience and Acceptance was apparent in all participants but there was a sense of fragility about this, which is further explored in the final theme.

The Turning Point for Health

i) The journey to diagnosis. All participants talked about the journey to diagnosis and for some participants this was lengthy. Louise (age 13) shared an example of her experience, which also captures the unpleasant pain associated with IBD:

At Christmas time I was in a lot of pain, I think. Then, I'd missed a lot of school before that Christmas break and then I'd missed a lot after. I think we had been to the GP quite a lot, maybe four times. I think that's when it started. Then, we got referred to private doctors and other places just to talk about it. We went to someone and then he said it could be colitis. I had the endoscopy and we found out it was Crohn's Disease.

This experience of time taken to gain answers for symptoms was also experienced by Marie (age 15):

It was confusing, to be honest. I didn't know what was going on and other people didn't know what's going on, but I just knew something was wrong. It was just the uncertainty of it, it just panicked me a bit when I was younger.

For these individuals, where diagnosis took time, there was a sense of confusion and uncertainty. James (age 14) described doctors as putting his symptoms down to ‘*something that it wasn't*’. This sense of uncertainty was described by Louise as ‘*not knowing who to believe*’. For Marie this uncertainty manifested in a feeling of not being believed by healthcare staff. It was acknowledged by these individuals that the process should not be as lengthy as it was. Louise described it as:

It was weird knowing that it had gone on for so long and that it should really have come to an end but it didn't.

For some participants the diagnostic process was considerably quicker and the benefit of this was acknowledged by Ella (age 15):

It wasn't very long from when I got unwell to when I was diagnosed. I guess I just wasn't really thinking about it. It was good that a diagnosis was early though because that meant it could be dealt with quicker.

ii) Relief in diagnosis. Irrespective of the time taken to diagnose symptoms, participants shared the experience of diagnosis being a relief. This appeared to come from having an understanding of the symptoms and, importantly, the move towards a treatment to help the symptoms. Harriet (age 15) described this:

It was a relief. I was like, "Okay, now, I understand why this is happening."

Marie describes a similar emotional response to diagnosis:

It was much easier when I knew what was wrong and then there was something that can be done about it.

Gemma (age 15) talks about the relief at being given a different diagnosis to what she was expecting:

I wasn't upset, I thought it was just weird because I always thought I was an Ulcerative Colitis person, I was, "Cool." But I was more like that's better though because I'm sure medication for Crohn's is more targeted.

There was a sense that diagnosis was a turning point as it brought hopefulness about medical intervention to help alleviate, or at least reduce, the symptoms participants were experiencing.

iii) The treatment journey. Participants' experience of finding the correct treatment for their IBD appears to be a process. This was described by Toby (15) when he said: *'I'd have to keep taking different types of medication, seeing what works, what doesn't.'*

But ultimately the participants saw this as the point where symptoms would start to improve. William (15) acknowledged this and hints at an expectation that normality would resume once the right treatment was discovered:

Obviously, other than finding the right medication for me to get to normal, then from there it's been pretty clean sailing all the way to here.

Harriet reflects with hindsight about the importance of getting her medication correct when she says: *'I didn't quite get how serious it could have gotten if the treatment hadn't happened as quick as it did.'* She later goes on to acknowledge the importance of the right treatment and the difference it made to her experience of having IBD: *'It got better because I was on the treatments and everything. I was getting more energy. I was putting on weight and I felt a lot healthier in myself.'*

At this point there is a sense that the adolescents have moved from a place of ambiguity and confusion into a place of more certainty and starting to live with treated IBD. There appears to be a shared experience that once the adolescent has reached this point, they will not return to the place they were, even when in a relapse of symptoms. Although, it is important to note that all participants were currently in remission of their IBD symptoms and therefore their reported lived experience at this time may have a more positive stance.

Resilience and Acceptance

i) Normality resumes vs. different normal. Some participants talked about a return to normality which captures a sense of going back to how life was before diagnosis and the onset of symptoms. In contrast, others felt a different normal was constructed following diagnosis that allowed life to continue with the addition of IBD related considerations. Louise describes her experience of normality resuming, which is summed up in the final sentence of this quote:

I think when it was really bad, I'd say it was really painful but now that I'm on better medication and that we found something that works at the moment. I think the hospital is doing pretty well. Living life like I was before I had IBD.

James describes a process of life returning to normal with the use of the word 'back', rather than there being a different type of normal: *'It was just like normal and then went bad for a while and then went back to normal.'* He later goes on to talk about life following surgery and says: *'It went back to normal. It wasn't that hard. A*

couple of weeks, my back ached when I walked. Off sports for a couple of weeks and then it went back to normal.'

For other participants, there was a sense of a different normal following the appearance of IBD in their lives. William reflected on what it was like taking more medication, following a recent increase: *'I don't know. I never really think of it, I just get into it. This is normal for me.'* Harriet talked about a period of adjustment and getting used to having IBD: *'I think as the years went by where I've had it, I've just gotten used to it and that's just the way I decided to sort everything out.'*

Toby talks about IBD not stopping him doing anything, however the use of words such as 'try' and 'most' (in bold below) may suggest that his life is different following diagnosis, despite an obvious determination to ensure it is not:

*It hasn't stopped me doing anything. I still **try** to get back into stuff that I used to do before I had a flare-up, or I used to have IBD. I still play **most** of the stuff, sports I used to play before I was diagnosed with it.*

The similarity within participants of normality resuming, or normality resuming in a different form, following diagnosis and treatment is an important aspect of an individual's lived experience and seems an important insight that should be shared with individuals who are earlier on in their IBD journey. The difference between participants in experiencing a return to normality versus establishing a

different normal is an interesting concept and may reflect a difference in coping strategies.

ii) Responsibility for self. The researcher was struck by the maturity of the participants involved in this study and this was exemplified by Marie:

It has been commented upon that I'm a lot more mature than most people my age would be, but that's simply because I spent so much time in hospital and it's just a different environment. I've basically grown up somewhere else than other people would have.

This maturity was also reflected in the responsibility the adolescents appeared to take for their own wellbeing and management of their IBD. This included developing a medication routine, self-monitoring physical symptoms and pacing activity. Gemma discussed this:

I make sure I'm not pushing myself, although I know I wouldn't push myself anyway. I'm more likely not to push myself than push myself too far, so that really wasn't really a worry for me.

Marie also discussed the responsibility she takes for monitoring her physical wellbeing:

It's made me a lot more aware of myself physically because I have to be constantly aware of what I'm doing, and if I'm pushing myself too hard, and

this would have consequences later on or just simply that I can't do that and that's a full stop.

Ella talked about the responsibility she takes for her treatment routine:

You just take medication at the right time and go for blood test, stuff like that. Just keep on top of everything and remember stuff.

The taking of responsibility for IBD was also observed in the attitude the adolescents had to their diagnosis. Gemma talked about the importance of acceptance of her IBD and how this can be difficult at times:

It's just accepting that it's not like it's anyone's fault. It's just there's not much you can do about that. You really do just have to suck it up and get on with it, which is hard to accept when you feel so tired.

Marie discussed her resilient attitude to having IBD and her determination to not let it affect her life, or be used as an excuse:

I like to think I deal with it well, because it doesn't affect me much. Other than the Infliximab, I don't consciously really do anything about it, because I don't like to use it as an excuse. I've never used it as an excuse for anything, other than when genuinely I can't do anything. It doesn't really affect me now anymore, because I don't let it affect me. I don't want it to. It's too boring to let that affect me.

William reflected on how IBD may have impacted him in a positive way:

I don't really see much difference. I remember myself obviously, before it, in a couple of bits at school, and that. I think it's made me stronger, I suppose, having it. I mainly say, "Just get on with it, just do it. Stop complaining, it could be worse."

Toby describes how his life could be different during the unpleasant experience of a flare up of IBD and acknowledged his resilience in the process of getting 'used to it' which presumably leads to it being 'not all that bad':

No, it's not all that bad other than the flare-ups. It's bearable. Sometimes when you just can't really do anything, it's quite annoying. You just get used to it and get on with it.

The level of responsibility, for self and IBD, taken by these participant's is evident in these interviews and this may be important in encouraging resilience in the face of IBD and accepting the changes that are made to life as a result of it.

Fragility of Position

Despite many participants feeling that they had returned to a sense of normality following diagnosis and treatment, and demonstrating impressive resilience and acceptance in the face of IBD, there was a feeling that this position of

health was fragile and could change at any time. Participants reflected on four main areas that contributed to this sense of fragility.

i) Invisible Unpredictability. IBD is an unpredictable condition and this was reflected in the participants experience. Toby talked about the unpleasantness of a flare up and captures the challenge of living with IBD:

It's like one minute it could be just fine and then it could just flare-up and then you'll be really ill. You have to be at the hospital, have some tests where it could just be minor and take some different medication and it's all alright, and it'll keep repeating like that.

Ella discussed IBD being an ‘*up and down*’ condition, but, consistent with the unidirectional ideas described above, she goes on to say: ‘*but it's never gone below the point where-- When I first was taking the Mesalazine, it's gone up and down but never below that point.*’ Gemma discussed the unpredictability, using an ‘edge’ as a representation of her delicate position: ‘*I'm always going to have to be just on edge of I might become ill any second*’

There were some frustrations about wanting to meet own or others expectations but needing to pace activity and not do anything that might lead to a flare up of symptoms. Marie talked about this in relation to participating in competitive sport and appearing healthy to others:

It can be frustrating, but also at times, it can be ‘why can't I do this’ because I want to do better and I don't want to not do what they're (the coaches) saying. I try to push myself to try and meet their expectations, but

then that usually means my medical side declines, so I try to meet their expectations, but it's not necessarily in my best interest.

The invisible nature of IBD was also pertinent for some participants and how this might impact others expectations and judgements. Marie said:

Because I don't look like the typical person who's sick or comes into the hospital every eight weeks, so people just think by that, it's like, "She can do this," but in reality, I can't.

Gemma talked about the dilemma of wanting to use a wheelchair because of her IBD-related fatigue:

It was physical, but it wasn't like I broke my leg. It wasn't like that. It was just I was choosing to, which I felt like I shouldn't choose to be in a wheelchair. It's like, no one wants to be in a wheelchair, so I felt that that was choosing to, in that way.

The unpredictability of IBD contributes to the feeling of fragility as described by the participants. The concept of an invisible illness appears to compromise the resilience to, and acceptance of, IBD for some participants and presents a dilemma of internal ability versus assumed ability.

ii) Different to peers. Some participants talked about the comparisons, made by themselves and others, to their peers and others. Louise viewed this difference from an anatomical perspective in how she made sense of her body difference. For the researcher, the use of the word ‘barnacles’ conjures up an unpleasant and painful experience:

It looked like a normal gut and then my one. The normal one was smooth on the inside like a flowing tube. Then, my one had bumps or like barnacles almost if you see on the bottom of the boat, the hole is big for the food to pass through.

Harriet discussed how comparison by her peers led to some unwanted attention:

Sometimes it's annoying because sometimes you're like "You've never paid attention to me before so why all of a sudden. I've been to hospital and now you want to know everything about me." It's just a bit like, do you really want to be there and support me or are you just wanting to know the ins and outs of everything I'm doing.

Harriet also acknowledged how she perceived her difference to her peers when she said: ‘*I couldn't quite do everything everybody else was doing and I was struggling more and things like that.*’ She later compared her physical symptoms with others, acknowledging difference: ‘*It's quite annoying because everyone will have a tummy ache but this is constant whether I realise it or not and they're very different. This one can make you feel tired. It can make you feel sick. It can just*

make you just not want to move whereas a tummy ache just go whereas this could last a whole day or week.'

Marie reflected on how this comparison to peers can be evident within the school environment:

You're not meant to be going to the toilet because other students without the condition weren't going to the toilet. It's not that they were being completely rude about it, it's just they didn't know or understand.

At a stage of life where similarity and fitting in with others is important, the difference described by these participants may present some difficulties in continuing to be resilient in the face of IBD.

iii) Impact of others. The role of others in either contributing to the fragility of the health position, or providing strength to reduce the fragility, was evident for a number of participants.

Gemma talked about the difficulty of sharing her experiences with others. She felt that others struggled to understand her IBD because they were not going through it themselves but she also appeared to feel a sense of responsibility to protect others from her condition:

I'm not scared about telling people it's more just they can do without me telling, not me telling them. If they really want to know about it, they can just look for it.

She reflected on the importance of having a friend with a similar diagnosis and how this ensured understanding between the friends. This quote also provides an insight into the unpleasant symptoms associated with IBD:

It was just nice to have someone there who understood it and we don't, sorry TMI (too much information), but we call it burning bumhole and she's like, "I had burning bumhole last night" and I was like, "I know what you mean"

Marie also talked about the role of the understanding of others in impacting her IBD coping:

(When talking about friends) It was something they didn't fully understand and that put something between us in a way, but they got over that because it was just at first it was quite difficult.

(When talking about a teacher) she's doesn't quite understand it so she gets almost over the top at times. It's not unwanted, but it also is because it's nice that she has a concern, but she doesn't know how to deal with it.

Toby reported a positive experience of family support which appears to play an important role in his resilience:

Everyone knows what happens and everyone's really nice. They do whatever to help me to keep going and see if there's anything I can do in the house while I'm off.

It seems that understanding of IBD, and the experience of living with it, is fundamental for others to have a positive impact on the participants. This allows for more beneficial support, which may play a part in enhancing the resilience of the individual.

iv) Physical vs Psychological. Some participants reflected on their experience of the link between their IBD symptoms and psychological wellbeing. Ella gave a coherent explanation of her experience:

I'm not quite sure how to explain it in the way that-- When the IBD is worse, I have to go to more appointments and get more blood tests. If I've got a lot of work on and I can't go to school, having to miss school, then I feel like I'm behind and then I have to catch up. That makes me more stressed. Then the stress also affects the IBD a bit more. Only a little bit.

Louise considered whether psychological processes, such as worry, may have impacted on her IBD:

I think it probably was myself, to be honest, just me, mentally, maybe worrying a bit too much and just about worrying about what's going to happen and what I'm missing while I'm at home just sitting on the toilet

..... I think sometimes I did get a little bit more worse when I was stressed about school and friends and everything and missing work, missing out and everything but I think, yes, it just, got worse a little bit not by much I wouldn't say.

Gemma discussed the dilemma of whether symptoms are physical or psychological: *'That was always hard trying to find a balance of what is a nervous my tummy hurts because I'm about to do something new, and what is an actual pain.'* James also expressed some difficulty between knowing whether a symptom has its origins in IBD, or was psychosomatic, and this was also noticed by his parents:

Like my dad said he's noticed it, as well as my mum. From stress or something. I get more belly aches..... I've never taken much notice, but I think, there could actually be a link. I do think whenever I get stressed I do get belly aches. I just don't really make the link.

For some of the participants, their experience seems to include links between stress and IBD. This is particularly pertinent at a developmental period where adolescents are sitting exams and are under pressure to fulfil their academic potential. For an unpredictable condition, that can lead to needing time off school, it is understandable how this could impact psychological wellbeing.

Discussion

The results from this study provide us with some insight into the lived experience of adolescents with IBD. Furthermore, it provides some understanding about how IBD, and living with IBD, is made sense of by these adolescents. This study adds to a body of literature that has researched the phenomenon of living with IBD in a number of ways. Firstly, it utilises an IPA approach to gain an in-depth understanding of an individual's experience and, secondly, it is the first study to explore an adolescent's experience of living with IBD within the UK health system.

The importance of diagnosis, and the process of finding the correct treatment, was evident in the lived experience of all participants and is interpreted by the researcher as being 'The Turning Point for Health'. This experience for young people with IBD has not been phenomenologically explored before and, given that peak onset of IBD is in adolescent years (Kelsen & Baldassanno, 2008), this understanding of an adolescent's lived experience of diagnosis is of value for clinicians and other IBD patients. Research into adolescents receiving a cancer diagnosis (Bellizzi et al., 2012) found that it could have a positive impact on health competence (i.e. confidence in an individual's ability to take care of health). It may be that this is experienced by our adolescents and explains why this theme has a sense of a 'turning point' and was not returned to, even when discussing relapse. Although it is again noted that the participants within this study were currently in remission which may affect how relapse is discussed.

This idea of health competence is also reflected in the second theme of “Resilience and Acceptance”. The themes within this are supported by previous research by Sykes et al. (2015), who found an overarching theme of ‘balancing my disease’, and Matini and Ogden’s (2015) theme of the ‘new normal’. It seems a similar process is experienced by some of our adolescents who establish a ‘different normal’ following diagnosis. Interestingly, some of our adolescents felt that they could live as they did before IBD, rather than needing to make changes. These adolescents had made changes to their life, such as taking daily medication or visiting the hospital regularly, but it seems these are not seen as being different to before IBD. This return to normality is not talked about in the adult literature and it may be that the time of diagnosis for these individuals (in early adolescence) means these changes can be more integrated into their lives. Adolescence is a transitional period with an abundance of change happening (Williams et al. 2002) and for some of our participants, changes made due to IBD may be included in this and therefore a different normal may not need to be established.

There are a number of themes, under the umbrella of ‘Fragility of Health Position’, that describe experiences that could play a part in modifying the adolescent’s ability to maintain acceptance and resilience in the face of IBD. The ‘face’ of IBD refers to the unpredictability of a condition that can be challenging, unpleasant and painful. The themes contained within ‘Fragility of Health’ have a number of crossovers with the ideas presented in Nicholas et al. (2007). This research was conducted on an adolescent population with IBD in Canada and also highlighted the difficulty with the unpredictable nature of IBD and feeling different

to peers. Adolescence is a stage of life where being similar to others and fitting in is important (Greenley et al., 2010) and it is likely that healthy peers also experience feelings of being different to peers but IBD complicates this normal developmental stage further.

The importance of social support is also evident in Nicholas et al. (2007) and Shepanski et al. (2005), who demonstrated that attendance at an IBD specific summer camp, with an abundance of social support and normalising of the disease, improved quality of life. Interestingly, participants in the current study highlighted the importance of others' understanding in improving ability to provide support. This sense making of what valuable support looks like for adolescents may be of benefit for clinical teams.

Study limitations

The majority of the interviews took place at the participant's home. While this was convenient due to the wide geographical area, it may have had an impact on an individual's openness as parents were present in five of the eight interviews. There was a lack of content pertaining to intimate relationships and the presence of parents may have impacted on these themes being discussed. However, this may be indicative of chronic health difficulties leading to some slowing in development (Christie & Viner, 2005) and therefore this developmental stage may not have been reached. Despite the presence of parents, the data were of rich quality and the young people appeared eager to share their experiences enabling a phenomenological analysis to be carried out. It is acknowledged that having parents

present may have provided support to the young person and, at times, the parent was able to prompt the young person to provide more detail.

The participants were purposefully sampled by the care team, and while this was necessary for sufficient experience of living with IBD, it may have also meant that a certain type of patient was asked to participate in the research. The researcher is not aware of anyone who declined to take part in the study, which may indicate that individuals more willing to share their experiences were approached. Furthermore, this sample appear to be well supported by a specialist multi-disciplinary team and this valuable support may be reflected in the impressive resilience and maturity observed by the researcher. This would mean that the experiences that were found to be shared by this cohort of patients, may not be transferable to other adolescents with IBD.

Participants were representative of a younger, and quite narrow, adolescent cohort, and while this was necessary for recruitment, it does present challenges for the generalisability of the findings throughout a wider adolescent group. This may be further complicated by the delay in development that can be observed in children with chronic health conditions (Christie & Viner, 2005). This is pertinent as children and young people's services are increasingly adopting a 0-25-year-old model and the understanding of adolescents and their lived experience could be very different throughout this age range. The sample had an equal gender representation and while this provided an illustrative sample it may have been helpful to focus on a particular gender to further understand the phenomenon and idiography of living with IBD.

At the point of interview none of the participants were in a period of relapse. Relapse can be challenging in terms of unpleasant symptoms and changes in treatment. Participants being in remission may have been necessary to conduct an interview in appropriate circumstances but it may also change how someone talks about their lived experience. Retrospective reporting of being in relapse may not be reliable, as it is not adaptive to remember negative experiences, and many of the participants were settled with their treatment routine meaning that a relapse may not have happened recently. Furthermore, the young sample, some with fairly recent diagnosis, means participants may not have experienced some of the most difficult aspects of IBD, such as repeated episodes. Therefore, it may be that the themes that emerge from a cohort of patients who have recently experienced, or are in, a relapse may be quite different. Nonetheless the IPA approach is concerned with an individual's experience, rather than trying to generalise across all adolescents with IBD and that is reflected in this study.

Implications for clinical practice and suggestions for future research

The findings of this study highlight the importance of early diagnosis for young people with IBD. Encouragingly, once participants were seen by specialist services, diagnosis happened quickly. However, for a number of participants, the process to reach this point was lengthy and contradictory and, for a disease where peak onset is in adolescence, it seems education about the signs and symptoms of IBD would be beneficial for healthcare providers so timely onward referrals can be made.

The participants shared a number of ways they had taken responsibility for their health and the similarities in these may suggest that early intervention to introduce these ideas to patients with recent diagnosis may be beneficial. The importance of the understanding of others to provide helpful social support was evident for our participants. Therefore, early intervention could benefit from being a group format to allow opportunity for participants to access social support where understanding is coming from a place of lived experience. In addition, services would benefit from offering support to families and schools, and any other individuals involved in the young person's system, to build their understanding of IBD and therefore provide more helpful social support. CBT informed interventions for young people with IBD have been developed and evaluated (Szigethy et al. 2004, 2007, 2014 & Reigada et al. 2013, 2014, 2015) however these are aimed at patients who present with depression or anxiety. Our research would suggest that any young person diagnosed with IBD, not just those with depression or anxiety symptoms, may benefit from some intervention to provide social support and consider how they might take responsibility for health. This would need to include an element of parent involvement in order to promote understanding and facilitate helpful social support.

Further research may wish to consider the lived experience of adolescents during a relapse and consider how this might differ to an experience of remission. This would provide a more holistic view of the lived experience of an adolescent with a relapsing and remitting disease such as IBD.

Conclusion

The experience of diagnosis, and finding the correct treatment, was important in our participants' IBD story. At the time of interview our participants were in a place of resiliency and acceptance of their IBD and the responsibility and maturity of their approach to IBD was noticeable and encapsulated in the themes. Our participants lived experience includes IBD-related difficulties such as comparison to peers and living with unpredictability of when a flare up of painful and unpleasant symptoms might happen. Social support appeared beneficial particularly when it is provided by someone with understanding of the disease. The importance of this is highlighted to help improve the support from clinical services and the young person's wider system.

Acknowledgements

The authors would like to thank Sally Benson and Megan Maidment for their help, knowledge and support in setting up this study. Thank you to Mary Brennan, Anna Foley and Caroline Lindsay for their help in identifying and recruiting participants. We would also like to thank the wonderful young people, and their families, who took part in this research for their valuable contribution to the study. We were also grateful for the time given by PPI boards for their advice on research material.

Disclosure statement

The authors have no conflict of interest to declare. This research was supported by the University of East Anglia as fulfilment of the Doctoral Programme in Clinical Psychology.

References

- Arvikar, S.L., & Fisher, M.C. (2011). Inflammatory bowel disease associated arthropathy. *Current Reviews in Musculoskeletal Medicine*, 4, 123-131. doi: 10.1007/s12178-011-9085-8
- Bellizzi, K.M., Smith, A., Schmidt, S., Keegan, T.H.M., Zebrack, B., Lynch, C.F., ... Simon, M. (2012) Positive and negative psychosocial impact of being diagnosed with cancer as an adolescent or young adult. *Cancer*, 118, 5155-5162. doi: 10.1002/cncr.27512
- Bielefeldt, K., Davis, B. & Binion, D.G. (2009). Pain and Inflammatory Bowel Disease. *Inflammatory Bowel Diseases*, 15, 778-788. doi:10.1002/ibd.20848
- Bishop, J., Lemberg, D.A. & Day, A. (2014). Managing inflammatory bowel disease in adolescent patients. *Journal of Adolescent Health, Medicine and Therapeutics*, 6, 1-13. doi: 10.2147/AHMT.S37956
- Brydolf, M. & Segesten, K. (1996). Living with ulcerative colitis: Experiences of adolescents and young adults. *Journal of Advanced Nursing*, 23, 39-47. doi: 10.1111/j.1365-2648.1996.tb03133.x
- Christie, D & Viner, R. (2005). ABC of Adolescence: Adolescent Development. *BMJ (online)*, 330, doi: 10.1136/bmj.330.7486.301

Crohn's and Colitis Foundation (2008). The burden of Inflammatory Bowel

Disease in Canada. Retrieved from

<http://www.ccfc.ca/atf/cf/%7B282e45d9-a03a-49d1-883c->

[39f4feaf7246%7D/BIBDC%20FINAL%20OCTOBER%2029TH%20EN.P](http://www.ccfc.ca/atf/cf/%7B282e45d9-a03a-49d1-883c-39f4feaf7246%7D/BIBDC%20FINAL%20OCTOBER%2029TH%20EN.P)

DF

Dibley, L., Czubier-Dochan, W., Wade, T., Duncan, J., Burch, J., Warusavitarne, J.,

... Cann, D. (2018). Patient decision-making about emergency and planned

stoma surgery for IBD: A qualitative exploration of patient and clinician

perspectives. *Inflammatory Bowel Disease*, 24, 235-246. doi:

10.1093/ibd/izx043.

Engel, G.L. (1980). The clinical application of the biopsychosocial model. *The*

American Journal of Psychiatry, 137, 535-544.

Gibson, R. & Possamai, A. (2002). What young people think about CAMHS?

Clinical Psychology, 18, 20-24.

Greenley, R.N., Hommel, K.A., Nebel, J., Raboin, T., Li, S., Simpson, P. &

Mackner, L. (2010). A meta-analytic review of the psychosocial adjustment

of youth with Inflammatory Bowel Disease. *Journal of Paediatric*

Psychology, 35, 857-869. doi: 10.1093/jpepsy/jsp120

Havelka, M., Lucanin, J.D., & Lucanin, D. (2009). Biopsychosocial model – The integrated approach to health and disease. *Collegium Antropologicum*, 33, 303-310.

Horsburgh, D. (2003) Evaluation of qualitative research. *Journal of Clinical Nursing*, 12, 307-312. doi:10.1046/j.1365-2702.2003.00683.x

Jordan, C. (2011). Stress and inflammatory bowel disease: Encouraging adaptive coping in patients. *Gastrointestinal Nursing*, 8, 28-33. doi: 10.12968/gasn.2010.8.10.28

Karwowski, C.A., Keljo, D. & Szigethy, E. (2009). Strategies to improve quality of life in adolescents with Inflammatory Bowel Disease. *Inflammatory Bowel Disease*, 15, 1755-1764. doi:10.1002/ibd.20919

Kelsen, J. & Balassano, R.N. (2008). Inflammatory bowel disease: The difference between children and adult. *Inflammatory Bowel Diseases*, 14, 9-11. doi: 10.1002/ibd.20560

Larkin, M., Watts, S., & Clifton, E. (2006). Giving voice and making sense in interpretative phenomenological analysis. *Qualitative Research in Psychology*, 3, 102-120, doi: 10.1191/1478088706qp062oa

- Lindfred, H., Saalman, R., Nilsson, S., Sparud-Lundin, C. & Lepp, M. (2012). Self-reported health, self-management, and the impact of living with Inflammatory Bowel Disease during adolescence. *Journal of Paediatric Nursing*, 27, 256-264. doi: 10.1016/j.pedn.2011.02.005
- Mackner, L.M., Sisson, D.P. & Crandall, W.V. (2004). Review: Psychosocial issues in paediatric Inflammatory Bowel Disease. *Journal of Paediatric Psychology*, 29, 243-257. doi: 10.1093/jpepsy/jsh027
- Matini, L. & Ogden, J. (2015). A qualitative study of patient's experience of living with inflammatory bowel disease: A preliminary focus on the notion of adaptation. *Journal of Health Psychology*, 1-10.
doi:10.1177/1359105315580463
- Nicholas, D.B., Otley, A., Smith, C., Avolio, J., Munk, M & Griffiths, A.M. (2007). Challenges and strategies of children and adolescents with inflammatory bowel disease: a qualitative examination. *Health and Quality of Life Outcomes*, 5:28. doi:10.1186/1477-7525-5-28
- Pietkiewicz, I. & Smith, J.A. (2014). A practical guide to using Interpretative Phenomenological Analysis in qualitative research psychology. *Psychology Journal*, 20, 7-14. doi: 10.14691/CPPJ.20.1.7

- Reigada, L.C., Benkov, K.J., Bruzzese, J-M., Hoogendoorn, C., Szigethy, E.,
Briggie, A., Walder, D.J., & MasiaWarner, C. (2013). Integrating illness
concerns into cognitive behavioural therapy for children and adolescents
with inflammatory bowel disease and co-occurring anxiety. *Journal for
Specialists in Pediatric Nursing*, 18, 133-143. doi: 10.1111/jspn.12019
- Reigada, L.C., McGovern, A., Tudor, M.E., Walder, D.J. MasiaWarner, C. (2014).
Collaborating with pediatric gastroenterologists to treat co-occurring
Inflammatory Bowel Disease and Anxiety in pediatric medical settings.
Cognitive and Behavioural Practice, 21, 372-385. doi:
10.1016/j.cbpra.2014.03.004
- Reigada, L.C., Polokowski, A.R., Walder, D.J., Szigethy, E.M., Benkow, K.J.,
Bruzzese, J-M. & Warner, C.M. (2015). Treatment for comorbid pediatric
gastrointestinal and anxiety disorders: A pilot study of a flexible health
sensitive cognitive-behavioral therapy program. *Clinical Practice in
Pediatric Psychology*, 3, 314-326. doi: 10.1037/cpp0000116
- Sammut, J., Scerri, J. & Borg Xuere, R. (2015). The lived experience of adults with
ulcerative colitis. *Journal of Clinical Nursing*, 24, 2659-2667. doi:
10.1111/jocn.12892
- Shepanski, M.A., Hurd, L.B., Culton, K., Markowitz, J.E., Mamula, P., Baldassano,

R.N. (2005). Health-related quality of life improves in children and adolescents with inflammatory bowel disease after attending a camp sponsored by the Crohn's and Colitis Foundation of America. *Inflammatory Bowel Diseases*, 11, 164-170. doi:10.1097/00054725-200502000-00010

Smith, J. & Osborn, M. (2003). Interpretive phenomenological analysis. In J.A. Smith (Ed.) *Qualitative psychology: A practical guide to research methods* (pp.51-80). London: Sage.

Smith, J.A., Flowers, P. & Larkin, M. (2009). *Interpretative Phenomenological Analysis: Theory, Method and Research*. London: Sage.

Smith, R.C. (2002). The biopsychosocial revolution. Interviewing and provider-patient relationships becoming key issues for primary care. *Journal of General Internal Medicine*, 17, 309-310. doi: 10.1046/j.1525-1497.2002.20210.x

Sykes, D.N., Fletcher, P.C. & Schneider, M.A. (2015). Balancing my disease: Women's perspectives of living with inflammatory bowel disease. *Journal of Clinical Nursing*, 24, 2133-2142. doi: 10.1111/jocn.12785

Szigethy, E., Whitton, S.W., Levy-Warren, A., DeMaso, D.R., Weisz, J. & Beardsless, W.R. (2004). Cognitive-behavioral therapy for depression in adolescents With Inflammatory Bowel Disease: A pilot study. *Journal of*

American Academy of Child and Adolescent Psychiatry, 43, 1469-1477. doi: 10.1097/01.chi.0000142284.10574.1f

Sziegthy, E., Kenney, E., Carpenter, B.A., Hardy, D.M. Fairclough, D., Bousvaros, A., ... DeMaso, D.R. (2007). Cognitive-behavioral therapy for adolescents with Inflammatory Bowel Disease and subsyndromal depression. *Journal of American Academy of Child and Adolescent Psychiatry*, 46, 1290-1298. doi: 10.1097/chi.0b013e3180f6341f

Szigethy, E., Bujoreanu, S.L., Youk, A.O., Weisz, J., Benhayon, D., Fairclough, D., ... Newara, M. (2014). Randomized efficacy trial of two psychotherapies for depression in youth with Inflammatory Bowel Disease. *Journal of American Academy of Child and Adolescent Psychiatry*, 53, 726-735. doi: 10.1016/j.jaac.2014.04.014

Tong, A., Sainsbury, P., & Craig, J. (2007) Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. *International Journal of Health Care Quality Assurance*, 19, 349-357. doi:10.1093/intqhc/mzm042

Williams, P.G., Holmbeck, G.N. & Greenley, R.N. (2002). Adolescent health psychology. *Journal of Consulting and Clinical Psychology*, 70, 828-842. doi: 10.1037/0022-006X.70.3.828

World Health Organisation (2018). Adolescent Health. Available from:

https://www.who.int/topics/adolescent_health/en/

Wright, J., Elwell, L., McDonagh, J.E., Kelly, D.A., Wray, J. (2015). 'It's hard but you've just gotta get on with it' – The experience of growing-up with a liver transplant. *Psychology and Health*, 30, 1129-1145. doi:

10.1080/08870446.2015.1024245

Chapter 4
Extended Methodology of Empirical Paper

Word Count: 3172

Chapter 4: Extended Methodology of Empirical Paper

This additional chapter is an extension of the methodology of the empirical paper. It will consider the qualitative approach in more detail and demonstrate why an IPA (Interpretative Phenomenological Analysis) approach was chosen to answer the research questions. A more comprehensive view of the data analysis is provided. Finally, the quality and rigour of the research process is explored.

Interpretative Phenomenological Analysis

Ontology and Epistemology

Qualitative research is concerned with meaning and experience and this, combined with the concepts of ontology and epistemology, make qualitative research notably different to quantitative research. Ontology refers to the study of being and to what extent reality is separate from human practices and understandings (Braun & Clarke, 2013). Ontology can be thought of as a continuum of positions ranging from realism to relativism. Realism is a dominant paradigm which believes there is an objective truth in the world. In contrast, the relativism perspective believes there are multiple constructed realities and therefore not one objective truth. These varying ontological positions are important within empirical research to provide a basis for the chosen methodology, for example a realism position would align with a quantitative methodology whereas relativism is more likely to inform a qualitative approach (Braun and Clarke, 2013).

For the empirical paper my ontological stance is from a critical realism perspective, which lies in the middle of the continuum described above. In the empirical paper there is an interest in seeking a truth but an acknowledgement that context is important and the truth could never be fully accessed as it understood through the researcher's interpretation of the participants' experience. From this stance, the world is real and identifiable but it is acknowledged that there is an inherent subjectivity in the production of knowledge (Madill, Jordon & Shirley, 2000). This stance seeks to explore causative mechanisms for what is experienced and observed. Because of this it is seen as an appropriate stance for the empirical paper as it illuminates the complexity of health through recognising that knowledge of this intricacy is filtered through an interpretative lens (Walsh & Evans, 2014). Critical realism encourages holistic exploration of a phenomena and this can be done through multiple research questions and research methods. Consequently, this stance has shaped the wider thesis portfolio in terms of research questions and the types of knowledge produced.

Epistemology is the theory of knowledge (Cohen, Manion & Morrison, 2007) and is concerned with how knowledge is created, acquired and communicated (Scotland, 2012). Again, this can be thought of as a continuum ranging from the dominant paradigm of positivism, believing we can know the truth, to constructionism, believing that what we know of the world is not separate from ourselves and knowledge is the product of social influences. Positivism provides a basis for quantitative research as it believes we can use empirical methods, while controlling for biases, in order to discover the truth. Whereas constructionism is wedded to qualitative research by a mutual appreciation for

human life complexities. Consequently, ontological and epistemological positions are not independent of one another and they inform the most appropriate methodology by which to access knowledge and answer a research question. The epistemological position of the empirical paper is discussed in more detail below.

Epistemological Underpinnings of Interpretative Phenomenological Analysis (IPA)

Phenomenology. This philosophical approach is committed to studying and understanding the experience of various aspects of human life and it provides us with a richness of ideas that help psychologists comprehend lived experience (Smith, Flowers & Larkin, 2009). Phenomenology was first discussed by Edmund Husserl, who described a careful examination of human experience by finding a way to help someone accurately know their own experience. Husserl's phenomenological method included the need to 'bracket' out our 'taken for granted world' in order to access our perception of the world (Smith et al., 2009) and use a series of 'reductions' to provide a different way of thinking about a phenomenon. These reductions ensure against the enquirer being misdirected by their own assumptions and instead allow the essence of the phenomenon to be captured. However, Husserl's work focussed on himself understanding his own experiences whereas psychological research is concerned with understanding others' experiences.

Later philosophers highlighted that we could only partially bracket out our preconceptions, and interpretation would lead us to be able to access an individual

lived experience (Smith et al., 2009). The empirical study has a phenomenological underpinning as it is interested in interpreting others' relationships to their world and how they make sense of their lived experience.

Hermeneutics. Hermeneutics is the second major theoretical underpinning of IPA and describes the theory of interpretation. Smith et al. (2009) describe a 'double hermeneutic' of IPA which acknowledges the interpretation the individual has of their lived experience, in addition to the interpretation that the researcher has on the participants interpretation. This hermeneutic approach is relevant to the empirical project as the researcher is making sense of the participants' sense making of their lived experience through her own interpretation.

Idiography. Idiography is concerned with the particular, with reference to the depth of detail and understanding of a particular experience for a particular person at a particular time. Therefore, IPA is an idiographic approach. This is in contrast to much psychological research which is concerned with generalising findings to a group or population level. Idiography highlights the importance of the single case study however acknowledges that more general ideas can be sought from more individuals, albeit with caution. This is accounted for within an IPA approach where analysis techniques move from single cases to patterns across individuals. This approach was utilised in the empirical study by demonstrating the unique experiences of each individual whilst highlighting any patterns across the group (Smith et al., 2009).

Reflexivity

Reflexivity is a necessity in qualitative research. Shaw (2010) describes the process of reflexivity as important for researchers to reflect on how they might impact the data during collection and analysis. A reflexive approach enables a more holistic approach to qualitative research as the researcher and researched are of the same order (both living human beings). Linking back to the double hermeneutic described earlier (Smith et al., 2009), IPA recognises the importance of the researcher's assumptions and that it has a role in both enhancing and hindering the interpretation process (Shaw, 2010). Consequently, the lead researcher used a research journal to record thoughts and feelings about the research process. This allowed the lead researcher's subjectivity to be acknowledged, and considered, throughout the data collection and analysis. An important entry, written during the time of interviews, is detailed below. Similar reflections were apparent throughout the research process:

I am very aware that the young people I am interviewing are receiving ongoing care from the same hospital as my son, albeit for a very different diagnosis. My family's experiences of the hospital have been excellent and I am aware that I am an advocate for the good work the hospital does and the impressive ongoing care we receive. I acknowledge that this stance makes me want to hear equally encouraging stories about the care the young people are receiving. I am very mindful of this and am keen to not let it bias what I hear from the young people and interpret as important. Although I have not yet heard any negative stories about the hospital, I am wondering

how this might feel for me and am keen not to let it influence my questioning or interpretation.

Another important reflection brings me to my family's approach to my son's chronic health problem. We take an optimistic view to the treatment he requires and manage any anxieties we have about his condition in a helpful way for our family network. We very much take a 'it could be much worse' stance. My acknowledgement of this is important in interview and analysis as I would not want my own positive framing to skew a participant's story about their lived experience.

These topics have remained in the lead researcher's mind throughout this project and an IPA approach accepts that the researcher's thoughts and feelings will have an impact on how they interpret another person's experience (double hermeneutic of IPA). The use of the diary was important to reflect on the lead researchers' thoughts and feelings and monitor developing interpretations. This commentary is vital in establishing credibility (Shenton, 2004).

Method: Data Analysis

Analysis of the interview data was informed by the steps outlined in Smith et al. (2009) and Smith and Osborn (2015). There is no single method for using IPA (Smith et al. 2009), rather a set of common processes that are outlined below:

Step 1: The researcher immerses themselves in the data by reading and re-reading a transcript. This reading and re-reading was undertaken while listening to the original audio recording. This stage ensures the participant is the focus of the analysis.

Step 2: This stage examines semantic content and language on an exploratory level and anything of interest is noted in the margins of the transcript. The process produces descriptive, linguistic and/or conceptual comments. Highlighting was used to pick out important data which were then commented upon.

Step 3: The next stage seeks to identify emergent themes from the initial noting by reducing the volume of detail while maintaining the complexity of the data. This process demonstrates a hermeneutic circle as the whole of the interview is becoming a set of parts which will then become a whole by the end of the analysis. The emergent themes reflect both the participant's words and the analyst's interpretation.

Step 4: Connections across these emergent themes are now searched for to draw together the themes and produce a structure to show the most important aspects of the participant's account. This was done by typing all the emergent themes into a list and moving themes around to create clusters. A process of abstraction, putting similar themes together and giving them a

name, was most usually employed and these headings represent the superordinate themes for that participant.

Step 5: The next step involves moving onto the next transcript and repeating the above process. It is important to treat the next case on its own terms so it is important to bracket the ideas from the previous case to maintain the idiographic commitment of IPA. The lead researcher left time (at least half a day) between analysing each script to help bracket the ideas although it was ensured this did not compromise being immersed in the data.

Step 6: Finally, patterns are looked for across the cases. It was evident in this process that some of the emergent and superordinate themes that were seen in an individual case, represented higher order concepts that were shared across cases. A large surface was used to lay out the themes to help look for connections. From this, three overarching superordinate themes, encompassing nine subordinate themes, were identified.

The following section considers a specific section of a transcript from Gemma and details the movement through the stages detailed above and the arrival at the group level superordinate themes. Table 1 shows the transcript and the initial notes and subsequent emergent themes documented by the researcher. Appendix P and Q further demonstrates how the master themes were evident in the original transcripts across participants.

Table 1.

Gemma's transcript with initial notes and emergent themes.

Initial Notes (Step 2)	Transcript	Emergent Themes (Step 3)
Concern over others judgement	Gemma: It was more especially when I started missing a lot of school. I was more like I don't know what people are going to think I was like. It was better because I wasn't there so I wasn't there to see people talking or giving me weird looks but it was more just like the unknown. While there were people and then when I came back after that huge- I had like two- or three-week gap of not going to school and when I came back someone said, "Oh yes people thought it was because of your anxiety".	Importance of others judgment
Assumptions about being talked about		Frustration at lack of understanding from others...it isn't 'just' anxiety
'huge'		
Frustration at a lack of understanding		
WHY?	I was like, "Why would I have missed it?" I mean, okay, but why would I of missed three weeks because of anxiety but there we go. and I was more like is not really a way of me to explain it without getting really TMI if it's a person who I don't know I'm more like I don't know how to explain it in a real way ...This is what happens without weirding them out a bit because it's a bit of a taboo subject it's like diarrhoea and stuff like that which is why I was like. I told someone once and didn't really know her and she was just like "Oh, yey" and I was like, "I have totally just weirded her out haven't I".	Taboo
What does she mean by 'real way' – an acceptable way?		
Difficult to explain 'weirding them out' – I'm weird?		
Responsibly for others reaction		Invisible illness
Strength in numbers – importance of support	I'm used to it that's why me and my friend Jane who has similar issues and she's like we can talk about it as we go through it but what I'm more like especially with my group of friends, I feel like they think I'm totally fine now and it's totally gone. I do try to explain it to them sometimes it is not gone. It could come back anytime but I'm just okay now without trying to put a downer on things.	Unpredictable
Others don't understand that I am not fine. Invisible illness. Unpredictable		Waiting game – for IBDs return
'could come back at any stage' - impending	I'm pretty much okay now but I'm still wary that even though I am on the right stuff now, it could come back at any stage.	

	Interviewer: How is it living with that, the unpredictability.	Its ok when it is ok.
Waiting for its return - apprehension Defeated by IBD Fragile.	Gemma: It's like I'll try not to think about it because I was like I'm okay now that is just- because always so used for ages just waiting for it to come back. After I'd come off the steroids I'd wait like a day or two and be like well it's going to come back soon then it would and I'd be just disappointed while now I'm more okay let's keep it like this, let's not think about going south just keep it as it is.	

During step 4 connections were made across these emergent themes, along with all others identified within this transcript. Two superordinate themes are demonstrated in this section of transcript. These are shown in Table 2. Abstraction was used to pool similar emergent themes together and give them a heading that captured their essence.

Table 2.

Emergent and superordinate themes from this section of transcript

Emergent themes (Step 3)	Superordinate themes (Step 4)
Importance of others' judgment	Role of others
Frustration at lack of understanding from others...it isn't 'just' anxiety	
Taboo	Contradictions of the disease
Invisible illness	
Unpredictable	
Waiting game – for IBDs return	
Its ok when its ok	

During step 6, these superordinate themes were clustered together and represented in the overarching subordinate and superordinate themes presented in the final results. The theme for Gemma of ‘role of others’ was represented in the subordinate theme ‘impact of others,’ which was under the superordinate theme of ‘Fragility of Health Position’. Gemma’s theme ‘contradictions of the disease’ was represented in ‘Invisible unpredictability’ which was also under the superordinate theme of ‘Fragility of Health Position.’

Personal Reflections of Analysis

The process of qualitative data analysis was a new experience for me and it felt a privilege to have access to such personal data. Being able to picture, and hear, the person saying the words added a welcomed layer of meaningfulness and having met most participants in their own homes, I felt I had an added insight into their lives.

The analysis process was all-consuming and required a lot of concentration and dedication. At times I felt so overwhelmed by the sheer quantity of data and the idea that any kind of connections could be made felt impossible. I recall looking at a list of the emergent themes from my first transcript and not being able to see any connections between any of the themes. However, the minute I started moving themes around, I seemed to gain an additional insight that lead to connections standing out to me. This cycle of confusion to clarity and back to confusion continued throughout the process. Although for me, this finished at a position of clarity where I feel I have captured the essence of the adolescents’ lived experience and feel the overarching themes are true to, and embedded in, the original data.

Quality and Rigour

The quality and validity of qualitative research is an important consideration and this should be assessed in relation to criterion that are specifically developed for qualitative research, and not quantitative research. Yardley (2000) suggests four broad principles for assessing qualitative research quality; sensitivity to context, commitment and rigour, transparency and coherence, and impact and importance. These principles offer a variety of ways to establish quality and are appropriate for any theoretical orientation of a qualitative study. Each principle will be considered in terms of the current IPA project.

Sensitivity to context. My interviewing skills, including active listening, empathic approach and ability to build rapport, demonstrate sensitivity to context. This is further seen through the described immersive process of data analysis and the evidence of interpretations being grounded in the original data, as demonstrated by the number of quotes provided in the write up.

Commitment and rigour. This principle is demonstrated in the methods described above. In addition, the sample was purposively selected to ensure the research questions were answered and each overarching theme was supported by quotes from the majority of participants. Furthermore, data, and resulting themes, were discussed during research supervision to substantiate quality and promote rigour.

Transparency and coherence. To ensure transparency the write up comprehensively details the stages of the research process. The alignment of the project to IPA epistemological underpinnings is demonstrated in this chapter and drafting, re-drafting, and input from a supervisor of the empirical paper helped ensure coherence.

Impact and importance. This was demonstrated in this unique project that gave a voice to a previously unheard population and has addressed a gap in the literature. The results from the research have clinical implications and this is more pertinent in the current, and changing face, of the National Health Service where the psychological aspects of chronic health conditions are receiving increased recognition.

To enhance quality and rigour further, the project could have benefitted from further consultation with colleagues to allow examination of the data from a number of perspectives. This would help improve credibility, not to undermine the lead researcher's interpretations but to ensure completeness and rigour in the analysis process.

References

- Braun, V., & Clarke, V. (2013). *Successful qualitative research: A practical guide for beginners*. London: Sage Publications.
- Cohen, L., Manion, L., & Morrison, K. (2007). *Research methods in education* (6th Edition). London: Routledge.
- Madill, A., Jordon, A., & Shirley, C. (2010). Objectivity and reliability in qualitative analysis: Realist, contextualist and radical constructionist epistemologies. *British Journal of Psychology*, 91, 1-20. doi: 10.1348/000712600161646
- Scotland, J. (2012). Exploring the Philosophical Underpinnings of Research: Relating Ontology and Epistemology to the Methodology and Methods of the Scientific, Interpretive, and Critical Research Paradigms. *English Language Teaching*, 5, 9-16. doi: 10.5539/elt.v5n9p9
- Shaw, R.L. (2010). Embedding reflexivity within experiential qualitative psychology. *Qualitative Research in Psychology*, 7, 233-243. doi: 10.1080/14780880802699092

Shenton, A. K. (2004). Strategies for Ensuring Trustworthiness in qualitative research projects. *Education for Information*, 22, 63-65. doi: 10.3233/EFI-2004-22201

Smith, J.A., Flowers, P., & Larkin, M. (2009). *Interpretative Phenomenological Analysis: Theory, method and research*. London: Sage.

Smith, J. A. and Osborn, M. (2015). Interpretative phenomenological analysis. In J. A. Smith (Ed) *Qualitative Psychology: A Practical Guide to Methods*. London: Sage.

Walsh, D., & Evans, K. (2014). Critical realism: An important theoretical perspective for midwifery research. *Midwifery*, 30, 1-6. doi: 10.1016/j.midw.2013.09.002

Yardley, L. (2000). Dilemmas in qualitative health research. *Psychology and health*, 15, 215-228. doi: 10.1080/08870440008400302

Chapter 5

Discussion and Critical Evaluation

Word Count: 2342

Chapter 5: Discussion and Critical Evaluation

This chapter provides an overall discussion and critical evaluation for the thesis portfolio. The chapter begins by setting the scene for the current research followed by a summary of the findings. The strengths and limitations of the overall portfolio are discussed. The findings from both papers are synthesised to offer clinical implications and suggest areas for possible future research. The chapter concludes with some personal reflections on the research process.

Summary of Research

Inflammatory Bowel Disease (IBD) is a chronic, autoimmune disease that describes a group of intestinal disorders that cause parts, or all, of the gastrointestinal tract to become inflamed (Sykes, Fletcher & Schneider, 2015). The peak age for the onset of IBD is between 15 and 35 years of age (Bishop, Lemberg & Day, 2014), with around 30% being diagnosed before the age of 21 (Karwowski, Kelijo & Svirgely, 2009). Literature suggests that an adolescent patient with IBD is more likely to experience emotional and behavioural difficulties than healthy peers (Mackner, Sisson & Crandall, 2004; Greenley et al., 2010). This is unsurprising given that IBD can negatively influence important aspects of adolescent development, such as puberty and social acceptance (Greenley, et al., 2010).

In response to this, cognitive behavioural based psychological interventions for children and adolescents with IBD have been developed. A systematic review of the literature, conducted as part of this thesis portfolio, suggests that there is a trend

towards improvement in anxiety, depression and general functioning for the young people who participate in these interventions. These findings are encouraging, particularly in the current National Health Service (NHS), where the importance of integrating physical and mental health care is crucial to the future of the NHS (Five Year Forward View, 2014). However, the available literature concerning the psychosocial aspects of young people with IBD is fairly limited. Much of the current research is focussed at an adult population. This is reflected in National Institute for Health and Care Excellence (NICE) guidelines where guidance is available for managing depression in adults with chronic health problems (NICE, 2009) but there is no comparable guideline for young people. Consequently, to contribute to the evidence base concerning young people and IBD, an Interpretative Phenomenology Analysis (IPA) was undertaken to give an insight into an adolescent's lived experience of IBD.

The in-depth exploration, using an IPA approach, of an adolescent's lived experience of IBD provided some useful and interesting findings. Group level superordinate themes highlighted a 'Turning Point for Health' which described the adolescents experience of diagnosis and finding the right treatment. 'Resilience and Acceptance' appeared crucial for our participants in living well with IBD although this position came with a sense of 'Fragility' where IBD related difficulties experienced by our adolescents meant resilience and acceptance could be compromised. This provides us with some understanding of what it is like for an adolescent living with IBD and adds to a biopsychosocial understanding of young people with IBD.

Strengths and limitations of the present study

The current study presents original research, and a novel review of current research, in the area of young people with IBD. This study has given a voice to young people to have their lived experiences of IBD heard and considered how psychological intervention can benefit young people with IBD specifically.

Previous research may have not considered young people only and, instead, studied young people and adults under the umbrella of ‘patient’ without acknowledging the differences between these two groups. Given that adolescence is a crucial transitional period, which is characterized by more biological, psychological and social changes than any other life stage, with the exception of infancy (Williams et al., 2002), it is right that the current project takes a focus specific to young people.

This research contributes to the biopsychosocial understanding for young people with IBD and has real benefit in helping us to appreciate the factors that can influence the development, course and outcome of the disease (Havelka, Lucanin & Lucanin, 2009). The biopsychosocial approach has even more value given the future focus of the NHS ensuring parity of esteem between physical and mental health. Furthermore, it is documented that when the biopsychosocial elements of adolescence intersect with the biopsychosocial components of a health condition, there can be unique challenges in the management of the health concern (Christie & Viner, 2005). The current project helps enrich our understanding of the psychosocial elements for young people with IBD.

It is acknowledged that the age range throughout the wider project is variable. Due to available papers, the review encompasses children from eight through to 18, while the original research reflects 13 to 15-year olds. Adolescence is defined by the World Health Organisation (WHO; 2018) as between 10 and 19 and therefore it is recognised that the lowest age range within some of the current research is concerned with children (defined by WHO as anyone under 19 that is not within the age range for adolescence). In addition, adolescence is often broadly separated into early, mid and late adolescence to acknowledge the variance throughout this developmental stage and therefore the current research may contain young people from early and mid-adolescence. Furthermore, this broad age range could span up to three stages of Erikson's (1950) psychosocial development theory. The broad age range in the current project presents a challenge in the synthesis of these two projects and generalisability going forward. Details about the lived experience of a 13 to 15-year-old may not be beneficial throughout a wider paediatric service (which is often up to age 18) and may be more representative of the lived experience of an individual in early to middle adolescence. Furthermore, the content of a psychological intervention for an eight-year-old compared to an 18-year-old would need to be quite different in order to account for the different cognitive, emotional and psychological developmental stage. These differences are not accounted for within the current research.

It is important to acknowledge the wide range of countries in which the current research has been conducted. The phenomenon of living with IBD for adolescents has been explored in other countries, Canada (Nicholas et al., 2007) and Sweden (Brydolf & Segesten, 1996; Lindfred, Saalman, Nilsson, Sparud-Lundin &

Lepp, 2012), but this is the first project to consider the lived experience of adolescents within a UK health setting. This research in other countries has also considered a broader age range than the focussed 13-15-year-old age range in the current study. Research into psychological intervention for young people with IBD has primarily been conducted within America. Synthesising these fields of research together may present some difficulties due to the UK and America having very different healthcare systems. Nonetheless, the understanding gained about the lived experience of adolescents with IBD in the UK could be used to consider the helpfulness of the content of American developed psychological intervention programmes.

There is a lack of statistical methods within this wider project which may compromise the reliability, validity and generalisability of the findings. Despite quantitative methods being considered, it was felt that a qualitative approach, preceded by a narrative synthesis, would be most appropriate for the research questions. This is partly due to the area of young people with IBD having a small, but growing, psychological evidence base and the exploration of a young persons lived experience provides an important basis on which to consider other areas of research that may benefit this cohort.

Quality assurance was considered throughout the current project and a selection of data from each paper was subject to review by a second author or reviewer in order to substantiate quality. Furthermore, evidence-based guidelines were utilised throughout to help assess the quality of data and ensure accurate

reporting. However, it is acknowledged that, in the context of completing this piece of as part of a wider Clinical Psychology doctorate, there are some limitations. Primarily there was a lack of time in which to thoroughly consider independent audit and consultation of the data involved in the current project. For example, it would have been of value to reflect back the superordinate themes with the clinical care team and participants, as identified by Noble and Smith (2015), in order to improve reliability and validity of project and ensure the final themes are reflective of the phenomena being investigated. Future research could endeavour to implement this stage to ensure increased methodological rigour.

Clinical Implications and Suggestions for Further Research

The resiliency demonstrated by the young people interviewed as part of this wider project was reflected in the overall superordinate themes and the current review would suggest that children and adolescents can benefit from psychological intervention, potentially to a greater extent than an adult patient (Timmer et al., 2011). Clinically, these findings may suggest there is a valuable opportunity to enhance young people's resiliency by offering cognitive behavioural based psychological support to help manage the identified characteristics of IBD that can compromise this position of resilience. It is widely acknowledged that a prevention and early intervention approach is beneficial for children and young people's wellbeing (Membride, 2016) and the future of the NHS is shifting to a focus of prevention and early intervention (NHS Five Year Forward View, 2014). The findings from this current research could help inform service development to ensure this is available to service users to meet their psychological needs.

Furthermore, it is noted from the current research that the involvement of family, and the young person's wider system, is key. Psychological intervention for young people with IBD tended to have better outcomes with family involvement and the participants interviewed as part of this project highlighted the understanding of IBD by others as important to maintaining their resilience in the face of IBD. If not already offered in clinical services, there could be great benefit in providing IBD related information to teachers involved with the young person with IBD to promote their understanding of the condition and how the child can be best supported. This may help in minimising how different young people with IBD feel to their peers which in turn may help with resiliency. Deciding how much, or how little, the family and wider system are involved in this is a clinical judgment that should be considered carefully given the transitional period of adolescence.

It is hoped that the findings from the current projects will help inform psychological support for young people with IBD in the NHS. The current research provides evidence that cognitive behavioural based interventions demonstrate a trend to improvement in symptoms of anxiety and depression and general functioning. A richer understanding of the lived experience of adolescents with IBD in England provides insight into what is important for an adolescent with IBD and this can help shape the content of the aforementioned psychological interventions to align with their experiences within a UK healthcare system.

Future work may benefit from combining the understanding of the lived experience of an adolescent with IBD with the development of a UK specific cognitive behavioural programme which, in line with the future focus of the NHS,

is provided as a prevention intervention rather than a reactive intervention. It would also be of benefit for future research to focus on a consistent age group within the 0-18 age range so findings can be more clearly integrated in relation to developmental stage.

Personal Reflections

The process of undertaking and writing up research is a new experience for me and one that came with feelings of anxiety and responsibility. I was grateful for the use of guidelines and tools that helped provide a specific framework on which to work through the wider piece of work but I felt overwhelmed by the project and it was very much outside of my comfort zone. I recognise that I have moved through the stages of competence as identified by Broadwell (1969), initially starting the research process at a place of being unconsciously incompetent. Throughout the process I feel I have moved on from this position to being more consciously competent. However, there have been times of unconscious competence, which have been made conscious through good supervision, and times of conscious incompetence, which has led me to seek out appropriate learning material.

A critical realism stance was taken throughout the project as I had an interest in seeking a truth but acknowledged that context is important and the truth could never be fully understood. Reflections about the stance taken were most pertinent throughout the qualitative research project and this approach aligns well with an IPA methodology. However, this stance was extended throughout the wider

project and is reflected in conducting a narrative synthesis, rather than a meta-analysis, in order to reflect the homogeneity of the current literature in the field.

It is acknowledged that the researcher's experiences and personal narratives contribute to the interpretative process and credibility of the research (Horsburgh, 2003) and the bracketing of personal bias and assumptions is important in order to reflect the stories of the participants (Ahern, 1999). It was important for me to reflect on my own experience and perspective in order to minimise the impact on the analysis process but, despite this, I also acknowledge that the analysis is formulated through the lens of my own perspective. The context of this lens is I am a parent to a child (an infant) with a long-term condition (not IBD) who is treated within the same hospital as the participants within this study. I used my reflective diary and research supervision to consider how my experiences might impact on my interpretation of the lived experience of the young people.

Overall Conclusion

This wider project has suggested that cognitive behavioural based psychological intervention is of benefit for young people with IBD and it has provided a voice to adolescents to highlight their lived experience of IBD. This feels a timely project with the focus of the NHS moving towards a more integrated approach to physical and mental health. These findings could be utilised in order to implement this within clinical settings and enhance the care that is already offered to young people with IBD.

References

- Ahern, K. J. (1999). Pearls, Pith, and Provocation: Ten Tips for Reflexive Bracketing. *Qualitative Health Research*, 9, 407–411.
- Brydolf, M. & Segesten, K. (1996). Living with ulcerative colitis: Experiences of adolescents and young adults. *Journal of Advanced Nursing*, 23, 39-47. doi: 10.1111/j.1365-2648.1996.tb03133.x
- Broadwell, M.M. (1969). Teaching for learning. *The Gospel Guardian*, 20, 1-3.
- Christie, D & Viner, R. (2005). ABC of Adolescence: Adolescent Development. *BMJ (online)*, 330, doi: 10.1136/bmj.330.7486.301
- Erikson, E.H. (1950). *Childhood and Society*. New York:Norton.
- Greenley, R.N., Hommel, K.A., Nebel, J., Raboin, T., Li, S., Simpson, P. & Mackner, L. (2010). A meta-analytic review of the psychosocial adjustment of youth with Inflammatory Bowel Disease. *Journal of Paediatric Psychology*, 35, 857-869. doi: 10.1093/jpepsy/jsp120

- Havelka, M., Lucanin, J.D., & Lucanin, D. (2009). Biopsychosocial model – The integrated approach to health and disease. *Collegium Antropologicum*, 33, 303-310.
- Karwowski, C.A., Keljo, D. & Szigethy, E. (2009). Strategies to improve quality of life in adolescents with Inflammatory Bowel Disease. *Inflammatory Bowel Disease*, 15, 1755-1764. doi:10.1002/ibd.20919
- Lindfred, H., Saalman, R., Nilsson, S., Sparud-Lundin, C. & Lepp, M. (2012). Self-reported health, self-management, and the impact of living with Inflammatory Bowel Disease during adolescence. *Journal of Paediatric Nursing*, 27, 256-264. doi: 10.1016/j.pedn.2011.02.005
- Membride, H. (2016). Mental health: Early intervention and prevention in children and young people. *British Journal of Nursing*, 8, 556-557. doi: 10.12968/bjon.2016.25.10.552.
- Mackner, L.M., Sisson, D.P. & Crandall, W.V. (2004). Review: Psychosocial issues in paediatric Inflammatory Bowel Disease. *Journal of Paediatric Psychology*, 29, 243-257. doi: 10.1093/jpepsy/jsh027
- NHS (2014). Five Year Forward View. Available from:
<https://www.england.nhs.uk/wp-content/uploads/2014/10/5yfv-web.pdf>
- Nicholas, D.B., Otley, A., Smith, C., Avolio, J., Munk, M & Griffiths, A.M. (2007). Challenges and strategies of children and adolescents with inflammatory

bowel disease: a qualitative examination. *Health and Quality of Life Outcomes*, 5:28. doi:10.1186/1477-7525-5-28

Noble H, & Smith J. (2015). Issues of validity and reliability in qualitative research. *Evidence-Based Nursing*, 18, 34-35. doi: 10.1136/eb-2015-102054

National Institute for Health and Clinical Excellence (2009). Depression in adults with a chronic physical health problem: recognition and management. Available from: <https://www.nice.org.uk/Guidance/CG91>

Sykes, D.N., Fletcher, P.C. & Schneider, M.A. (2015). Balancing my disease: Women's perspectives of living with inflammatory bowel disease. *Journal of Clinical Nursing*, 24, 2133-2142. doi: 10.1111/jocn.12785

Timmer, A., Preiss, J.C., Motschall, E., Rucker, G., Iantschek, G., & Moser, G. (2011). Psychological interventions for treatment of inflammatory bowel disease. *Cochrane Database of Systematic Reviews*. doi: 10.1002/14651858.CD006913.pub2.

Williams, P.G., Holmbeck, G.N. & Greenley, R.N. (2002). Adolescent Health Psychology. *Journal of Consulting and Clinical Psychology*, 70, 828-842. doi: 10.1037/0022-006X.70.3.828

World Health Organisation (2018). Adolescent Health. Available from:

https://www.who.int/topics/adolescent_health/en/

Appendices

Appendix	Description
A	Author Guidelines for Journal of Pediatric Psychology for systematic review paper
B	PRISMA Checklist for systematic review
C	Full search terms for systematic review
D	Blank example of QualSyst tool used in systematic review
E	Risk of bias decisions for each included paper in systematic review
F	QualSyst scores for each paper in systematic review
G	Author Guidelines for Psychology and Health for empirical paper
H	Semi-structured interview used in empirical paper
I	Consolidating Criteria for reporting Qualitative Research (COREQ)
J	Consent to contact form
K	Participant information sheets –parent and participant
L	Consent form for parent and assent form for participant
M	Demographic questionnaire
N	Healthcare professional letter advising of participation in research
O	Ethical Approval – Research Ethics Committee acknowledgement, Health Research Approval and capacity and capability approval from NHS trust
P	Master tables of themes
Q	Table of recurrent themes
R	Diagrammatic representation of themes

Appendix A: Author Guidelines for Journal of Pediatric Psychology for systematic review paper

Instructions to Authors

The *Journal of Pediatric Psychology* is an official publication of the Society of Pediatric Psychology, Division 54 of the American Psychological Association. *JPP* publishes articles related to theory, research, and professional practice in pediatric psychology.

Author Guidelines

We would like to inform our authors that we now detect plagiarism easily. *JPP* employs the CrossCheck plagiarism screening system. By submitting your manuscript to this journal you accept that your manuscript may be screened for plagiarism against previously published works.



Journal of Pediatric Psychology will not consider papers that have been accepted for publication or published elsewhere. Copies of existing manuscripts with potentially overlapping or duplicative material should be submitted together with the manuscript, so that the Editors can judge suitability for publication. The Editors reserve the right to reject a paper on ethical grounds.

Organization of manuscripts

Manuscript Central will guide authors through the submission steps, including: Abstract, Keyword selection, and the Manuscript. The manuscript must contain an Introduction, Methods, Results, Discussion, Acknowledgements and Reference List.

Length of manuscript: Original research articles should not exceed 25 pages, in total, including title page, references, figures, tables, etc. In the case of papers that report on multiple studies or those with methodologies that necessitate detailed explanation, the authors should justify longer manuscript length to the Editor in the cover letter. Review articles should not exceed 30 pages. Invited commentaries should be

discussed with the Editor. The *Journal of Pediatric Psychology* no longer accepts brief reports but will accept manuscripts that are shorter in length.

Manuscripts (text, references, tables, figures, etc.) should be prepared in detailed accord with the Publication Manual of the American Psychological Association (6th ed.). There are two exceptions:

The academic degrees of authors should be placed on the title page following their names, and a structured abstract of not more than 250 words should be included. The abstract should include the following parts:

1. Objective (brief statement of the purpose of the study);
2. Methods (summary of the participants, design, measures, procedure);
3. Results (the primary findings of this work); and
4. Conclusions (statement of implications of these data).

Key words should be included, consistent with APA style. Submissions should be double-spaced throughout, with margins of at least 1 inch and font size of 12 points (or 26 lines per page, 12-15 characters per inch).

Informed consent and ethical treatment of study participants: Authors should indicate in the Method section of relevant manuscripts how informed consent was obtained and report the approval of the study by the appropriate Institutional Review Board(s). Authors will also be asked to sign a statement, provided by the Editor that they have complied with the American Psychological Association Ethical Principles with regard to the treatment of their sample.

Clinical relevance of the research should be incorporated into the manuscripts. There is no special section on clinical implications, but authors should integrate implications for practice, as appropriate, into papers.

Terminology should be sensitive to the individual who has a disease or disability. The Editors endorse the concept of "people first, not their disability." Terminology should reflect the "person with a disability" (e.g., children with diabetes, persons with HIV infection, families of children with cancer) rather than the condition as an adjective (e.g., diabetic children, HIV patients, cancer families). Nonsexist language should be used.

Review articles:

(a) **Topical reviews:** Topical reviews summarize contemporary findings, suggest new conceptual models, or highlight noteworthy or controversial issues in pediatric psychology. Topical reviews are not intended to provide short data summaries or syntheses. Rather they are intended to foster new ways of thinking about a topic area and provide a direction for future research or practice. They are limited to 2,000 words, contain no more than 2 tables or figures, and have an upper limit of 30 references. Supplementary online material (e.g., additional tables) may be considered on a case by case basis.

(b) **Systematic reviews:** Systematic reviews should not exceed 30 pages. Authors are required to attach the PRISMA checklist and flow diagram as supplementary material for each submission. Authors can find the PRISMA checklist and flow diagram in downloadable templates that can be re-used [here](#). Authors of systematic reviews that do not include a meta-analysis must provide a clear justification in the manuscript explaining why such an analysis is not included for all or relevant portions of the report.

Please consult this editorial ([New Guidelines for Publishing Review Articles in JPP](#)) which further describes guidelines for review articles, and the Checklist for Preparing and Evaluating Review Articles.

Additional Guidance

The following links provide additional guidance for authors and reviewers: Editorial Policy, Authors' Checklist, Guidelines for Reviews, Suggestions for Mentored Reviews, "People First," NIH policy, Replication of research, Duplicate and redundant policies, Conflict of interest.

See the following articles for detailed guidance concerning preparation of manuscripts: Editorial: Thoughts in Improving the Quality of Manuscripts Submitted to the *Journal of Pediatric Psychology*: How to Write a Convincing Introduction; Methods: Editorial: How to Report Methods in the *Journal of Pediatric Psychology*; Results and Discussion: Editorial: How to Write an Effective Results and Discussion Section for the *Journal of Pediatric Psychology*.

Funding

Details of all funding sources for the work in question should be given in a separate section entitled "Funding." This should appear before the "Acknowledgements" section.

The following rules should be followed:

- The sentence should begin: "This work was supported by ..."
- The full official funding agency name should be given, i.e. "the National Cancer Institute at the National Institutes of Health" or simply "National Institutes of Health," not "NCI" (one of the 27 subinstitutions) or "NCI at NIH" (full RIN-approved list of UK funding agencies)
- Grant numbers should be complete and accurate and provided in parentheses as follows: "(grant number xxxx)"
- Multiple grant numbers should be separated by a comma as follows: "(grant numbers xxxx, yyyy)"
- Agencies should be separated by a semi-colon (plus 'and' before the last funding agency)
- Where individuals need to be specified for certain sources of funding the following text should be added after the relevant agency or grant number "to [author initials]." Oxford Journals will deposit all NIH-funded articles in PubMed Central. See [this page](#) for details. Authors must ensure that manuscripts are clearly indicated as NIH-funded using the guidelines above.

Color Figure Charges

Authors are charged for the print reproduction of color figures. The cost is \$600 / €525 / £325 per color page. Figures can be published in black and white in the print edition and in color online for free. If you choose this option, please ensure that your figures are clear and readable in both black and white and color.

Permission for Illustrations and Figures

Permission to reproduce copyright material, for print and online publication in perpetuity, must be cleared and if necessary paid for by the author; this includes applications and payments to DACS, ARS, and similar licensing agencies where

appropriate. Evidence in writing that such permissions have been secured from the rights-holder must be made available to the editors. It is also the author's responsibility to include acknowledgements as stipulated by the particular institutions. Oxford Journals can offer information and documentation to assist authors in securing print and online permissions: please see the Guidelines for Authors section. Information on permissions contacts for a number of main galleries and museums can also be provided. Should you require copies of this, please contact the editorial office of the journal in question or the Oxford Journals Rights department.

Language Editing

Language editing, if your first language is not English, to ensure that the academic content of your paper is fully understood by journal editors and reviewers is optional. Language editing does not guarantee that your manuscript will be accepted for publication. For further information on this service, please [click here](#). Several specialist language editing companies offer similar services and you can also use any of these. Authors are liable for all costs associated with such services.

Appendix B: PRISMA Checklist for systematic review

Section/topic	#	Checklist item	Reported on page #
TITLE			
Title	1	Identify the report as a systematic review, meta-analysis, or both.	11
ABSTRACT			
Structured summary	2	Provide a structured summary including, as applicable: background; objectives; data sources; study eligibility criteria, participants, and interventions; study appraisal and synthesis methods; results; limitations; conclusions and implications of key findings; systematic review registration number.	12
INTRODUCTION			
Rationale	3	Describe the rationale for the review in the context of what is already known.	13-15
Objectives	4	Provide an explicit statement of questions being addressed with reference to participants, interventions, comparisons, outcomes, and study design (PICOS).	15
METHODS			
Protocol and registration	5	Indicate if a review protocol exists, if and where it can be accessed (e.g., Web address), and, if available, provide registration information including registration number.	16
Eligibility criteria	6	Specify study characteristics (e.g., PICOS, length of follow-up) and report characteristics (e.g., years considered, language, publication status) used as criteria for eligibility, giving rationale.	17-18
Information sources	7	Describe all information sources (e.g., databases with dates of coverage, contact with study authors to identify additional studies) in the search and date last searched.	18
Search	8	Present full electronic search strategy for at least one database, including any limits used, such that it could be repeated.	18 and 142
Study selection	9	State the process for selecting studies (i.e., screening, eligibility, included in systematic review, and, if applicable, included in the meta-analysis).	16-18
Data collection process	10	Describe method of data extraction from reports (e.g., piloted forms, independently, in duplicate) and any processes for obtaining and confirming data from investigators.	18 -19

Data items	11	List and define all variables for which data were sought (e.g., PICOS, funding sources) and any assumptions and simplifications made.	18
Risk of bias in individual studies	12	Describe methods used for assessing risk of bias of individual studies (including specification of whether this was done at the study or outcome level), and how this information is to be used in any data synthesis.	19
Summary measures	13	State the principal summary measures (e.g., risk ratio, difference in means).	N/A
Synthesis of results	14	Describe the methods of handling data and combining results of studies, if done, including measures of consistency (e.g., I^2) for each meta-analysis.	20

Page 1 of 2

Section/topic	#	Checklist item	Reported on page #
Risk of bias across studies	15	Specify any assessment of risk of bias that may affect the cumulative evidence (e.g., publication bias, selective reporting within studies).	19
Additional analyses	16	Describe methods of additional analyses (e.g., sensitivity or subgroup analyses, meta-regression), if done, indicating which were pre-specified.	N/A
RESULTS			
Study selection	17	Give numbers of studies screened, assessed for eligibility, and included in the review, with reasons for exclusions at each stage, ideally with a flow diagram.	20-21
Study characteristics	18	For each study, present characteristics for which data were extracted (e.g., study size, PICOS, follow-up period) and provide the citations.	22-24
Risk of bias within studies	19	Present data on risk of bias of each study and, if available, any outcome level assessment (see item 12).	33-34 & 144-148
Results of individual studies	20	For all outcomes considered (benefits or harms), present, for each study: (a) simple summary data for each intervention group (b) effect estimates and confidence intervals, ideally with a forest plot.	23-25
Synthesis of results	21	Present results of each meta-analysis done, including confidence intervals and measures of consistency.	N/A
Risk of bias across studies	22	Present results of any assessment of risk of bias across studies (see Item 15).	33-34 & 144-148

Additional analysis	23	Give results of additional analyses, if done (e.g., sensitivity or subgroup analyses, meta-regression [see Item 16]).	N/A
DISCUSSION			
Summary of evidence	24	Summarize the main findings including the strength of evidence for each main outcome; consider their relevance to key groups (e.g., healthcare providers, users, and policy makers).	35-39
Limitations	25	Discuss limitations at study and outcome level (e.g., risk of bias), and at review-level (e.g., incomplete retrieval of identified research, reporting bias).	35-39
Conclusions	26	Provide a general interpretation of the results in the context of other evidence, and implications for future research.	35-39
FUNDING			
Funding	27	Describe sources of funding for the systematic review and other support (e.g., supply of data); role of funders for the systematic review.	40

From: Moher D, Liberati A, Tetzlaff J, Altman DG, The PRISMA Group (2009). Preferred Reporting Items for Systematic Reviews and Meta-Analyses: The PRISMA Statement. PLoS Med 6(7): e1000097. doi:10.1371/journal.pmed1000097

For more information, visit: www.prisma-statement.org.

Appendix C: Full search terms for systematic review

These 3 'categories' of terms were used to search electronic databases. 'MM' refers to the MeSH term used for that category which ensures a wider reaching search.

(MM "Cognitive Therapy") or psycho* intervention or psycho* treatment or psycho* therapy or CBT or cognitive behaviour* or cognitive behavior*

(MM " Inflammatory Bowel Diseases") or inflammatory bowel disease or ibd or ulcerative colitis or Crohn*

(MM "Child") or (MM "Adolescent") or adolescen* or teen* or young people or young person or youth or child*

Appendix D: Blank example of QualSyst tool used in systematic review (Kmet, Lee & Cook, 2004)

Criteria		YES (2)	PARTIAL (1)	NO (0)	N/A
1	Question / objective sufficiently described?				
2	Study design evident and appropriate?				
3	Method of subject/comparison group selection or source of information/input variables described and appropriate?				
4	Subject (and comparison group, if applicable) characteristics sufficiently described?				
5	If interventional and random allocation was possible, was it described?				
6	If interventional and blinding of investigators was possible, was it reported?				
7	If interventional and blinding of subjects was possible, was it reported?				
8	Outcome and (if applicable) exposure measure(s) well defined and robust to measurement / misclassification bias? Means of assessment reported?				
9	Sample size appropriate?				
10	Analytic methods described/justified and appropriate?				
11	Some estimate of variance is reported for the main results?				
12	Controlled for confounding?				
13	Results reported in sufficient detail?				
14	Conclusions supported by the results?				

Appendix E: Risk of bias decisions for each included paper in systematic review

Article: Evaluation of a psychoeducational intervention for adolescents with inflammatory bowel disease.

Author: Grootenhuis 2009

Entry	Judgement	Support for judgement (Quote/comment)
Random sequence generation (selection bias)	High	'All 40 adolescents who were interested in joining the intervention and participating in the study completed the questionnaires at baseline. The 18 adolescents who lived too far away to participate in the intervention at the Emma Children's Hospital AMC were placed on a waiting list (control group). The remaining 22 participated in the intervention (experimental group).'
Allocation concealment (selection bias)	High	Allocation by location of participant compared to intervention Allocation based on proximity to clinic
Blinding of participants and personnel (performance bias)	High	'... were invited by letter to participate in the intervention study' No blinding attempted.
Blinding of outcome assessment (detection bias)	High	High blinding of outcome assessment as all outcomes assessed by patient or parent.
Incomplete outcome data	High	Imbalance in numbers at follow up. No reasons given for missing data although the 'nonrespondents did not differ from the respondents 6-8 months after the intervention with respect to their demographic and medical characteristics.'
Selective reporting (reporting bias)	Low	Study protocol available and all pre-specified outcomes were reported.
Other bias	High	The study is evaluating a CBT program developed by the same authors as the current paper.

Article: Effects of a CBT intervention trial to improve disease outcomes in children with

IBDAuthor: Levy, 2016

Entry	Judgement	Support for judgement (Quote/comment)
Random sequence generation (selection bias)	Low	'Randomization was then performed by a different researcher using a computerized random-number generator...'
Allocation concealment (selection bias)	Low	'Randomization was then performed by a different researcher using a computerized random-number generator'
Blinding of participants and personnel (performance bias)	Low	'Participants were blind to their group assignment, and were told that they would be randomly assigned to one of two treatment groups, and that the topics they would discuss would vary depending on the group to which they were assigned. They were not informed which condition was the treatment versus control condition.'
Blinding of outcome assessment (detection bias)	Low	'Children completed assessments through a scheduled telephone call with a highly trained research nurse who was blinded to the participant's treatment assignment.'
Incomplete outcome data (attrition bias)	Low	Missing outcome data balanced in number across intervention, with similar reasons for missing data across groups
Selective reporting (reporting bias)	Low	The study protocol is available and the studies predefined outcomes are reported in the pre-specified way.
Other bias	Low	No other bias identified

Article: Treatment for comorbid pediatric gastro and anxiety disorders: A pilot study of a flexible health sensitive CBT program

Author: Reigada, 2015

Entry	Judgement	Support for judgement (Quote/comment)
Random sequence generation (selection bias)	Low	'Condition pre-assignment was decided using a random numbers chart ensuring equal numbers across groups.'
Allocation concealment (selection bias)	Unclear	
Blinding of participants and personnel (performance bias)	Unclear	The study did not address this outcome
Blinding of outcome assessment (detection bias)	Low	'Assessments were conducted by independent evaluators (IEs), who were blind to participant randomization at all three assessment times: baseline, immediately following treatment, and three months later.'
Incomplete outcome data (attrition bias)	Low	No missing outcome data from pre to post. Outcome data missing at follow up. Missing data have been imputed using appropriate methods.
Selective reporting (reporting bias)	Low	Study protocol reported and pre-specified outcomes are reported as identified.
Other bias	High	Paper is evaluating outcomes for a CBT programme developed by the same authors

Article Title: Randomized Efficacy Trial of two psychotherapies for depression in youth with IBD.

Author: Szigethy, 2014

Entry	Judgement	Support for judgement (Quote/comment)
Random sequence generation (selection bias)	Low	The investigators describe a random component in the sequence generation process: 'Participants (N = 217) were randomized to receive a 12-week course of CBT or SMDT.'
Allocation concealment (selection bias)	Unclear	Method of concealment is not described.
Blinding of participants and personnel (performance bias)	Unclear	The study did not address this outcome
Blinding of outcome assessment (detection bias)	Low	Assessments completed by blinded assessors where appropriate: 'Both measures were rated by a blinded gastroenterologist.....Completed by blinded evaluators trained in its administration'
Incomplete outcome data addressed (attrition bias, short term outcomes less than 6 weeks)	High	although not significantly different at least 6 sessions were completed by 91% of CBT compared to 74% of SMDT. No reasons for attrition given
Selective reporting (reporting bias)	Low	Study protocol available and all pre-specified outcomes were reported.
Other bias	High	This paper evaluates a CBT programme developed by the same authors

Article Title: Integrating illness concerns into CBT for children and adolescents with IBD and co-occurring anxiety.

Author: Reigada, 2013

Entry	Judgement	Support for judgement (Quote/comment)
Selection bias	High	High risk due to study design (nonrandomized study, before and after design with no comparison group)
Blinding of outcome assessment (detection bias)	High	Raters independent but not blinded 'Clinical Global Impression Scale-Severity and Improvement Scales (CGI-S and CGI-I, respectively; Guy, 1976) was completed by independent evaluators pre- and post-intervention.'
Incomplete outcome data (attrition bias)	Low	Reasons for missing data given and not likely to be related to the true outcome.
Selective reporting (reporting bias)	Low	Protocol available and all study outcomes pre-specified were reported.
Other bias	High	Small number of participants and lack of control group - potential source of bias Paper is evaluating outcomes for a CBT programme developed by the same authors

Article Title: Cognitive behavioural therapy for depression in adolescents with IBD: A Pilot Study

Author: Szigethy, 2004.

Entry	Judgement	Support for judgement (Quote/comment)
Selection bias	High	'The selection of patients to participate involved a twostep screening process.... of 16 adolescents meeting the criteria, 11 participated in treatment. 5 did not participate due to suicidal ideation and travel distance (n=2).' High risk due to study design (nonrandomized study, before and after design with no comparison group)
Detection bias	Low	'The same interviewer, not the primary therapist, completed the pre- and posttreatment assessments; raters blinded to treatment status rated a randomly selected 42% of pre-treatment and 36% of posttreatment taped sessions, with 100% agreement on diagnoses' 'Correlations between two independent physician raters' scores who were blinded to treatment status for all subjects....'
Attrition bias	Low	All participants completed all post outcome measures
Reporting bias	Low	The study protocol is available and all of the study's pre-specified (primary and secondary) outcomes that are of interest in the review have been reported in the pre-specified way
Other Bias	High	Potential source of bias relating to the design used. No comparison group. This paper evaluates a CBT programme developed by the same authors

Article Title: Case Study: Longitudinal Treatment of Adolescents With Depression and Inflammatory Bowel Disease

Author: Szigethy, 2006

Entry	Judgement	Support for judgement (Quote/comment)
Random sequence generation (selection bias)	High	High risk due to study design (nonrandomized study, before and after design with no comparison group)
Blinding of outcome assessment (detection bias)	Low	Interviewers blind to baseline and posttreatment symptomatology assessed adolescents at each follow-up assessment.
Incomplete outcome data (attrition bias)	Low	No missing outcome data
Selective reporting (reporting bias)	Low	Study protocol specified and adhered to
Other bias	High	Small participant numbers and lack of control group This paper evaluates a CBT programme developed by the same authors

Article Title: Cognitive behavioural therapy for adolescents with inflammatory bowel disease and subsyndromal depression.

Author: Szigethy, 2007.

Entry	Judgement	Support for judgement (Quote/comment)
Random sequence generation (selection bias)	Low	The investigators describe a random component in the sequence generation process: 'Forty-one participants were randomized to either modified CBT (n = 22) or the comparison treatment (n = 19).'
Allocation concealment (selection bias)	Unclear	Method of concealment is not described.
Blinding of participants and personnel (performance bias)	Unclear	The study did not address this outcome
Blinding of outcome assessment (detection bias)	Low	'All of the assessments were administered to both groups by independent evaluators unaware of the participants treatment condition'
Incomplete outcome data addressed (attrition bias, short term outcomes less than 6 weeks)	Low	No differences between participants and those lost to attrition on baseline characteristics 'There were no significant differences between these three PASCET-PI noncompleters and the 19 completers in terms of demographic variables or depressive severity.'
Selective reporting (reporting bias)	Low	The study protocol is available and the studies predefined outcomes are reported in the pre-specified way.
Other Bias	High	This paper evaluates a CBT programme developed by the same authors

Article Title: Longitudinal results of a CBT for youths with IBD and depressive symptoms

Author: Thompson, 2012

Entry	Judgement	Support for judgement (Quote/comment)
Random sequence generation (selection bias)	Low	Participants underwent randomisation
Allocation concealment (selection bias)	Unclear	Concealment method not described
Blinding of participants and personnel (performance bias)	Unclear	Study did not address this outcome
Blinding of outcome assessment (detection bias)	Low	'Follow-up raters were blind to baseline and post treatment symptomatology, as well as treatment group assignment.'
Incomplete outcome data (attrition bias)	Low	Missing data was nearly equal in each group. No significant differences between those who did and didn't complete follow up.
Selective reporting (reporting bias)	Low	Study protocol outlines and adhered to
Other bias	Low	No other bias identified

Appendix F: QualSyst (Kmet, Lee & Cook, 2004) scores for each paper in systematic review.

Study Identifier	C1	C2	C3	C4	C5	C6	C7	C8	C9	C10	C11	C12	C13	C14	Summary Score
Grootenhuys, 2009	2	2	1	1	0	N/A	N/A	2	1	2	1	1	2	2	.70
Levy, 2016	2	2	2	2	2	2	2	2	2	2	2	2	2	1	.96
Reigada, 2013	2	2	1	2	N/A	N/A	N/A	1	1	1	1	N/A	1	2	.70
Reigada, 2015	2	2	2	2	1	2	N/A	2	1	2	1	2	2	2	.88
Szigethy, 2004	2	2	2	2	N/A	2	N/A	2	0	2	2	1	2	2	.87
Szigethy, 2007	2	2	2	2	2	2	N/A	2	1	2	1	1	2	2	.88
Sziegthy, 2014	2	2	2	2	2	2	1	2	2	2	2	2	2	2	.96
Thompson, 2012	2	2	2	0	1	2	N/A	2	1	2	2	2	2	2	.84
Szigethy, 2006	2	2	2	2	N/A	2	N/A	2	0	2	1	1	2	2	.83

Appendix G: Author Guidelines for Psychology and Health for empirical paper

Instructions for authors

Thank you for choosing to submit your paper to us. These instructions will ensure we have everything required so your paper can move through peer review, production and publication smoothly. Please take the time to read and follow them as closely as possible, as doing so will ensure your paper matches the journal's requirements. For general guidance on the publication process at Taylor & Francis please visit our [Author Services website](#).



SCHOLARONE MANUSCRIPTS™

This journal uses ScholarOne Manuscripts (previously Manuscript Central) to peer review manuscript submissions. Please read the [guide for ScholarOne authors](#) before making a submission. Complete guidelines for preparing and submitting your manuscript to this journal are provided below.

Contents

- [About the Journal](#)
- [Peer Review](#)
- [Preparing Your Paper](#)
- [Structure](#)
- [Word Limits](#)
- [Style Guidelines](#)
- [Formatting and Templates](#)
- [References](#)
- [Checklist](#)
- [Using Third-Party Material](#)
- [Submitting Your Paper](#)
- [Data Sharing Policy](#)
- [Publication Charges](#)
- [Copyright Options](#)
- [Complying with Funding Agencies](#)
- [Open Access](#)
- [My Authored Works](#)
- [Reprints](#)

About the Journal

Psychology & Health is an international, peer-reviewed journal publishing high-quality, original research. Please see the journal's [Aims & Scope](#) for information about its focus and peer-review policy.

Please note that this journal only publishes manuscripts in English.

Psychology & Health accepts the following types of article: Article, Editorial, Commentary, Registered Reports.

Registered Reports differ from conventional empirical articles by performing part of the review process before the researchers collect and analyse data. Unlike more conventional process where a full report of empirical research is submitted for peer review, RRs can be considered as proposals for empirical research, which are evaluated on their merit prior to the data being collected. For information on how to prepare Registered Reports (RR) submissions [please see here](#).

Peer Review

Taylor & Francis is committed to peer-review integrity and upholding the highest standards of review. Once your paper has been assessed for suitability by the editor, it will then be single blind peer reviewed by independent, anonymous expert referees. Find out more about [what to expect during peer review](#) and read our guidance on [publishing ethics](#).

Preparing Your Paper

Structure

Your paper should be compiled in the following order: title page; abstract; keywords; main text introduction, materials and methods, results, discussion; acknowledgments; declaration of interest statement; references; appendices (as appropriate); table(s) with caption(s) (on individual pages); figures; figure captions (as a list).

Word Limits

Article and Editorial: 30 Pages
Commentary: 1000 words.

Style Guidelines

Please refer to these [quick style guidelines](#) when preparing your paper, rather than any published articles or a sample copy.

Please use British (-ise) spelling style consistently throughout your manuscript.

Please use single quotation marks, except where 'a quotation is "within" a quotation'. Please note that long quotations should be indented without quotation marks.

Formatting and Templates

Papers may be submitted in Word format. Figures should be saved separately from the text. To assist you in preparing your paper, we provide formatting template(s).

[Word templates](#) are available for this journal. Please save the template to your hard drive, ready for use.

If you are not able to use the template via the links (or if you have any other template queries) please contact us [here](#).

References

Please use this [reference guide](#) when preparing your paper.

An [EndNote output style](#) is also available to assist you.

Checklist: What to Include

1. **Author details.** All authors of a manuscript should include their full name and affiliation on the cover page of the manuscript. Where available, please also include ORCiDs and social media handles (Facebook, Twitter or LinkedIn). One author will need to be identified as the corresponding author, with their email address normally displayed in the article PDF (depending on the journal) and the online article. Authors' affiliations are the affiliations where the research was conducted. If any of the named co-authors moves affiliation during the peer-review process, the new affiliation can be given as a footnote. Please note that no changes to affiliation can be made after your paper is accepted. [Read more on authorship](#).
2. Should contain a structured abstract of 200 words. Objective, Design, Main Outcome Measures, Results, Conclusion.
3. You can opt to include a **video abstract** with your article. [Find out how these can help your work reach a wider audience, and what to think about when filming](#).
4. Read [making your article more discoverable](#), including information on choosing a title and search engine optimization.
5. **Funding details.** Please supply all details required by your funding and grant-awarding bodies as follows:
For single agency grants
This work was supported by the [Funding Agency] under Grant [number xxxx].
For multiple agency grants
This work was supported by the [Funding Agency #1] under Grant [number xxxx]; [Funding Agency #2] under Grant [number xxxx]; and [Funding Agency #3] under Grant [number xxxx].
6. **Disclosure statement.** This is to acknowledge any financial interest or benefit that has arisen from the direct applications of your research. [Further guidance on what is a conflict of interest and how to disclose it](#).
7. **Data availability statement.** If there is a data set associated with the paper, please provide information about where the data supporting the results or analyses presented in the paper can be found. Where applicable, this should include the

hyperlink, DOI or other persistent identifier associated with the data set(s).

[Templates](#) are also available to support authors.

8. **Data deposition.** If you choose to share or make the data underlying the study open, please deposit your data in a [recognized data repository](#) prior to or at the time of submission. You will be asked to provide the DOI, pre-reserved DOI, or other persistent identifier for the data set.
9. **Supplemental online material.** Supplemental material can be a video, dataset, fileset, sound file or anything which supports (and is pertinent to) your paper. We publish supplemental material online via Figshare. Find out more about [supplemental material and how to submit it with your article](#).
10. **Figures.** Figures should be high quality (1200 dpi for line art, 600 dpi for grayscale and 300 dpi for colour, at the correct size). Figures should be supplied in one of our preferred file formats: EPS, PS, JPEG, GIF, or Microsoft Word (DOC or DOCX). For information relating to other file types, please consult our [Submission of electronic artwork](#) document.
11. **Tables.** Tables should present new information rather than duplicating what is in the text. Readers should be able to interpret the table without reference to the text. Please supply editable files.
12. **Equations.** If you are submitting your manuscript as a Word document, please ensure that equations are editable. More information about [mathematical symbols and equations](#).
13. **Units.** Please use [SI units](#) (non-italicized).

Using Third-Party Material in your Paper

You must obtain the necessary permission to reuse third-party material in your article. The use of short extracts of text and some other types of material is usually permitted, on a limited basis, for the purposes of criticism and review without securing formal permission. If you wish to include any material in your paper for which you do not hold copyright, and which is not covered by this informal agreement, you will need to obtain written permission from the copyright owner prior to submission. More information on [requesting permission to reproduce work\(s\) under copyright](#).

Submitting Your Paper

Please note that *Psychology & Health* uses [Crossref™](#) to screen papers for unoriginal material. By submitting your paper to *Psychology & Health* you are agreeing to originality checks during the peer-review and production processes.

On acceptance, we recommend that you keep a copy of your Accepted Manuscript. Find out more about [sharing your work](#).

Data Sharing Policy

This journal applies the Taylor & Francis [Basic Data Sharing Policy](#). Authors are encouraged to share or make open the data supporting the results or analyses presented in their paper where this does not violate the protection of human subjects or other valid privacy or security concerns.

Authors are encouraged to deposit the dataset(s) in a recognized data repository that can mint a persistent digital identifier, preferably a digital object identifier (DOI) and recognizes a long-term preservation plan. If you are uncertain about where to deposit your data, please see [this information](#) regarding repositories.

Authors are further encouraged to [cite any data sets referenced](#) in the article and provide a [Data Availability Statement](#).

At the point of submission, you will be asked if there is a data set associated with the paper. If you reply yes, you will be asked to provide the DOI, pre-registered DOI, hyperlink, or other persistent identifier associated with the data set(s). If you have selected to provide a pre-registered DOI, please be prepared to share the reviewer URL associated with your data deposit, upon request by reviewers.

Where one or multiple data sets are associated with a manuscript, these are not formally peer reviewed as a part of the journal submission process. It is the author's responsibility to ensure the soundness of data. Any errors in the data rest solely with the producers of the data set(s).

Publication Charges

There are no submission fees, publication fees or page charges for this journal.

Colour figures will be reproduced in colour in your online article free of charge. If it is necessary for the figures to be reproduced in colour in the print version, a charge will apply.

Charges for colour figures in print are £300 per figure (\$400 US Dollars; \$500 Australian Dollars; €350). For more than 4 colour figures, figures 5 and above will be charged at £50 per figure (\$75 US Dollars; \$100 Australian Dollars; €65). Depending on your location, these charges may be subject to local taxes.

Copyright Options

Copyright allows you to protect your original material, and stop others from using your work without your permission. Taylor & Francis offers a number of different license and reuse options, including Creative Commons licenses when publishing open access. [Read more on publishing agreements](#).

Complying with Funding Agencies

We will deposit all National Institutes of Health or Wellcome Trust-funded papers into PubMedCentral on behalf of authors, meeting the requirements of their respective open access policies. If this applies to you, please tell our production team when you receive your article proofs, so we can do this for

you. Check funders' open access policy mandates [here](#). Find out more about [sharing your work](#).

Open Access

This journal gives authors the option to publish open access via our [Open Select publishing program](#), making it free to access online immediately on publication. Many funders mandate publishing your research open access; you can check [open access funder policies and mandates here](#).

Taylor & Francis Open Select gives you, your institution or funder the option of paying an article publishing charge (APC) to make an article open access. Please contact openaccess@tandf.co.uk if you would like to find out more, or go to our [Author Services website](#).

For more information on license options, embargo periods and APCs for this journal please go [here](#).

My Authored Works

On publication, you will be able to view, download and check your article's metrics (downloads, citations and Altmeteric data) via [My Authored Works](#) on Taylor & Francis Online. This is where you can access every article you have published with us, as well as your [free eprints link](#), so you can quickly and easily share your work with friends and colleagues.

We are committed to promoting and increasing the visibility of your article. Here are some tips and ideas on how you can work with us to [promote your research](#).

Article Reprints

You will be sent a link to order article reprints via your account in our production system. For enquiries about reprints, please contact the Taylor & Francis Author Services team at reprints@tandf.co.uk. You can also [order print copies of the journal issue in which your article appears](#).

Appendix H: Semi-structured interview used in empirical paper**Semi Structured Interview Guide****What is it like to live with Inflammatory Bowel Disease?**

Study Title: The Lived Experience of Adolescents with Inflammatory Bowel Disease

Introductions

As part of this conversation some young people might like to start by telling me some things about themselves, to help them to settle in and help me to get to know them. Is there anything you would like to tell me about yourself to help me get to know you?

Prompt – This could be anything you see as important as this will help me to get to know you a little better. This could be your hobbies, interests, favourite subjects, pets.

What is your understanding of what Inflammatory Bowel Disease (IBD) is?

- What word do you use to describe your IBD?
- Can you tell me how you would describe IBD to someone who had never heard of it before?
- Can you tell me about your journey, or history, with IBD?
- When were you diagnosed with IBD? How was it explained to you?
- What is your understanding of your diagnosis?
- What has been important for you to know about IBD?

Prompt – If you had to remember one thing about IBD, what would it be?

What is it like living with IBD in day to day life?

- IBD can be a little different for everyone, what are the main symptoms you have had? How do they affect you?
 - How does IBD impact on the things that you do day to day?
 - Has having IBD changed the things that you do?
- Prompt – Can you tell me more about that?*
- How does IBD impact on activities you do?
 - How does it feel to think about this?
 - What is it like having IBD at home?
 - What is it like having IBD at school?
 - What is it like having IBD outside of home and school?

What impact has IBD had on you as a person?

- How do you see yourself?
- How have your thoughts and feelings changed since you were diagnosed?
- What is life like for you having IBD?
- How does having IBD make you feel?
- What do you remember about life before IBD?
- What is life like for you after being told you have IBD?
- How do you think about the future?

Prompt – how does having IBD change how you think about the future?

- Has having IBD made you think about yourself differently?

Prompt – Why?

- What is the most difficult thing about having IBD?
- Is there anything about having IBD that you don't mind?

What impact has IBD had on relationships?

- How does IBD impact life with your family, if at all?
- How does IBD impact relationships at school, if at all?
- How does IBD impact relationships with your friends?
- How much do others at school (teachers and peers) understand about your IBD?
- Who have you told about IBD and what have you chosen to tell them?
- Does anyone else you know have IBD?

How do you look after your IBD?

- How much do you think about IBD?
- How do you look after yourself and your IBD?
- How do you deal with having IBD?

*Prompt – do you have any particular strategies or techniques?
How did you learn these?*

Closing

- Is there anything I haven't asked about that you think is important about you?
- Is there anything I haven't asked about that you think is important about IBD?
- Is there anything you would like to add?
- Is there anything you would like to ask me?
- Would you like to be sent a brief summary of the findings following completion of the research project?

Appendix I: Consolidating Criteria for Reporting Qualitative Studies (COREQ)

Developed from:

Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. *International Journal for Quality in Health Care*. 2007. Volume 19, Number 6: pp. 349 – 357

No. Item	Guide questions/description	Reported on Page #
Domain 1: Research team and reflexivity		
<i>Personal Characteristics</i>		
1. Inter viewer/facilitator	Which author/s conducted the interview or focus group? <i>HC</i>	67
2. Credentials	What were the researcher's credentials? <i>BSc Hons, PGDip, PGCert</i>	59
3. Occupation	What was their occupation at the time of the study? <i>Trainee Clinical Psychology</i>	59
4. Gender	Was the researcher male or female? <i>Female</i>	69
5. Experience and training	What experience or training did the researcher have? <i>Project completed as part of clinical psychology doctorate</i>	59
<i>Relationship with participants</i>		
6. Relationship established	Was a relationship established prior to study commencement? <i>Yes</i>	69
7. Participant knowledge of the interviewer	What did the participants know about the researcher? That she was a clinical psychology trainee and conducting research as part of training.	164
8. Interviewer characteristics	What characteristics were reported about the inter viewer/facilitator? <i>Information in participant information sheet and interviewer is a mum to a child with health problem</i>	164 & 68
Domain 2: study design		
<i>Theoretical framework</i>		
9. Methodological orientation and Theory	What methodological orientation was stated to underpin the study? <i>IPA</i>	67
<i>Participant selection</i>		
10. Sampling	How were participants selected?	66

	<i>Purposively</i>	
11. Method of approach	How were participants approached? <i>Initially face to face by clinical staff and then on the phone by lead researcher</i>	69
12. Sample size	How many participants were in the study? <i>Eight</i>	66
13. Non-participation	How many people refused to participate or dropped out? Reasons? <i>None</i>	91
<i>Setting</i>		
14. Setting of data collection	Where was the data collected? <i>Mostly at home, one in hospital and one at place of work</i>	68
15. Presence of non-participants	Was anyone else present besides the participants and researchers? <i>Yes, parents on five occasions</i>	68
16. Description of sample	What are the important characteristics of the sample? e.g. demographic data, date	66-67
<i>Data collection</i>		
17. Interview guide	Were questions, prompts, guides provided by the authors? Was it pilot tested? <i>Yes</i>	Interview schedule in appendix H, pg 156-157 Pg. 67
18. Repeat interviews	Were repeat inter views carried out? If yes, how many?	N/A
19. Audio/visual recording	Did the research use audio or visual recording to collect the data? <i>Yes</i>	70
20. Field notes	Were field notes made during and/or after the inter view or focus group? <i>Yes</i>	108-109
21. Duration	What was the duration of the inter views or focus group? <i>30-75minutes</i>	70
22. Data saturation	Was data saturation discussed? <i>Yes – amount of participants and length of interviews.</i>	66 & 69
23. Transcripts returned	Were transcripts returned to participants for comment and/or correction? <i>No but reflected on</i>	124-125
Domain 3: analysis and findings		
<i>Data analysis</i>		
24. Number of data coders	How many data coders coded the data? <i>One</i>	69
25. Description of the coding tree	Did authors provide a description of the coding tree? <i>Yes</i>	72 and in appendix Q (pg. 190) and R (pg. 191)

26. Derivation of themes	Were themes identified in advance or derived from the data? <i>Derived from data</i>	71
27. Software	What software, if applicable, was used to manage the data? <i>Nvivo</i>	71
28. Participant checking	Did participants provide feedback on the findings? <i>No – this is reflected upon</i>	124-125
<i>Reporting</i>		
29. Quotations presented	Were participant quotations presented to illustrate the themes/findings? Was each quotation identified? <i>Yes</i>	72-87
30. Data and findings consistent	Was there consistency between the data presented and the findings? <i>Yes</i>	72-87
31. Clarity of major themes	Were major themes clearly presented in the findings? <i>Yes</i>	72
32. Clarity of minor themes	Is there a description of diverse cases or discussion of minor themes? <i>Yes</i>	72 and throughout results

Appendix J: Consent to contact form**Consent to be contacted about study**

- I discussed the IBD research project being conducted by Hannah Crook, Trainee Clinical Psychologist with XXXXXXXX and family.
- I explained it would require participants to talk for around an hour about their experiences of living with IBD.
- The aim of the research is to provide us with a better understanding of what it is like living with IBD to help inform clinical services.
- I highlighted that all information would be kept confidential and be stored securely.
- XXXXXX and family understood that they are able to decline to participate and can withdraw up to the point of data analysis, which will take place 7 days after the interview.
- They understood that their decisions would not affect their care from the hospital.
-

Decision indicated below -

Please tick

XXXXXXX and family declined to participate in this study.

☐

XXXXXXX and family expressed an interest in participating in this study and I have consent to pass their contact details onto Hannah Crook. These are detailed below.

☐**Participant**

Name: _____

Participant Date of

Birth _____

Parent

Name: _____

—

Contact telephone

number: _____

Can a voicemail be left on this number by Hannah?

What is the best time to

call? _____

Name of Staff

Member: _____

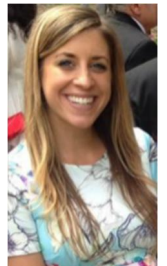
Appendix K: Participant information sheets – Parent and Participant**Participant Information Form - Parent****Parent or Guardian Information Sheet****What is it like to live with Inflammatory Bowel Disease?**

Study Title: The Lived Experience of Adolescents with Inflammatory Bowel Disease

Thank you for taking the time to read this information sheet. As previously discussed your child is being invited to take part in this research study. Before deciding whether they should take part, it is important that you understand why the study is being done and what it will involve for your child. This information is provided below, please take the time to read this carefully and discuss it with your child. A child friendly information sheet is available for your child to read. If anything is not clear, or you have any questions, then please speak to us. Please take time to decide whether you wish for your child to take part.

Who are the researchers?

This research is being conducted by Hannah Crook, Chief Investigator and Trainee Clinical Psychologist at the University of East Anglia, and is being supervised by Judith Young, Clinical Lecturer, University of East Anglia. If you would like to discuss anything in this information sheet, or discuss taking part in the study, then Hannah can be contacted on Hannah.crook@uea.ac.uk or 07857 320955.



Hannah Crook

Why are we carrying out this study?

The aim of this research is to explore, through an interview, what it is like for an adolescent living with Inflammatory Bowel Disease (both Crohn's Disease and Ulcerative Colitis). We are interested in talking to your child to help build a rich understanding of their lived experience of IBD. To our knowledge this is an area that has not been previously researched in the UK. We feel it is important that adolescents are given a voice about their experiences of living with IBD to help services provide the best treatment to this population.

Why has my child been asked to participate?

Your child has been asked to participate because they have been diagnosed with either Crohn's Disease or Ulcerative Colitis for at least 6 months. We want to talk to adolescents between the age of 12 to 19.

Does my child have to take part?

It is up to you whether or not your child takes part. If you would like your child to take part then you are asked to sign a consent form to show your agreement. We will also ask your child to sign an assent form to say they are happy to participate. Your child can withdraw from the study at any time, without giving a reason, up until the point that the data is analysed. This is because the data is then anonymised and it is therefore impossible to know which data to remove. Data will be analysed 7 days after the interview. Please note that declining to take part in the study, or withdrawing at a later stage, does not affect the standard of care your child receives. Should you and your child wish to withdraw from the study then please let the researcher know on the contact telephone number or email above.

What will happen to my child if they take part?

If you, and your child, agree to take part then you will be offered an appointment to meet with Hannah, the chief investigator, for an interview. This could be at the hospital, and may coincide with pre-booked clinic appointments, or at your home. You and your child can choose whether you are present for the interview or not.

This interview will take around 60 minutes. In this time, we will complete a brief demographic questionnaire, which asks about age, gender, ethnicity and diagnosis, followed by questions about living with IBD. You and your child do not have to answer any question you do not wish to answer. It might be difficult to remember some of the information in the demographic questionnaire, so we can ask the clinical team to check your child's medical history so we can complete the questions.

The interview will be recorded on a Dictaphone. Following the interview, it will be immediately transferred to a password protected computer and password protected encrypted memory stick and deleted from the Dictaphone. Any paper based information will be kept locked in a filing cabinet and transported in a locked briefcase.

Recordings will be transcribed 7 days after the interview. It is up until this point that you have a right to withdraw your child from the study. Any audio recordings that are sent for transcribing will be password protected and a confidentiality agreement will be signed. A pseudonym (a fake name) will be used to protect your child's identity when writing up the study and any identifiable information will be changed or removed. Direct quotes from the interviews may be used in the report from this study and these will be anonymised. The upmost will be done to protect your child's identity however this cannot be guaranteed 100% due to the use of direct quotes. Transcripts and recordings will be kept in a locked filing cabinet and according to data protection legislation will be destroyed after 10 years. We will also write to the clinical team at Addenbrooke's to let them know that your child has participated in this research.

If during the interview your child mentioned anything that indicated a risk to themselves or others, this information may need to be shared with the professional responsible for your child's care. Both you and your child would be informed before this happened so it is clear why it is important to break confidentiality.

What are the possible benefits of taking part?

There are no expected direct benefits of your child taking part in this study however some people find that talking about their experiences in detail can be helpful for them.

Your child will also be contributing to research that we don't believe has been conducted in this country before. It may be helpful for professionals to have an insight into what it is like, as an adolescent, to live with IBD, and this may shape the way they deliver care.

Are there any disadvantages to me or my child?

It may be difficult or tiring for your child to talk to someone new about their experiences and it may bring up some good or bad feelings. If your child feels that they need to take a break, then this can be arranged and support can be offered by the chief investigator. Alternatively, your child may want to rearrange the interview for another time.

The interview will take around 60 minutes and unfortunately although we cannot pay you or your child for your time, your child will be offered a £10 shopping voucher. The chief investigator will endeavour to arrange interview appointments that best suit you and these could be at home or at the hospital. Unfortunately, we are unable to reimburse travel or parking costs.

How have patients and the public been involved in this study?

Written information, such as this information sheet, has been discussed with a reader panel organised with the Patient and Public Involvement Co-ordinator at Cambridge University Hospitals NHS Foundation Trust. The children's involvement board 'Active' has also helped shape the information that is provided to you and your child and the questions your child will be asked during the interview.

What if there is a problem?

If you have any concerns about this study then please speak to Hannah, contact details above, who will do her best to answer your questions. Alternatively, you can also contact Judith Young on Judith.young@uea.ac.uk. If you wish to make a complaint you can contact Professor Ken Laidlaw (Director of the UEA Clinical Psychology Course) on 01603 593076.

Who is organising and funding this study?

This research is being undertaken as part of a professional doctorate in Clinical Psychology at the University of East Anglia. The study has been checked at a number of stages. This includes with the team at the hospital, with other patients, with UEA review panels and the study has been ethically reviewed and approved by RES Committee Yorkshire and the Humber – Leeds West.

What will happen with the findings?

The researchers are keen to share the results of the research so others can benefit from the findings. This may be done through a presentation or a written summary. The findings

will be presented to the clinical team at the hospital and may be presented at a research conference. In addition, you and your child will be asked if they would like to receive a summary of the findings once the study has been completed. The findings will be submitted for publication to a journal and written as a professional doctorate thesis.

Thank you for taking the time to read this information sheet. If you feel that you do not wish for your child to take part in this research, or have any further questions, then please contact Hannah on the details above.

Appendix K Continued: Participant Information Sheet – Under 16's

Participant Information Sheet for 12-15 year olds

What is it like to live with Inflammatory Bowel Disease?

Study Title: The Lived Experience of Adolescents with Inflammatory Bowel Disease

Introduction

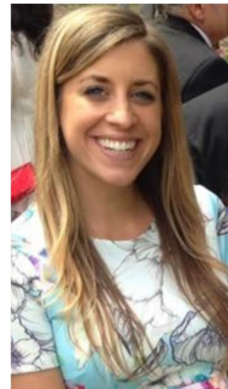
We are inviting you to take part in some research. Before deciding if you would like to join in, it is important to understand why the research is being done and what it will mean for you. Please read the leaflet carefully and talk to friends, family, doctors or nurses if you would like to.

Please ask if anything is not clear or you would like more information.

Thank you for taking the time to read this information.

Who is doing this research?

This research is being conducted by Hannah Crook, Chief Investigator and Trainee Clinical Psychologist at the University of East Anglia, and is being supervised by Judith Young, Clinical Lecturer, University of East Anglia. Hannah can be contacted on Hannah.crook@uea.ac.uk or 07857 320955.



Hannah Crook

Why are we doing this research?

We think it is important for others to be able to understand what it is like for you living with IBD. We want to find out more about your experiences of having IBD so we can help hospitals to help children and young people like you, in the best possible way.

Why have I been asked to take part?

You have been asked to take part because you have had a diagnosis of IBD for at least 6 months. You are also between 12 and 19 years of age and that is the age group we want to talk to in more detail.

Do I have to take part?

Not at all! It is completely up to you and we only want people to take part if they want to. Whatever you decide is your choice and it won't affect how you are looked after by the doctors and nurses. If you decide to take part and then change your mind then that is ok to. You can choose to stop taking part and you don't need to give a reason.

If you do want to take part then we will ask you to write your name on an 'assent form.' This is to say that you understand the study and what will happen.

What will happen if I take part?

If you agree to take part then you will come to an appointment to talk to Hannah who is doing the research. She will ask questions about you and what it is like having IBD. There are no right or wrong answers, we are interested in knowing what it is like



for you. If there are any questions you don't want to answer then that is ok. It will take about an hour to do and we can have some breaks if that makes it easier. This will be recorded on a Dictaphone and the recording will be stored safely. Hannah will also ask the adult that comes with you to the appointment to complete a questionnaire about your IBD.

Is there anything to worry about if I take part?

When we talk about ourselves it can make us feel different emotions. Talking about your IBD might make you feel good emotions but it might also make you feel not so good emotions. If you do feel sad at any point then we can talk about this and Hannah can help support you with this. Remember we can also stop the conversation if you want to.



What happens with the information about me?

Anything that is written down about you will be kept locked away and can only be seen by people who have permission to see it. Anything that is recorded will be kept locked away and can only be listened to by people who have permission to listen to it. The recordings will be typed up and direct quotes, or things you have said, may be written in the report but we will use a different name for you so nobody knows it is you that is talking about your experience. Any recordings that are sent elsewhere for typing up will be protected with a password and a confidentiality agreement will be signed. We will let the team at Addenbrooke's know that you have taken part in this research.

What will happen to the results of the study?

We hope to be able to write about the results of the study and if you would like a copy of this then we can send you one. No one will know it is you that we are writing about. We also hope to present our findings to the team at the hospital so they can understand more about what it is like having IBD.

Who has reviewed the study?

All research in the NHS is looked at by an ethics committee to check that it is safe to do. This study has been ethically reviewed and approved by RES Committee Yorkshire and the Humber – Leeds West. The team at the hospital are also aware of this study and other patients have been asked to help set it up.

Who is organising and funding the study?

This research is part of a professional doctorate in Clinical Psychology at the University of East Anglia.

What if there is a problem?

If you have any concerns about this study then please speak to Hannah, details above, who will do her best to answer your questions. Alternatively, you can also contact Judith Young on Judith.young@uea.ac.uk.

Thank you for reading this. If you feel that you do not wish to take part in this research, or have any further questions, then please contact Hannah on the details above.

Appendix L: Consent form for Parent and Assent forms for Participant**Parent Consent Form****PARENT OR GUARDIAN CONSENT FORM****What is it like to live with Inflammatory Bowel Disease?**

Study Title: The Lived Experience of Adolescents with Inflammatory Bowel Disease

Participant ID:

Name of Researcher: Hannah Crook (email: Hannah.crook@uea.ac.uk; telephone: 07857 320955)

Please Initial box

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

☐

2. I understand that my child's participation is voluntary and that my child is free to withdraw, without giving any reason, without their medical care being affected.

☐

3. I understand that the interview will be tape-recorded and the file securely stored.

☐

4. I confirm that I am signing this consent form at least 48 hours after having first had the study explained to me.

☐

5. I understand that my child can change their mind and withdraw their interview data from the study up to 7 days after the interview. It will be my responsibility to contact the researcher to let her know.

☐

6. I understand that the Gastroenterology clinical team will be made aware that my child has participated in this research

☐

7. I understand that the clinical team may check my child's medical history to help complete the demographic information.

☐

8. I understand that a pseudonym will be used when writing up the study. I understand that absolute anonymity cannot be guaranteed due to the use of direct quotes but all potentially identifiable information will be removed or changed to protect confidentiality.

☐

9. I understand that the summary research findings will be disseminated to the Gastroenterology Service and wider audiences, including submission for publication in a journal and written as a professional doctorate thesis.

☐

10. I understand that information collected about my child may be used to support other research in the future, and may be looked at by other researchers in the current research team, from regulatory authorities or the NHS trust, where it is relevant to my child taking part in this research.

☐

11. I understand that my child's answers are confidential. However, I understand that if following the interview it is identified that your child may need more input from the clinical team, this information would be passed on once it has been discussed with you and your child.

☐

12. I agree that my child can take part in the above study.

☐

Name of participant

Name of parent

Date

Signature

Name of researcher

Date

Signature

If you would like to receive a brief summary of the research findings following completion of the study, then please provide an email address or postal address below:-

When completed: 1 for copy for participant/parent; one copy for researcher site file; original for medical notes

Appendix L Continued: Participant Assent Form**Child Assent Form****What is it like to live with Inflammatory Bowel Disease?**

Study Title: The Lived Experience of Adolescents with Inflammatory Bowel Disease

Participant ID:

Name of Researcher: Hannah Crook (email: Hannah.crook@uea.ac.uk; telephone: 07857 320955)

Child (or if unable, the parent on their behalf)/young person to circle all they agree with please:

Have you read, or had read to you, the information about this study?

YES/NO

Has somebody explained the study to you?

YES/NO

Do you understand what the study is about?

YES/NO

Have you asked all the questions you want?

YES/NO

Have you had your questions answered in a way you understand?

YES/NO

Do you understand that it's OK to stop taking part at any time?

YES/NO

Are you happy to take part in this study?

YES/NO

If any answers are 'no' or you don't want to take part, then please don't sign your name!

If you do want to take part, then please write your name and today's date:

Your name _____

Date _____

Your parent or guardian must write their name here too if they are happy for you to do the project

Print Name _____

Sign _____

Date _____

The researcher who explained this project to you needs to sign too

Print Name _____

Sign _____

Date _____

Appendix M: Demographic questionnaire**Participant Demographic Information Form****What is it like to live with Inflammatory Bowel Disease?**

Study Title: The Lived Experience of Adolescents with Inflammatory Bowel Disease

Participant ID:

Please provide the following information, if you are happy to do so. Collecting this information will be helpful to see similarities and differences between the participants in this study. It can help us to see if different experiences can be due to factors such as age or when you were diagnosed.

1) What is your gender? Please circle your answer.

Male
Female
Other

2) What is your date of birth?

3) What is your ethnic group? Circle one option that best describes your ethnic group or background:

White

Mixed/Multiple ethnic groups

Asian/Asian British

Black/ African/Caribbean/Black British

Other ethnic group

4) Which diagnosis do you have? Please circle your answer.

Ulcerative Colitis

Crohn's Disease

Inflammatory Bowel Disease - Unclassified

Other (please give further details below.)

5) When were you diagnosed?

6) Are you currently on any treatment (for example medication, nutritional supplements etc) for IBD? Please circle your answer.

YES

NO

If yes, please state what treatment:

7) Have you had any surgery as a result of IBD? Please circle your answer.

YES

NO

If yes, please state what surgery: _____

8a) Please circle which school year you are in. If you are no longer in school, please answer question 8b.

Year 7	Year 9	Year 11	Year 13
Year 8	Year 10	Year 12	

8b) If you are no longer in school please circle the option that best suits you below.

College	Full time employment	Part time employment
University	Apprenticeship	Unemployed

Please give further details

Appendix N: Healthcare professional letter advising of participation in research

Name

Date of Birth

I am writing to inform you that the above patient has taken part in a research project entitled 'The Lived Experience of Adolescents with Inflammatory Bowel Disease.' This involved an hour long semi structured interview where participants were asked about their experiences of living with Inflammatory Bowel Disease.

This is an under-researched area and it is hoped that a richer understanding of what it is like to live with Inflammatory Bowel Disease for an adolescent will be of value to clinical practice.

This project is being undertaken as part of my professional doctorate in Clinical Psychology at the University of East Anglia. This study has been ethically reviewed and approved by RES Committee Yorkshire and the Humber – Leeds West. If you have any further questions please do not hesitate to contact me via my email Hannah.crook@uea.ac.uk.

Yours sincerely

Hannah Crook

Appendix O: Ethical Approval

Research Ethics Committee Acknowledgement



Health Research
Authority

Yorkshire & The Humber - Leeds West Research Ethics Committee
Jarrow Business Centre
Rolling Mill Road
Jarrow
NE32 3DT

Telephone: 0207 104 8086

Please note: This is an acknowledgement letter from the REC only and does not allow you to start your study at NHS sites in England until you receive HRA Approval

06 February 2018

Mrs Hannah Crook
Department of Clinical Psychology,
Norwich Medical School,
University of East Anglia, Norwich Research Park, Norwich,
NR4 7TJ

Dear Mrs Crook

Study title: The Lived Experience of Adolescents with Inflammatory Bowel Disease
REC reference: 18/YH/0002
IRAS project ID: 211267

Thank you for your letter of 6th February. I can confirm the REC has received the documents listed below and that these comply with the approval conditions detailed in our letter dated 26 January 2018

Documents received

The documents received were as follows:

Document	Version	Date
Copies of advertisement materials for research participants [Poster version 2]	2	06 February 2018
GP/consultant information sheets or letters [letter to HCP]	2	06 February 2018
Letters of invitation to participant [Consent to Contact]	2	06 February 2018
Participant consent form [16 year plus Consent Form]	2	06 February 2018
Participant consent form [Parent Consent Form]	2	06 February 2018
Participant information sheet (PIS) [PIS 16 year old]	2	06 February 2018
Participant information sheet (PIS) [PIS Parent]	2	06 February 2018
Participant information sheet (PIS) [PIS under 16]	2	06 February 2018

Approved documents

The final list of approved documentation for the study is therefore as follows:

Document	Version	Date
Copies of advertisement materials for research participants (Poster version 2)	2	06 February 2018
Covering letter on headed paper (Covering Letter)	1	11 November 2017
Evidence of Sponsor insurance or indemnity (non NHS Sponsors only) (& letter)	1	01 December 2017
GP/consultant information sheets or letters (letter to HCP)	2	06 February 2018
Interview schedules or topic guides for participants (Interview Schedule)	1	11 November 2017
IRAS Application Form (IRAS_Form_01122017)		01 December 2017
Letters of invitation to participant (Consent to Contact)	2	06 February 2018
Participant consent form (Children Assent Form)	1	11 November 2017
Participant consent form (16 year plus Consent Form)	2	06 February 2018
Participant consent form (Parent Consent Form)	2	06 February 2018
Participant information sheet (PIS) (PIS 16 year old)	2	06 February 2018
Participant information sheet (PIS) (PIS Parent)	2	06 February 2018
Participant information sheet (PIS) (PIS under 16)	2	06 February 2018
Referee's report or other scientific critique report (Proposal Feedback)	1	11 November 2017
Research protocol or project proposal (Thesis Proposal)	1	06 November 2017
Summary CV for Chief Investigator (CI) (CI research CV)	1	10 November 2017
Summary CV for supervisor (student research) (Primary Supervisor CV)	1	11 November 2017
Summary CV for supervisor (student research) (Secondary Supervisor 1)	1	11 November 2017
Summary CV for supervisor (student research) (Clinical team supervisor)	1	29 November 2017
Summary, synopsis or diagram (flowchart) of protocol in non technical language (Lay Summary)	1	11 November 2017

You should ensure that the sponsor has a copy of the final documentation for the study. It is the sponsor's responsibility to ensure that the documentation is made available to R&D offices at all participating sites.

18/YH0002	Please quote this number on all correspondence
-----------	------------------------------------------------

Yours sincerely



Christle Ord
REC Manager

E-mail: nrescommittee.yorkandhumber-leedswest@nhs.net

Copy to: Ms Tracy Assart, Cambridge University Hospitals NHS Foundation Trust

Appendix O continued: Health Research Authority Approval



Health Research Authority

Mrs Hannah Crook
 Trainee Clinical Psychologist
 Cambridgeshire and Peterborough Foundation Trust
 Department of Clinical Psychology
 Norwich Medical School
 University of East Anglia, Norwich Research Park, Norwich,
 NR4 7TJ

Email: hra.approval@nhs.net

09 February 2018

Dear Mrs Crook

Letter of HRA Approval

Study title:	The Lived Experience of Adolescents with Inflammatory Bowel Disease
IRAS project ID:	211267
REC reference:	18/YH/0002
Sponsor	University of East Anglia

I am pleased to confirm that HRA Approval has been given for the above referenced study, on the basis described in the application form, protocol, supporting documentation and any clarifications noted in this letter.

Participation of NHS Organisations in England

The sponsor should now provide a copy of this letter to all participating NHS organisations in England.

Appendix B provides Important Information for sponsors and participating NHS organisations in England for arranging and confirming capacity and capability. Please read Appendix B carefully, in particular the following sections:

- *Participating NHS organisations in England* – this clarifies the types of participating organisations in the study and whether or not all organisations will be undertaking the same activities
- *Confirmation of capacity and capability* - this confirms whether or not each type of participating NHS organisation in England is expected to give formal confirmation of capacity and capability. Where formal confirmation is not expected, the section also provides details on the time limit given to participating organisations to opt out of the study, or request additional time, before their participation is assumed.
- *Allocation of responsibilities and rights are agreed and documented (4.1 of HRA assessment criteria)* - this provides detail on the form of agreement to be used in the study to confirm capacity and capability, where applicable.

Further information on funding, HR processes, and compliance with HRA criteria and standards is also provided.

IRAS project ID	211267
-----------------	--------

It is critical that you involve both the research management function (e.g. R&D office) supporting each organisation and the local research team (where there is one) in setting up your study. Contact details and further information about working with the research management function for each organisation can be accessed from the [HRA website](#).

Appendices

The HRA Approval letter contains the following appendices:

- A – List of documents reviewed during HRA assessment
- B – Summary of HRA assessment

After HRA Approval

The document '*After Ethical Review – guidance for sponsors and investigators*', issued with your REC favourable opinion, gives detailed guidance on reporting expectations for studies, including:

- Registration of research
- Notifying amendments
- Notifying the end of the study

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

In addition to the guidance in the above, please note the following:

- HRA Approval applies for the duration of your REC favourable opinion, unless otherwise notified in writing by the HRA.
- Substantial amendments should be submitted directly to the Research Ethics Committee, as detailed in the *After Ethical Review* document. Non-substantial amendments should be submitted for review by the HRA using the form provided on the [HRA website](#), and emailed to hra.amendments@nhs.net.
- The HRA will categorise amendments (substantial and non-substantial) and issue confirmation of continued HRA Approval. Further details can be found on the [HRA website](#).

Scope

HRA Approval provides an approval for research involving patients or staff in NHS organisations in England.

If your study involves NHS organisations in other countries in the UK, please contact the relevant national coordinating functions for support and advice. Further information can be found through [IRAS](#).

If there are participating non-NHS organisations, local agreement should be obtained in accordance with the procedures of the local participating non-NHS organisation.

IRAS project ID	211267
-----------------	--------

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](#).

HRA Training

We are pleased to welcome researchers and research management staff at our training days – see details on the [HRA website](#).

Your IRAS project ID is 211267. Please quote this on all correspondence.

Yours sincerely

Kevin Ahmed
Assessor

Telephone: 0207 104 8171
Email: hra.approval@nhs.net

Copy to: *Ms Tracy Moulton, Sponsor Contact, University of East Anglia*
Ms Tracy Assari, R&D Contact, Cambridge University Hospitals NHS Foundation Trust

IRAS project ID	211267
-----------------	--------

Appendix A - List of Documents

The final document set assessed and approved by HRA Approval is listed below.

Document	Version	Date
Copies of advertisement materials for research participants (Poster version 2)	2	06 February 2018
Covering letter on headed paper (Covering Letter)	1	11 November 2017
Evidence of Sponsor Insurance or Indemnity (non NHS Sponsors only) (& letter)	1	01 December 2017
GP/consultant information sheets or letters (letter to HCP)	2	06 February 2018
HRA Schedule of Events	1.0	09 February 2018
HRA Statement of Activities	1.0	09 February 2018
Interview schedules or topic guides for participants (Interview Schedule)	1	11 November 2017
IRAS Application Form (IRAS_Form_01122017)		01 December 2017
Letters of invitation to participant (Consent to Contact)	2	06 February 2018
Participant consent form (Children Assent Form)	1	11 November 2017
Participant consent form (16 year plus Consent Form)	2	06 February 2018
Participant consent form (Parent Consent Form)	2	06 February 2018
Participant information sheet (PIS) (PIS Parent)	2	06 February 2018
Participant information sheet (PIS) (PIS under 16)	2	06 February 2018
Participant information sheet (PIS) (PIS 16 year old)	2	06 February 2018
Referee's report or other scientific critique report (Proposal Feedback)	1	11 November 2017
Research protocol or project proposal (Thesis Proposal)	1	06 November 2017
Summary CV for Chief Investigator (CI) (CI research CV)	1	10 November 2017
Summary CV for supervisor (student research) (Primary Supervisor CV)	1	11 November 2017
Summary CV for supervisor (student research) (Secondary Supervisor 1)	1	11 November 2017
Summary CV for supervisor (student research) (Clinical team supervisor)	1	29 November 2017
Summary, synopsis or diagram (flowchart) of protocol in non technical language (Lay Summary)	1	11 November 2017
211267, 18.YH.0002 FO conditions met 08.02.18		08 February 2018

Appendix B - Summary of HRA Assessment

This appendix provides assurance to you, the sponsor and the NHS in England that the study, as reviewed for HRA Approval, is compliant with relevant standards. It also provides information and clarification, where appropriate, to participating NHS organisations in England to assist in assessing and arranging capacity and capability.

For information on how the sponsor should be working with participating NHS organisations in England, please refer to the, participating NHS organisations, capacity and capability and Allocation of responsibilities and rights are agreed and documented (4.1 of HRA assessment criteria) sections in this appendix.

The following person is the sponsor contact for the purpose of addressing participating organisation questions relating to the study:

Name: Ms Tracy Moulton
Email: t.moulton@uea.ac.uk

HRA assessment criteria

Section	HRA Assessment Criteria	Compliant with Standards	Comments
1.1	IRAS application completed correctly	Yes	No comments
2.1	Participant information/consent documents and consent process	Yes	No comments
3.1	Protocol assessment	Yes	No comments
4.1	Allocation of responsibilities and rights are agreed and documented	Yes	<p>The sponsor has submitted the HRA Statement of Activities and intends for this to form the agreement between the sponsor and study sites.</p> <p>The sponsor is not requesting, and does not require any additional contracts with study sites.</p>

IRAS project ID	211287
-----------------	--------

Section	HRA Assessment Criteria	Compliant with Standards	Comments
4.2	Insurance/Indemnity arrangements assessed	Yes	Where applicable, independent contractors (e.g. General Practitioners) should ensure that the professional indemnity provided by their medical defence organisation covers the activities expected of them for this research study
4.3	Financial arrangements assessed	Yes	No application for external funding has been made. No study funding will be provided to sites, as detailed at Schedule 1 of the Statement of Activities.
5.1	Compliance with the Data Protection Act and data security issues assessed	Yes	No comments
5.2	CTIMPS – Arrangements for compliance with the Clinical Trials Regulations assessed	Not Applicable	No comments
5.3	Compliance with any applicable laws or regulations	Yes	No comments
6.1	NHS Research Ethics Committee favourable opinion received for applicable studies	Yes	No comments
6.2	CTIMPS – Clinical Trials Authorisation (CTA) letter received	Not Applicable	No comments
6.3	Devices – MHRA notice of no objection received	Not Applicable	No comments
6.4	Other regulatory approvals and authorisations received	Not Applicable	No comments

Participating NHS Organisations in England

This provides detail on the types of participating NHS organisations in the study and a statement as to whether the activities at all organisations are the same or different.

All participating NHS organisations will undertake the same study activities. There is therefore only one study site 'type' involved in the research.

The Chief Investigator or sponsor should share relevant study documents with participating NHS organisations in England in order to put arrangements in place to deliver the study. The documents should be sent to both the local study team, where applicable, and the office providing the research management function at the participating organisation. For further guidance on working with participating NHS organisations please see the HRA website.

If chief investigators, sponsors or principal investigators are asked to complete site level forms for participating NHS organisations in England which are not provided in IRAS or on the HRA website, the chief investigator, sponsor or principal investigator should notify the HRA immediately at hra.approval@nhs.net. The HRA will work with these organisations to achieve a consistent approach to information provision.

Confirmation of Capacity and Capability

This describes whether formal confirmation of capacity and capability is expected from participating NHS organisations in England.

NHS organisations in England that are participating in the study **will be expected to formally confirm their capacity and capability** to host this research.

- Following issue of this letter, participating NHS organisations in England may now confirm to the sponsor their capacity and capability to host this research, when ready to do so. How capacity and capability will be confirmed is detailed in the Allocation of responsibilities and rights are agreed and documented (4.1 of HRA assessment criteria) section of this appendix.
- The Assessing, Arranging, and Confirming document on the HRA website provides further information for the sponsor and NHS organisations on assessing, arranging and confirming capacity and capability.

Principal Investigator Suitability

This confirms whether the sponsor position on whether a PI, LC or neither should be in place is correct for each type of participating NHS organisation in England and the minimum expectations for education, training and experience that PIs should meet (where applicable).

A Principal Investigator should be appointed at study sites.

GCP training is not a generic training expectation, in line with the [HRA statement on training expectations](#).

IRAS project ID	211267
-----------------	--------

HR Good Practice Resource Pack Expectations

This confirms the HR Good Practice Resource Pack expectations for the study and the pre-engagement checks that should and should not be undertaken

Where arrangements are not already in place, network staff (or similar) undertaking any of the research activities listed in A18 of the IRAS form be expected to obtain a Letter of Access based on standard DBS checks and occupational health clearance would be appropriate.

Other Information to Aid Study Set-up

This details any other information that may be helpful to sponsors and participating NHS organisations in England to aid study set-up.

The applicant has indicated that they do not intend to apply for inclusion on the NIHR CRN Portfolio.

Appendix O continued: Capacity and Capability Assessment approval from participating NHS trust



Research and Development Department

25th April 2018

R&D ref: A094736

Mrs Hannah Crook
Department of Clinical Psychology,
Norwich Medical School,
University of East Anglia, Norwich Research
NR4 7TJ

Box 277
Addenbrooke's Hospital
Hills Road
Cambridge
CB2 0QQ

Direct Dial: 01223596371 Ext 6371
Switchboard: 01223 245151

E-mail: jane.grancis.geffe@addenbrookes.nhs.uk
rd.enquiries@addenbrookes.nhs.uk
www.addenbrookes.org.uk

Dear Mrs Crook,

IRAS ID: 211267

The Lived Experience of Adolescents with Inflammatory Bowel Disease

REC Ref:18/YH/0002

Thank you for sending details of the above named study.

The R&D department has received the HRA Approval letter and reviewed the study documents. The project has been allocated the internal R&D reference number of **A094736**. Please quote this in all future correspondence regarding this study.

Capacity and capability to conduct this study at Cambridge University Hospitals NHS Foundation Trust is confirmed. Recruitment can commence at this site from the date of this letter.

We would like to take this opportunity to remind you of your responsibilities under the terms of the Research Governance Framework for Researchers, Chief Investigators, Principal Investigators and Research Sponsors and to also of the requirement to notify R&D of any amendments or changes made to this study.

You will be aware that the Trust is subject to national reporting requirements for first patient recruitment within 70 days. Further details on this can be found on the NIHR website: <http://www.nihr.ac.uk/research-and-impact/nhs-research-performance/performance-initiating-and-delivering-research/>

If you have any questions or concerns about this, please contact me.

I wish you every success with this study.

Yours sincerely

Tracy Cripps
Research Governance Manager

Appendix P: Master table of themes for group

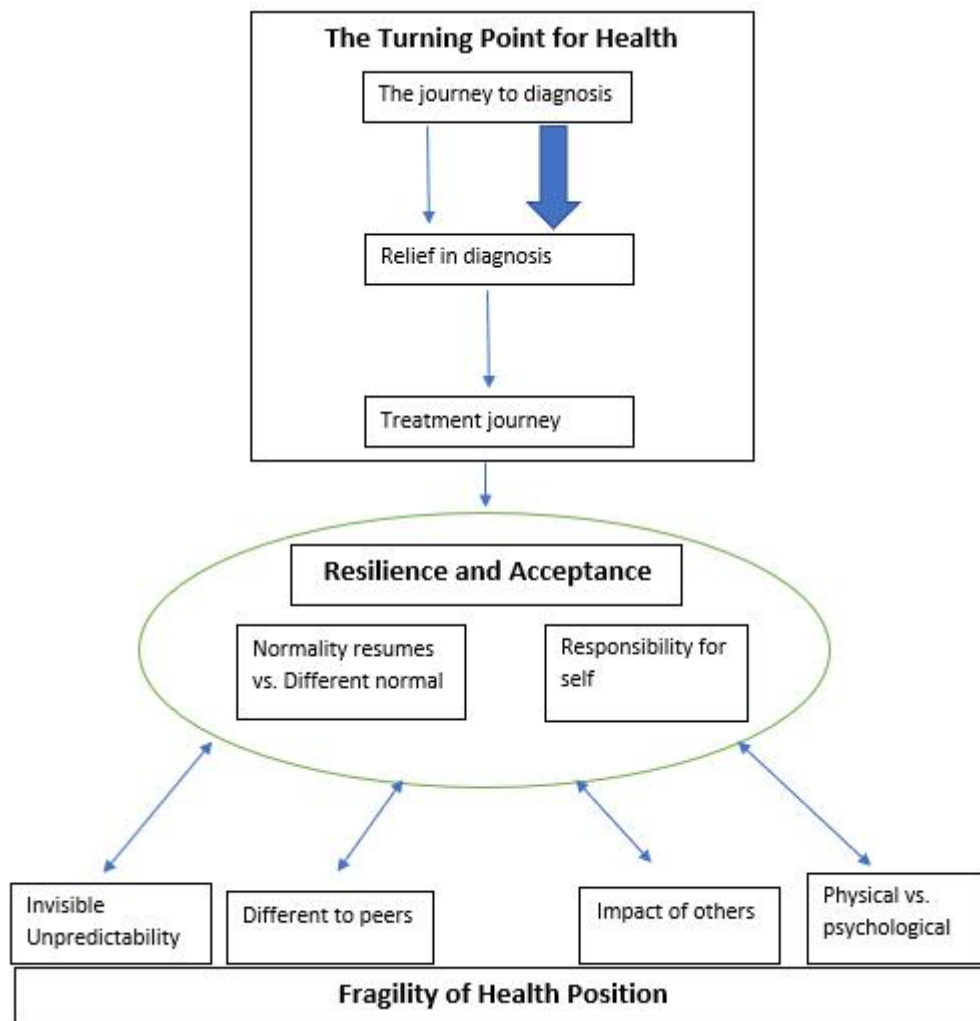
The Turning Point for Health	<i>The journey to diagnosis</i>	<p>Louise: ‘I think it's just sort of having faith in doctors and thinking, right, what next? What next?’</p> <p>Ella: ‘It wasn't very long from when I got unwell to when I was diagnosed. I guess I just wasn't really thinking about it.’</p> <p>James: ‘I've only had bad stomachs, but it didn't get diagnosed for ages.’</p> <p>Marie: ‘We went to the hospital and then they just didn't know what to do about it.’</p> <p>Gemma: ‘They'd kind of said, "We don't think we are going to put you on another course of steroids." But when we went to that out of hours' doctors they were kind of like, "We think that they are probably going to put you on another course of steroids."’</p>
	<i>Relief in diagnosis</i>	<p>Harriet: ‘It was a relief. I was like, "Okay, now, I understand why this is happening.”’</p> <p>Marie: ‘You can do something about it and you just fully understand what's wrong with you.’</p> <p>Toby: ‘Once I was told everything, I settled down and I thought, "It's not too bad." Obviously, with the flare-ups, up and down, it's obviously quite annoying but nice to know what it's now.’</p> <p>Gemma: ‘Definitely definitely that's why I was so happy. I think I cried when I found out because I was like this is what I need. This is what I wanted.’</p> <p>Ella: ‘It was good that a diagnosis was early though because that meant it could be dealt with quicker.’</p>
	<i>The treatment journey</i>	<p>Harriet: ‘Whereas now I've found a treatment that's working, it's not stopping me as much.’</p> <p>Louise: ‘I think when it was really bad, I'd say it was really painful but now that I'm on better medication and that we found something that works at the moment.’</p> <p>William: I tried eating a little bit more food and stuff, but it didn't really work in the end, so I went to steroids. I remember that made a big difference’</p> <p>Ella: ‘Once I had the diagnosis, I was started on Mesalazine straight away. That completely brought my health back up to a point where I could go to school and I felt okay. So...that was great.’</p> <p>Marie: ‘it was always in liquids but when I got the medication it was in tablet form. I'd never taken tablets before so it was- [laughs] Yes. It was a bit of a tiring experience to try and get me to have my first tablet. It was good after I'd figured out how to take them. It's just taking them to begin with.’</p> <p>Gemma: ‘I've gone through two courses of steroids, I had azathioprine for a while, I've got a lot of inflammation from that. What they think happened is because you can get liver inflammation with IBD, they think that I had that as well as another inflammation from azathioprine, kind of a double whammy of it—’</p> <p>Toby: ‘I'd have to keep taking different types of medication, seeing what works, what doesn't.’</p>

Resilience and Acceptance	<i>Normality resumes vs. different normal</i>	<p>Gemma: "Oh, don't feel bad, it's just life isn't it. I've got it now so I might as well suck up and deal with it."</p> <p>Marie: 'It was just affecting a lot of my work because I was missing so many lessons and then it was just constant hospital appointment after hospital appointment. I was going to hospital so much it would be rare of me to go one week without visiting the hospital at least twice.'</p> <p>Harriet: 'I said I wouldn't let it get to me. I wouldn't let it stop me doing what I want to do'</p> <p>Ella: 'It's fine because I don't really notice it on my day-to-day life. The symptoms don't really matter. Just going around normally.'</p> <p>James: 'I don't think it can get much better because it's already pretty good'</p> <p>Louise: 'I think when I was really ill, I didn't go dancing but then when I got better, I did go and then when I was better it didn't affect me.'</p> <p>Toby: 'I just got used to it.'</p> <p>William: 'It's not really a big deal at the end of the day. It's just one of those things.'</p>
	<i>Responsibility for self</i>	<p>Gemma: 'even if I am well I still have got to keep taking these to make sure I am well, but I have kind of accepted it now.'</p> <p>Marie: 'I can't push myself as hard as other people would be able to or just in fear of it flaring up.'</p> <p>William: 'Yes, every day as it comes. Obviously, I didn't know my flare-up was going to come. There's no point before that, worrying about having a flare-up. When it came it came, dealt with it'</p> <p>Ella: 'You just take medication at the right time and go for blood test, stuff like that. Just keep on top of everything and remember stuff.'</p> <p>Harriet: 'I make sure I'm eating properly and that. When my weight goes down or something, I'll make sure I keep an eye on it and make sure it gets up.'</p> <p>Toby: 'If I think this might trigger it, I'll just won't eat it and I'll tell mum I'm not going to eat it.'</p> <p>Louise: 'I just also felt annoyed that I wasn't in school because it wasn't that I didn't want to be in school, it's that I couldn't be in school and that just made me upset.'</p>
Fragility of Health Position	<i>Invisible unpredictability</i>	<p>Louise: 'You never know how you are going to feel the next day and every day is a new day so you never know'</p> <p>Gemma: 'Yes because I guess I don't really- that's the trouble with illnesses--" They don't know you're ill because when you're at your worse you aren't going to be there and be with them. They're not going to see you when you're at your worst.'</p> <p>Marie: 'Yes because I don't look like the typical person who's sick or comes into the hospital every eight weeks, so people just think by that, it's like, "She can do this," but in reality, I can't.'</p>

		<p>Toby: 'It just keeps going up and then it's back down again. I'm all right one minute and then the next I might not be.'</p> <p>Ella: 'It's gone a bit up and down, but it's never gone below the point where-- When I first was taking the Mesalazine, it's gone up and down but never below that point.'</p>
	<i>Different to peers</i>	<p>Marie: 'It's just, I feel quite uncomfortable when I talk to other people about it because it's on this part especially to friends because they've never had to experience hardly anything to do, maybe the hospital at all, let alone home with medication.'</p> <p>Harriet: 'It's quite annoying because everyone will have a tummy ache but this is constant whether I realize it or not and they're very different. This one can make you feel tired. It can make you feel sick. It can just make you just not want to move whereas a tummy ache just go whereas this could last a whole day or week.'</p> <p>Louise: "'Oh you're not meant to be in", because there was this, a slightly separate room and there are of course other teachers and I think may look after other children that might need a bit more help. '</p> <p>James: 'No big pain, just an ache. Probably, what everyone has.'</p>
	<i>Impact of others</i>	<p>James: 'Only a close few people know on the outside. They're nice about it.'</p> <p>Gemma: 'Because I was like, what makes you think you can say that about me when you don't even know me and you don't even know what I've been through'</p> <p>Marie: 'If I have a problem or there's just something concerning me, I can quickly pop down at break or lunch to quickly ask one of the nurses if this is normal or actually just keeping an eye on it.'</p> <p>Ella: 'I feel like you have more freedom of what you can do and where you can go, but with the school trip you have to follow that program.'</p> <p>Toby: 'Better, everyone knows what happens and everyone's really nice. They do whatever to help me to keep going and see if there's anything I can do in the house while I'm off.'</p>
	<i>Physical vs psychological</i>	<p>Ella: 'Then the stress also affects the IBD a bit more.'</p> <p>Louise: 'I think it probably was myself, to be honest, just me, mentally, maybe worrying a bit too much and just about worrying about what's going to happen and what I'm missing while I'm at home just sitting on the toilet'</p> <p>James: 'I've never taken much notice, but I think, there could actually be a link. I do think whenever I get stressed I do get belly aches. I just don't really make the link.'</p> <p>Gemma: 'That was always hard trying to find a balance of what is a nervous my tummy hurts because I'm about to do something new, and what is an actual pain.'</p>

Appendix Q: Table of recurrent themes

	Themes	Harriet	Gemma	Louise	Marie	William	James	Ella	Toby	Present in over half of sample?
The Turning Point for Health	<i>The journey to diagnosis</i>	No	Yes	Yes	Yes	No	Yes	Yes	No	Yes
	<i>Relief in diagnosis</i>	Yes	Yes	No	Yes	No	No	Yes	Yes	Yes
	<i>The treatment journey</i>	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes
Resilience and Acceptance	<i>Normality resumes vs. different normal</i>	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
	<i>Responsibility for self</i>	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes
Fragility of Health Position	<i>Invisible unpredictability</i>	No	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
	<i>Different to peers</i>	Yes	No	Yes	Yes	Yes	Yes	Yes	Yes	Yes
	<i>Impact of others</i>	No	Yes	No	Yes	No	Yes	Yes	Yes	Yes
	<i>Physical vs psychological</i>	No	Yes	Yes	No	No	Yes	Yes	No	Yes

Appendix R: Diagrammatic representation of themes

As informed by Wright et al. (2015), this diagrammatic representation demonstrates the connections between the themes, at a group level, as interpreted by the lead researcher. The different sized arrows from 'journey to diagnosis' represent the different journeys taken by our participants to arrive at 'relief in diagnosis'. The flow of arrows downwards demonstrates the uni-directional journey of the 'Turning Point of Health' which finishes at 'Resilience and Acceptance'. There demonstrates a sense that once participants had moved through their 'treatment journey', things would not return to the way they were before the 'journey to diagnosis', even during relapse. 'Resilience and Acceptance' represents the current position of the participants in this study. However, this could be challenged, or made stronger, at any time by the aspects of the 'Fragility of Health Position.' The bi-directional arrows represent the movement between these fragilities and a place of resilience and acceptance.