Young people with Inflammatory Bowel Disease: the relationship with their disease, identity, and illness perceptions and healthcare at a time of transition

A thesis submitted in fulfilment of the requirements for the degree of:

Doctor of Philosophy

Dr Alenka Jane Brooks (MBChB, FRCP)

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Declaration

I confirm that this is my own work and the use of all material from other sources has been properly and fully acknowledged.

Alenka Jane Brooks

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Abstract

Background: Young people living with inflammatory bowel disease (IBD) face a range of challenges as they develop through their adolescent years in to adulthood, alongside transition from child to adult healthcare services. Psychological morbidity in young people with IBD is increased, but there is little understanding of the experiences, risk factors and impacts of this into adulthood.

Aims: To examine and evaluate the psychological wellbeing and illness perceptions of young people aged 16-21 years living with IBD, in order to better understand the challenges of growing-up with IBD and transitioning from child to adult healthcare leading to service delivery recommendations.

Methods:

1. Systematic literature review of risk factors and impacts of psychological morbidity in young people aged 10-24 years living with IBD.
2. Prospective quantitative questionnaire based study of the prevalence of psychological morbidity and the relationship between illness perceptions and other risk factors and in 121 young people with IBD aged 16-21 years, with 100 young people participating 1 year later.
3. Qualitative study using Interpretative Phenomenological Analysis with interviews of 14 young people with IBD aged 16-21 years investigating their lived experiences with IBD.

4. Qualitative study using Interpretative Phenomenological Analysis with interviews of 19 young people with IBD aged 16-21 years regarding the experiences of transitioning from child to adult IBD healthcare services.

Findings: Young people living with IBD have a high prevalence of psychological morbidity, which is stable over time. Predictive factors for psychological morbidity included being female, active disease and negative illness perceptions. Young people with IBD have highly individual experiences based on symptoms, healthcare experiences and personal factors. The experiences often result in isolation and revised life goals. Transition from child to adult services is empowering but with a sense of accelerated entry into adulthood. Young people can feel passive and lack personal control during the process of transition.

Conclusions: Recommendations from this work include promotion of an individualised, flexible and developmentally appropriate approach to healthcare for young people with IBD. Young people with IBD are at risk of psychological morbidity and illness perceptions may be an appropriate target for psychological interventions.

Plain English Summary

Young people diagnosed with Inflammatory Bowel Disease (IBD) face a number of challenges as they grow through their teenage years into young adults. For young people with IBD, everyday challenges are greater than for those without a chronic health condition, as living with IBD can impact on negotiating key milestones successfully. It is also during this complicated period of adolescence when young people need to move ('transition') from child (paediatric) healthcare services into adult IBD services. Young people with IBD are known to have a greater risk of poor psychological well-being (depression, anxiety and quality of life) compared to those without IBD.

The aims of this research were:

1. To provide understanding into the experiences and challenges of young people growing up with IBD in late adolescence (aged between 16 and 21 years) in general and specifically during the time of transition from child to adult services, and
2. To provide understanding into the impact of IBD on the psychological wellbeing (depression, anxiety and quality of life) and illness perceptions (thoughts about how they view their diagnosis of IBD) of young people.

The research began with a literature review (of other studies done in the past in this area). This was followed by two interview based studies, one with 14 young people and the other with 19 young people. One of the interview studies focused on in depth questions regarding experiences of growing-up with IBD, whereas the other focused on the experiences of moving from child to adult healthcare services ('transition'). Alongside these interview based studies, a questionnaire based study of 121 young people aged 16-21 years with IBD was completed.

This examined psychological wellbeing outcomes (depression, anxiety and quality of life) and illness perceptions (thoughts about how they view their diagnosis of IBD) in a group of 121 young people (aged 16-21) with IBD. One-hundred young people also provided repeat questionnaire 12 months later.

The findings of this research showed that young people with IBD have high rates of anxiety in particular, but also higher rates of depression and a lower quality of life than the general population. This did not change over a one year period. Young people are more likely to develop lower psychological well-being if they were female, their IBD was active disease they had negative illness perceptions. When young people with IBD have lower psychological well-being they may show other signs other than anxiety or low mood, such as abdominal pain, poor sleep, forgetting to take medicines for IBD and experience negative thoughts about their IBD. Young people with IBD have highly individual experiences based on symptoms, experiences of healthcare and personal and family factors. The invisibility and visibility of IBD result in young people feeling alone and adjusting their life goals to accommodate IBD. Young people find the transition process of moving to adult healthcare hopeful and empowering, but can also feel passive and with a lack personal control. The transition process gives young people a sense of dependency on caregivers and can result in feeling as though they are growing up too fast. In order to build resilience and positive view of themselves in context of IBD, young people benefit from secure friend and family relationships and a person-centred developmentally appropriate approach to IBD healthcare. Young people with IBD should be involved in the design of their services in both child and adult settings healthcare settings.

Chapter 1 General Introduction

1.1 Overview of Chapter

Chapter 1 sets out a problem statement, which is the starting point for the thesis. The problem statement is followed by an overview of IBD in context of adolescence and psychological well-being. The chapter also includes an explanation regarding the motivation for this research, the rationale, research questions and a summary of each paper in this thesis.

1.2 Problem Statement

Young people living with Inflammatory Bowel Disease (IBD) face significant challenges in adolescence, with greater risk of poor psychological well-being (depression, anxiety and lower quality of life) compared to those without IBD. Alongside complex medications and need for life-long monitoring, there is uncertainty around the severity of symptoms, prognosis and impact on their future. IBD has the potential to have adverse outcomes on relationships, educational and employment opportunities for young people. It is also during this complicated period of adolescence when young people transition from child into adult IBD healthcare services. Given these far-reaching and potentially negative outcomes, furthering our understanding of psychological well-being and experiences of young people living with IBD and transitioning through healthcare systems is vital. This will help inform the development of high quality, developmentally appropriate, young person-centred healthcare services.

1.3 Background

i. Inflammatory Bowel Disease

Inflammatory bowel disease (IBD), comprising predominantly Crohn's disease and ulcerative colitis, is a chronic relapsing disorder characterised by chronic inflammation of the gastrointestinal tract. The exact aetiology of IBD is unclear, but it is considered to be an immune-mediated intestinal disorder, resulting from complex interactions between genetics, environmental factors and gut microbiota (1). Multiple factors such as intestinal immune disruption, gut microbiota disturbance, diet, infection, lifestyle, psychological stress, sleep disorders, smoking, and early life exposure to antibiotics, have been found to influence the progress of IBD (2).

IBD has an increasing incidence worldwide particularly in newly industrialised countries (3). In Western countries the prevalence of IBD is also increasing with most recent studies in 2018 demonstrating a prevalence of 1 in 125 (4), with a predicted prevalence of 1 in 100 by 2030 (5). Although IBD can present at any age, it is most commonly diagnosed under the aged of 18 years, with the prevalence of IBD in children having risen more than 15% within the last 15 years (6), with a peak onset in adolescence (7,8).

ii. Clinical presentation of IBD in young people

Crohn's disease and ulcerative colitis have overlapping clinical features, but are considered separate entities. Crohn's disease is characterised by inflammation involving any part of the gastrointestinal tract, with transmural and granulomatous inflammation often in a discontinuous pattern. Young people presenting with Crohn’s disease frequently experience abdominal pain, diarrhoea and systemic symptoms of weight loss and fatigue. Less commonly young people can present with anaemia, perianal disease (abscesses or fistulae) and are also at risk of growth failure and pubertal delay (9,10) often resulting in concerns over body image (11). Ulcerative colitis is characterised by mucosal inflammation which is continuous and affecting only the colon. Young people with ulcerative colitis most commonly present with abdominal pain, diarrhoea and rectal bleeding. They can also present with weight loss and fatigue.

Initial presentation of IBD can be non-specific with symptoms often evident for up to 10 years prior to diagnosis (12). The relapsing and remitting nature of the inflammation can also contribute to delayed diagnosis due to inconsistent symptoms, which are often embarrassing for young people to report. Both in Crohn’s disease and ulcerative colitis, patients can experience extra-intestinal manifestation in around 30% of patients, most commonly join and skin problems (13). Important differences exist between IBD presenting in adulthood compared to childhood, with those presenting in childhood described as being more likely to present with extensive disease location, a more severe phenotype and have upper gastrointestinal disease (14). In addition they are more likely to have higher rates of intestinal complications, leading to higher rates of surgery (15) and an increased risk of malignancy later in life (16).

iii. Progression of IBD in young people

Crohn's disease is well described as a chronic progressive destructive disease, with ongoing disease activity over time leading to complications (17). Complications including penetrating and/or structuring disease frequently lead to surgery, with 60% requiring surgical intervention within 20 years of diagnosis (18). Early complications are also common with a study of 306 18-40 years olds diagnosed with Crohn's disease, showing that within 90 days of diagnosis 18.6% develop a complication (19). Progression of disease in ulcerative colitis is also more common in younger people (<18 years old) compared to older patients, with disease extension from distal to extensive (pancolonic) disease in approximately 18% over 5 years (20). Such disease progression is a predictor of the need for colectomy within 10 years of diagnosis in IBD (21).

Children and young people are also at risk of delayed presentation to healthcare services, which is associated with poorer clinical outcomes attributed to delayed treatment and, as a result, delayed mucosal healing (22,23). Furthermore disease progression is likely to reduce disease related quality of life (24). In a large general practice population of 19, 555 patients with IBD, in the 3-4 years before a diagnosis of IBD, patients started to develop gastrointestinal symptoms pointing to the need for further investigation (12). Importantly in those diagnosed with IBD, less than half received a specialist review (defined as an IBD consultant) within 18 months from presenting symptoms. Factors associated with delay to specialist review were a previous diagnosis of irritable bowel syndrome and previous depression (12). Delayed Crohn's disease diagnosis appeared to be more common in adults compared to children (median delay 6 vs 3 months respectively), with those with the greatest delay between symptom onset and diagnosis associated with highest risk of complications (perforation and strictures) (25).

iv. Treatment of IBD in young people

Life-long treatment in IBD is focused on mucosal healing by inducing and maintaining remission, preventing complications with the fewest adverse effects from medications. Biologic treatments (large molecules produced in living cells designed to block specific part of the immune system) have revolutionised both the induction and maintenance treatment of IBD over the last 20 years. Early use in Crohn's disease of biologics has demonstrated a reduction in surgery, hospitalisation and other serious disease related complications (26). This has not translated yet to a reduction in mortality in young people with IBD. A recent study with a 50 year follow-up period demonstrated those diagnosed under the age of 18 years were at a 3-fold increase risk of death when followed into adulthood, compared to age matched controls (27).

Young people with IBD are more likely to receive biologics and immunosuppressive drugs (small non-biologic drugs such as azathioprine) than those diagnosed in adulthood (28). However, some treatments and surgery can impact on fertility and contraception at a time of sexual experimentation and engagement in health risk behaviour (such as cigarette/alcohol/recreational drug use) (29) and non-adherence to medications (30).

v. Adolescence and Psychological Morbidity

Adolescence is a developmental period characterised by change, exploration, risk-taking, identity development and a search for meaning (31–33). Psychological morbidity in the period of adolescence is of significant importance, with suicide surpassing maternal mortality as the leading, global cause of death among girls aged 15-19 years (34). ‘Adolescence’ is defined by the World Health Organisation as the developmental stage between 10-19 years, and ‘youth’ as 15-24 years and it is this later period that is thought to be a critical period of cognitive development (35).

In animal studies, stress during this critical period of brain development in adolescence has been demonstrated to contribute to increase in psychological morbidities (36,37). Psychological problems often present in adolescence including anxiety, depression, eating disorders, schizophrenia (38) and drug misuse (39), diagnosed formally on criteria based on the Diagnostic and Statistical Manual of Mental Disorders (DSM) (40). However, in research and healthcare settings symptoms of depression and anxiety are frequently measured with self-report questionnaires, with many experiencing milder (or subclinical) symptoms, which do not meet DSM criteria, but do adversely affect daily life.

vi. Brain - Gut Axis in IBD

Research to date suggests that psychological symptoms may increase inflammation and trigger clinical relapse of IBD, and the presence of intestinal inflammation negatively influences psychological symptoms (41–44). This relationship dates back as early as the nineteenth century, when emotional life events were linked to intestinal inflammation (45).

IBD in this period was considered a psychosomatic disorder (46). This bidirectional relationship between IBD and psychological distress is well described and commonly known as the ‘brain-gut’ axis. This axis describes the interactions between the central, autonomic and enteric nerve system the hypothalamic-pituitary-adrenal (HPA) axis, gut microbiome and mucosal immune system. Psychological stress activates the sympathetic system and the HPA axis leading to the release of pro-inflammatory neurotransmitters, hormones and cytokines. Stress and in particular, early life stress has been shown in animal models to promote increased risk of IBD in susceptible individuals (47). Exposure of mice to stress alters the composition of the gut microbiota, leading to intestinal inflammation (48).

Patients with IBD and other immune mediated inflammatory diseases (multiple sclerosis and rheumatoid arthritis) have an increased risk of psychiatric comorbidity (anxiety, depression and bipolar disorders) versus matched health cohorts, with increased risk associated with an increasing number of physical comorbidities (49). In a large US dataset, IBD was found to act as an independent risk factor for depression (50). In adults with IBD, depression has been identified as a risk factor for developing IBD, and furthermore antidepressants reduced the risk of developing IBD (51). More recent research suggests that there is a bidirectional influence between IBD and depression, with a large nested case-control study of 10 829 ulcerative colitis cases and 4531 Crohn’s disease cases and 15 360 controls demonstrating an excess of prevalent depression 5 years before IBD diagnosis relative to controls (UC: 3.7% vs 2.7%, CD 3.7% vs 2.9%) (52).

vii. IBD and the Prevalence of Psychological Morbidity

Psychological morbidity is twice as common in IBD compared to general population (53), and is central to the overall impact of living with IBD. At least one in four patients with IBD has depressive symptoms and a third have anxiety symptoms, with active disease a risk factor for both (54). More recent studies suggest a prevalence of 44.2% for anxiety disorders and 27.9% for depressive disorders (55). Several systematic reviews demonstrate increased levels of psychological morbidity in adults with IBD (56–58). In Canada, which has the highest incidence of IBD, there is a three-fold higher incidence of depression than healthy people (59). Individuals with IBD have been shown to have twice the odds of anxiety disorder compared to those without IBD (odds ratio = 2.18; 95% confidence interval, 1.50-3.16) (60). A comprehensive systematic review has demonstrated patients with IBD to have a 20% prevalence rate of anxiety and a 15% prevalence rate of depression (58).

In a recent UK based survey of IBD patients, 89% found it hard to cope with their IBD over the previous year with only 2% reporting sufficient psychological support, highlighting the gap in focus of attention and resource to psychological well-being in IBD (61). Post-traumatic stress (PTS) has more recently been investigated in IBD patients using the validated PTSD Checklist-Civilian Version, finding that 32% of IBD patients met the criteria for significant PTS. This was more likely in patients with Crohn's disease, those who had been hospitalised or experienced ileostomy surgery (62). Medical trauma related to IBD has been investigated in qualitative research, with medical procedures, surgery and disease uncertainty being identified as risk factors for PTS (63). Poorly managed anxiety and pain have been associated with the greatest risk of PTS development with positive interactions with the medical team potentially protective (64). This is a key area for further research in young people with IBD.

viii. IBD and Psychological Morbidity in young people

A diagnosis of a chronic disease such as IBD poses a threat to normal psychosocial and psychological development in adolescence and early adulthood (56,65). This has been associated with a loss of self-esteem (66), reduced social functioning (57), family problems, school problems (67), poorer quality of life and heightened levels of psychological distress (68). Adolescents with IBD are estimated to be at 4.6 times greater risk of having clinically significant symptoms of anxiety or depression than healthy peers (69). In a systematic review with meta-analysis in children and adolescents, including 28 studies (n=8107, mean age 14.3years, range 6-18 years), there was a pooled prevalence of 16.4% for anxiety symptoms and 15% for a depressive symptoms (70). A study including 374 IBD patients from the Netherlands found elevated symptoms of psychological comorbidities in both adolescents (10–17 years) and young adults (18–25 years) with no difference between the age groups (71). In a study examining 130 young people aged 14-25 years, anxiety symptoms were seen in was found in 51.8% and depressive symptoms in 53.8%, with a high proportion of participants reporting both anxiety and depressive symptoms (72).

Anxiety and depression are known to be highly comorbid with each other and belong to a broader category of internalizing disorders (73). The pathophysiology of these internalizing disorders is inconsistent with variance observed as a result of socioeconomic factors, age and clinical variables (74). Furthermore both IBD and internalizing conditions have complex aetiology are known to be highly polygenic (75). A polygenic risk score in 240 Canadian IBD patients with European ancestry has been demonstrated to have positive associations with psychological morbidity, with approximately 13% of this genetic influence explained by the expression of the *RBPMS* gene (76).

ix. IBD and Illness Perceptions

One model of an individual's perception of their illness is based on their beliefs regarding their illness across several dimensions (77). The Common Sense Model of Illness (78) proposes that when individuals experience a health threat they form cognitive and emotional representations related to the threat, known collectively as illness perceptions (79). Eight key dimensions are measured routinely: *illness identity* (number of symptoms that patients associate with IBD); *time-line chronic* (beliefs regarding chronicity of IBD); *time-line cyclical* (perceived variability in the symptoms of IBD); *consequences* (perceived impact of IBD on the patient's life); *personal control* (perceived effectiveness of controlling IBD by own behaviour); *treatment control* (perceived efficacy of IBD treatments); *emotional representations* (perceived emotional impact of IBD); and *illness coherence* (personal understanding of IBD). Illness perceptions are most commonly measured by the validated questionnaire; Illness Perception Questionnaire-Revised (IPQ-R), which been used extensively in a wide range of chronic conditions (77).

Illness perceptions have been shown to be related to clinical and psychological outcomes in IBD including coping strategies and psychological morbidity (80,81). Importantly dysfunctional coping strategies including health risk behaviours were associated with negative illness perceptions (82). In people living with IBD, negative illness perceptions and depressive symptoms are significantly and more strongly associated with lower health related quality than demographic and disease factors in IBD patients aged 10-20 years (83). A systematic review of illness perceptions in adults with IBD has demonstrated negative illness perceptions are associated with poor psychosocial outcomes including anticipated stigmatisation and fear related to incontinence (84). In adults, illness perceptions and coping have been associated with disease activity in IBD and quality of life (85). The research in this field has to date been predominately cross-sectional and in adults, with only one longitudinal study to date in IBD in adult patients finding that those with IBD and arthropathies had more negative illness perceptions that those without arthropathies at baseline and a follow-up at 1 year (86).

x. Risk Factors for Psychological Morbidity in IBD

As in the general population, there are clear risk factors for anxiety and depression in adults with IBD including low socio-economic status and adverse childhood experiences (87). Clinical factors such as active disease, Crohn's disease compared to ulcerative colitis, steroid treatment and higher hospitalisation rates have been associated with lower quality of life in IBD patients (88). In addition psychological factors such as negative illness perceptions (89), maladaptive coping (90) have been associated with reduced health related Quality of Life (HRQoL). Social factors such as lack of social support, high work stress and disability also associated with reduced HRQoL (91).

Identified risk factors for psychological morbidity in young people with IBD have to date not been extensively investigated, and no systematic review had been undertaken in this field prior to 2016 (92). Most recently Stapersma et al, through meta-regression in a systematic review of psychological morbidity in children and young people with IBD did not find that disease type or gender affected the prevalence of psychological morbidity, but studies with a higher proportion of participants with active disease also had higher rates of depression (70).

xi. Predicting development of Psychological Morbidity in IBD

Longitudinal studies are crucial to identify factors that are truly predictive of developing psychological morbidity, with a recent systematic review of predictive factors for development of psychological morbidity identifying a range of physical and psychological factors in adults and young people with IBD (93). There are to date only a handful of longitudinal studies in young people with IBD investigating factors which may predict development of psychological morbidity. In two separate studies of young people aged 13-17 years (94), and <18 years (95) both demonstrated that a higher burden of IBD symptomatology predicted the development of depressed mood. This finding has been demonstrated in adults with IBD by Gracie et al who found disease activity at baseline to be predictive of the development of anxiety after two-year follow-up period (96). A further study in young people with Crohn's disease and matched controls, found that those with Crohn's disease were not only at greater risk of psychological morbidity and use of psychotropic treatments, but were at particular risk if male (97). Parental stress has also been shown to predict depressive symptoms in adolescents after a 6 month follow-up (94).

xii. Impact of Psychological Morbidity in IBD

Overall IBD patients with psychological morbidity have been shown to have increased utilisation of health services including early rehospitalisation (98). A recent study has demonstrated that anxiety in IBD results in adverse disease related outcomes, including increased unplanned admissions and recurrent corticosteroid use and IBD-related hospitalisation (99,100).

Psychological morbidity experienced by people living with IBD is associated with failure to gain work and loss of employment (101), increased rates of sick leave (102), increased part-time work (103) and reduced work productivity (104). In addition those with psychological morbidity are at increased risk for reduced treatment adherence (105), and poorer self-management behaviours including smoking, poor diet and reduced exercise (106). Detrimental outcomes are observed in young people with IBD across education, employment, relationships, abdominal pain, sleep dysfunction, use of psychotropic drugs and non-adherence to medication (92,102,107).

xiii. Treatment of Psychological Morbidity in IBD

In current national and international guidelines for paediatric and adult IBD patients, screening for psychological morbidity is recommended in American and European guidelines (28,108,109). However, in the United Kingdom (UK) 12% of adult IBD services (110), compared with 67% of paediatric centres, provide access to a specialist psychologist. In a study of adult IBD patients the demand for psychotherapy was significant (111), and in those with severe anxiety and/or depressive symptoms half did not receive treatment (112). A lack of a preventative approach to psychological well-being in adult IBD patients is likely to impact negatively on health risk behaviours and self-management behaviours, with subsequent costs including from work impairment (113).

Psychological interventions such as cognitive behavioural therapy (CBT) is the most effective treatment for anxiety and/or depression in children and adolescents (114). In paediatric IBD patients CBT and psychotherapy has been found to be effective in reducing symptoms of anxiety and depression (115,116).

xiv. IBD and Transition to Adult services

Transition to adult healthcare is significant event in lives of young people with IBD diagnosed and managed in a paediatric healthcare setting. Transition is best defined as the 'process of purposeful planned movement of adolescents and young people living with chronic diseases from child to adult orientated healthcare' (117). In most western countries a transfer or transition of care occurs before young people have reached adulthood, usually between the ages of 16-18 years. In the UK, young people diagnosed with IBD before the age of 16 years are cared for in paediatric healthcare settings. National guidelines in the UK detail overarching principles of transition care which include the need to be developmentally appropriate, person-centred and that young people are involved in service design, delivery and evaluation (118).

The current evidence base for how transition care should be delivered and designed for young people with IBD is in its infancy (119). Moreover, this is based on qualitative studies on a heterogeneous group of conditions such as cystic fibrosis (120), juvenile diabetes (121) and juvenile arthritis (122) which have significant differences in mortality, disease course, presentation and symptoms from IBD. Outcomes following transition are poor in other specialities, with a doubling of admission rates in the 2 years following transfer to adult care in diabetes and congenital heart disease (121,123). Over three-quarters of young people with congenital heart disease have been found to be lost to follow-up once they move into adult services (124). Evidence demonstrates that where co-ordinated, structured multidisciplinary, evidence-based, transitional care programmes are in place both patients and their parents reported an improvement in health-related QOL, knowledge, satisfaction, and vocational readiness markers (125–127).

In IBD specifically, evidence suggests that traditional adult services are not well placed to support young people with IBD through the life changes they experience from adolescence to adulthood (128). The current delivery of care for young people with IBD is significantly different in adult compared with child services with shorter appointments, less multi-disciplinary team input (119) and a shift from family-focused appointments with parental decision making to the expectation of an autonomous adult capable of self-management. Importantly for young people with IBD, endoscopy in paediatrics is usually performed under deep sedation or general anaesthetic, whereas in adult settings endoscopy is performed without conscious sedation in general. In addition, the input of psychologists who are an integral part of the paediatric multidisciplinary team diminishes when young people are transferred to adult services (110). Finally there is a lack of training of adult and paediatric gastroenterologists in adolescent healthcare, with only 20% feeling their training offered adequate experience (129).

1.4 Motivation for research

My passion for this field of research stems from the clinical experience I have had over the last 20 years working in gastroenterology. My first lecture about IBD in medical school sparked my interest in this disease spectrum. I was fascinated by how a disease process could affect the young and the old in such a profound way and lead to life changing challenges. But, in particular, how did children, young people and their families learn to live with such a complex condition? I wanted to understand more about IBD and this passion led to successful appointment to my first choice junior doctor rotation which involved both medical gastroenterology and colorectal surgery with some of the best IBD specialists in the country. I remember vividly the first young patient I met who faced the unenviable decision regarding a colectomy for acute severe ulcerative colitis. The complexity and uncertainty of the decision this young person faced stuck with me as a fellow young person. I wondered how I would manage with a stoma and further surgery. My experiences of complex IBD in colorectal surgery was humbling with patients experiencing complex perianal disease, ileoanal pouch surgery and its complexity, pregnancy in IBD and short bowel syndrome due to IBD. But yet I also saw the lifesaving and giving nature of surgery in IBD care. These first experiences of observing young people cope and live with IBD filled me with admiration and compassion.

Over the last 15 years of specialist training in IBD I have remained fascinated by the complexity of IBD, not so much by the drugs and the procedures, but by the hidden disability that many people live with. Every day brings a new question from patients about how do they live alongside a complex and unpredictable condition, often flaring at key transition in their lives. The patients have taught me so much about how to teach others to live alongside IBD. But yet through their mentorship of me as a budding IBD clinician several years ago, it was startlingly clear to me that there remains so much we still have to do as health care professionals and as a health care system to improve the lives of people living with IBD.

We have little understanding of why some people live well and thrive alongside IBD at certain times in their lives, whilst others struggle and have adverse psychological outcomes as a result. Our IBD teams are filled with kind and compassionate doctors, nurses and administrative staff. But we are not trained to manage psychological distress no matter how hard we work. Currently we are the only place many patients can turn to when they are distressed. We need specialist psychological services to help people manage feelings, thoughts and psychological distress related to IBD to complement the medical and surgical treatments. This observation led to a lifelong passion. A passion to try and develop better psychological provision for patients with IBD, and in particular to those who are not yet adults namely children and young people where I believe that with early interventions we can make a significant difference.

As an adult physician I have focussed my research in young adults, aged 16 years and over, but I am a passionate advocate of improving developmentally appropriate services for young people across all our healthcare systems and structural divides. I currently lead the IBD Transition Service and am Associate Medical Director for Transition and Young People at Sheffield Teaching Hospitals. I hope that what I have learnt so far during this research has enabled me to champion and further improve young person friendly high quality healthcare services.

This thesis I hope is just the start of a lifetime's work. Work to understand how to promote psychological well-being in the context of IBD, and how to translate this to commissioning of high quality developmentally appropriate services for young people, which includes specialist psychological services.

1.5 Rationale for Research

The number of children and young people living with IBD is increasing worldwide. The complexity of disease and treatments is increasing at a rapid rate. Yet our understanding of the impact of IBD on the experiences of young people and their psychological wellbeing is lacking. Further work is needed to understand and evaluate the psychological wellbeing of young people aged 16-21 years living with IBD, in order to better understand the challenges of growing-up with IBD and transitioning from child to adult healthcare in order to improve healthcare and wider outcomes.

1.6 Aim of the research

The overarching aim of this body of work is to further knowledge regarding the experiences of young people living with IBD and their psychological well-being through two key themes relevant to young people with IBD;

1. *To examine psychological morbidity in IBD and the relationship with illness perceptions and identification of risk factors for psychological morbidity*
2. *To explore the lived experiences of young people living with IBD as a whole, and in those transitioning to adult services*

These overarching themes will be met through the following objectives using an inter-related set of methods (qualitative and quantitative research studies) to provide a deep understanding of the experiences of young people with IBD under the care of child services, adult services and across the transition between these services;

1. *To systematically review the scientific literature with regards to psychological morbidity in young people with the aim of identifying risk factors and impacts of psychological morbidity.*
2. *To study the prevalence of psychological morbidity and relationship with illness perceptions in young people with IBD longitudinally.*
3. *To gain a deeper understanding of the lived experiences of young people with IBD and the impact on their identity.*
4. *To gain a deeper understanding of the lived experiences of young people with IBD transitioning from child to adult services.*

1.7 The Research Questions

The research aims to address the following questions:

1. What is the current evidence base regarding the risk factors for and impact of psychological morbidity in young people with IBD?
2. What is the prevalence of psychological morbidity (symptoms of anxiety, depression and low health related Quality of Life (HRQoL)) in young people aged 16-21 years with IBD?
3. What are the lived experiences as a whole of young people aged 16-21 years with IBD?
4. What are the lived experiences of young people aged 16-21 years before and after transition to adult healthcare services?

1.8 Patients

The World Health Organisation defines adolescence as the developmental stage between 10-19 years and youth as 15-24 years (35). This broad age range was used for the systematic review in Chapter 2 due to the paucity of research in the 16-24 year old group. For the empirical research, a more focussed age range of 16-21 years was used. This developmental age group is a critical time for young people, when they are learning about their disease, transitioning from children's service provision through to adult care, and from parent-led care to self-management whilst at a life stage characterised by change, exploration, risk-taking and identity development. For the purposes of this thesis the term young people is used to describe young people aged 16-21 years.

1.9 Outline of Papers

The four papers included in this thesis explore the psychological wellbeing and illness perceptions of young people aged 16-21 years living with IBD, in order to better understand the challenges of transitioning into adulthood and from child to adult healthcare. The following section provides an overview of the research questions addressed and the methodology used in each paper.

i) Paper 1: Systematic Review: Psychological Morbidity in Young People with Inflammatory Bowel Disease - Risk Factors and Impacts

As outlined above, research regarding the risk factors and impacts of psychological morbidity in young people with IBD is lacking. The challenge of identifying psychological morbidity in young people with IBD is complex and under investigated, with studies almost exclusively examining either paediatric populations defined as <16 years, youth <18 years or investigate only adults defined as > 18 years. Furthermore published studies in this field are fraught with interpretative difficulties due the period in which many published reports arise from, reducing current day applicability. In addition many use continuous scales for assessment of psychological morbidity rather that diagnostic criteria of DSM-IV (130), making prevalence and incidence assessment difficult (56,65).

Two reviews in this field have examined various aspects of psychological functioning and adjustment. Firstly, Greenley et al. examined psychosocial adjustment of 'youths' (≤18 years) with IBD (including only studies with a comparison group or those where published normative data was available) and found that youths with IBD had higher rates of depressive disorders and internalising conditions compared to other chronic conditions (56). Ross et al examined psychosocial functioning in paediatric IBD (≤18 years) finding an increased incidence of psychiatric disorders (anxiety and depression) using standard diagnostic interviews (57).

A challenge in IBD is determining whether a symptom such as fatigue or abdominal pain is related to active IBD or to underlying psychological morbidity (131), accepting that that medical and psychological well-being are interrelated (132). It is vital that clinicians are able to identify those at risk of psychological morbidity, and the possible varied impacts of this.

Paper 1 reports on a systematic review of thirty studies examining associations (risk factors) and impacts of psychological morbidity in young people with IBD. It examines the hypotheses that in young people aged 10-24 years with IBD; (i) identifiable risk factors for psychological morbidity exist in three key domains including physical (e.g. IBD characteristics, disease activity, treatments), personal (e.g. age, gender, socio-economic status) and psychosocial factors (e.g. illness perceptions, parental stress), (ii) impacts of psychological morbidity in young people with IBD are varied and far reaching.

ii) Paper 2: Prospective Study of Psychological Morbidity and Illness Perceptions in Young People with Inflammatory Bowel Disease

Adolescents with IBD have been estimated to be at greater than four-fold increased risk of clinically significant symptoms of anxiety or depression than healthy peers (69). In adults with

IBD, research has shown substantially reduced health-related quality of life compared with healthy peers (133,134). In the systematic review presented in Paper 1, there was limited research available examining psychological morbidity specifically in an adolescent cohorts highlighting the research gap in high quality studies examining psychological morbidity specifically in adolescence living with IBD. This is a significant research gap when globally 14% of 10-19 year-olds experience a mental health problem (135) and 50% of mental health problems are established by 14 years and 75% by 24 years (136).

One of the key findings in the systematic review presented in in Paper 1 was that psychosocial factors were identified as manifestation of psychological morbidity, one these being negative illness perceptions. There are eight key dimensions: *illness identity* (number of symptoms that patients associate with IBD); *time-line chronic* (expected duration of IBD); *time-line cyclical* (perceived variability in the symptoms of IBD); *consequences* (perceived impact of IBD on patients' life); *personal control* (perceived effectiveness of controlling IBD by own behaviour); *treatment control* (perceived efficacy of IBD treatments); *emotional representations* (perceived emotional impact of IBD); and *coherence* (personal understanding of IBD) (77). Understanding the relationship between the domains of illness perceptions (cause, identity, consequences, timeline and cure/controllability of an illness) are vital to understanding the development of psychological morbidity. In other chronic health conditions there is a wealth of data demonstrating the association between illness perceptions and psychological distress (81,137). There is also data to suggest in other chronic diseases that illness perceptions are modifiable through psychological interventions (138,139), and that these may be most effective if delivered early. In IBD there are only a handful of studies in this field (80,82,140), demonstrating strong associations between the illness perception dimensions of consequences and timeline of IBD and psychological distress. However, all of these studies were cross-sectional and recruited adults (mean ages of 38, 36 and 40 years).

On the basis of previous studies in other chronic diseases and adult IBD cohorts, the hypotheses are that (i) young people aged 16-21 years with IBD will have a high burden of psychological morbidity, greater than that reported in adults with IBD and healthy peers, (ii) illness perceptions will predict the development of psychological morbidity over time, (iii) identifiable risk factors for psychological morbidity exist in three key domains including physical (e.g. IBD characteristics, disease activity, treatments), personal (e.g. age, gender, socio-economic status) and psychosocial factors (e.g. illness perceptions, parental stress) and (iv) psychological morbidity will remain stable over the duration of the follow-up period.

iii) Paper 3: The Lived Experience of Young People with Inflammatory Bowel Disease: Understanding Issues of Identity, Isolation, Life Goals and Resilience

In Paper 2, one of the key findings was the impact of illness perceptions on psychological morbidity. In particular emotional representations (i.e. greater perception of the emotional impact of IBD) was an independent predictor of all measures of psychological morbidity and quality of life. Therefore understanding the lived experience and as a result the emotional impact of IBD on the lives of young is crucial to improving healthcare and other resources to prevent development of future psychological morbidity.

Qualitative literature in the field of IBD in young people is extremely limited. In the first qualitative study by Brydolf et al, 28 adolescence and young adults with ulcerative colitis were investigated regarding their experiences using grounded theory (141). In a further study exploring the perceptions of five young adults living with IBD, most faced life-disrupting challenges that profoundly affect their personal, interpersonal, and social systems (142). Nicholas et al, conducted a qualitative study exploring the ‘challenges and strategies’ of 80 young people aged 7-19 with IBD using an interpretive ethnographic approach (143). Nicholas et al explored through an ethnographic study the experiences of 20 adolescents living with an ostomy (144). In a longitudinal qualitative diary study with children and young people aged 11-16 years, examining the value of an unclosed diary method in understanding how young people lived with IBD (145). Lynch et al used thematic analysis to ask ‘how do youth experience living with recently diagnosed Crohn’s disease?’ and examined the experiences of found young people aged 16-21 with CD diagnosed in the previous 18 months (146). Allison et al, used narrative study with semi-structured interviews in 24 18-25 year olds with IBD to explore the experiences of young people with IBD who had had, or were about to have surgery for IBD (147).

In this study presented in Chapter 3, an exploratory, qualitative approach to capture the lived experiences of young people with IBD was required. Qualitative methodologies were considered in study design and analysis, including; Discourse Analysis (148), Grounded Theory (149), Narrative Analysis (150) and Interpretative Phenomenological Analysis (IPA) (151). IPA was chosen as the most appropriate qualitative methodology as the aim of the study was to explore the meaning and interpretation of young people’s experiences of living with IBD. IPA is used within clinical and health psychology and aims to describe participant experience and identifying themes across a group sample, but also recognises that this involves a process of interpretation by the researchers (151). The researchers remain an active component in the analysis, via the interpretation of the participants' accounts and the derivation of themes. The part that the researchers' own issues play in the process of analysis is also considered.

Research questions in IPA research are framed broadly and openly. There is no attempt to test a predetermined hypothesis. The aim of this research was to explore in detail the lived experiences of receiving a diagnosis, the impact of IBD on being a young person and social networks, their identity with IBD, ways of coping and views about their future with IBD.

iv) Paper 4: Structured transition from child to adult services: characterising experiences of young people with Inflammatory Bowel Disease

Transition to adult healthcare is significant milestone for young people diagnosed with IBD in paediatric settings. In a recent longitudinal, observational study in three chronic health conditions, in five healthcare centres three features were strongly associated with improved outcomes; appropriate parent involvement, promotion of health self-efficacy and meeting the adult team before transfer (152). There is a paucity of research in patient experience of transition care in general, but particularly in transition care of patients with IBD and none specifically investigating experiences of a structured transition programme. This evidence gap is important and has significant service implications as national recommendations for transition care strongly recommend co-production with young people and their families (118).

Qualitative research is critical in understanding the individual experiencing an intervention such as transition for young people living with IBD, and can identify and define factors that influence successful transition outcomes (153). Qualitative literature in transition is extremely limited with survey based or mixed methods study design. Gray et al ran focus groups with young people, 40% of whom had transferred to adult care and through directed content analysis found that transition concerns focussed on the loss of relationships with paediatric providers, a perception of poorer quality care from adult providers, and high parent involvement preventing the development of youth self-management skills (154). Another study assessed experiences of twenty 17-20 year olds who had undergone transition in the last two years with thematic analysis and identified key themes of 'individualized and multi-faceted', 'teach about transition' and 'support the shift in responsibility' (155).

IPA was chosen as the most appropriate qualitative methodology as the aim of the study was to explore the lived experiences of young people with IBD before and following a structured transition programme to increase understanding of the impact of IBD in context of adolescence. In line with Paper 3, there was no attempt to test a predetermined hypothesis.

1.10 Summary

Living with IBD in adolescence poses additional burdens which can threaten healthy psychosocial development. It has been shown to reduce social functioning, negatively impact self-esteem, and result in poorer quality of life and heightened levels of psychological distress with an estimated four-fold increase in risk of clinically significant symptoms of anxiety or depression compared to healthy peers. Although research and treatments for the medical management of IBD have developed greatly over the last 30 years, research into psychological well-being of those living with IBD has been largely neglected. To date most research into psychological morbidity and limited lived experience research in IBD has been in younger children or adult cohorts. Evidence now suggests that adolescence is a distinct phase of development, characterised by extensive changes in biology, brain development, genetic influences, cognitive, social and family functioning. This important and distinct developmental phase requires bespoke healthcare training, design and delivery to meet the needs of young people to improve outcomes into adulthood. In order to improve identification and treatments of psychological morbidity and experiences of healthcare for young people the knowledge gap needs to be addressed.

The four papers in this thesis have the collective aim of addressing the knowledge gap in the lived experiences and psychological morbidity of young people living with IBD. Identification of risk factors for psychological morbidity and understanding factors leading to positive experiences of healthcare are focused upon as they are areas that could be amenable to psychological interventions and service redesign. Specifically the papers seek to (i) identify the current evidence base regarding the risk factors for and impact of psychological morbidity in young people with IBD (ii) the prevalence of psychological morbidity in young people with IBD (iii) understand the lived experiences as a whole of young people with IBD (iv) understand the lived experiences of young people aged 16-18 years before and after transition to adult services. An overview of findings and a consideration of their implications for clinical interventions and research will then be discussed in a final concluding chapter.

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Chapter 2: Systematic review: psychological morbidity in young people with inflammatory bowel disease – risk factors and impacts

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SHORT TITLE: SYSTEMATIC REVIEW: PSYCHOLOGICAL MORBIDITY IN IBD

Keywords: inflammatory bowel disease, paediatric gastroenterology, psychiatric disorders, Crohn’s disease, Ulcerative colitis

Authors: A. J. Brooks[1], G. Rowse[2], A. Ryder[2], E.J.Peach[2], B.M. Corfe[3], A.J. Lobo[1]

Addresses:

Author for correspondence

Dr Alenka J. Brooks

MBChB, MRCP

Clinical Research Fellow in Gastroenterology

Academic Department of Gastroenterology

Sheffield Teaching Hospitals NHS Foundation Trust

Royal Hallamshire Hospital

Sheffield, S10 2JF

Dr Georgina Rowse

BSc (Hons), Clin.Psy.D., CPsychol

Clinical Psychology Unit

Department of Psychology

University of Sheffield

Sheffield, S10 2TN

Dr Anna Ryder

BSc (Hons), DClinPsy

Clinical Psychology Unit

Department of Psychology

Sheffield, S10 2TN

Dr Emily J Peach

BSc (Hons), MSc

Clinical Psychology Unit

Department of Psychology

Sheffield, S10 2TN

Dr Bernard Corfe

BSc (Hons), PhD

Molecular Gastroenterology Research Group

Academic Unit of Surgical Oncology

Department of Oncology

The Medical School

Beech Hill Road

Sheffield, S10 2RX

Professor Alan J. Lobo

MD FRCP

Consultant Gastroenterologist and Professor of Gastroenterology

Sheffield Teaching Hospitals NHS Foundation Trust and University of Sheffield

Academic Department of Gastroenterology

Royal Hallamshire Hospital

Glossop Road

Sheffield

S10 2JF

ABSTRACT

Background: Psychological morbidity in young people aged 10-24 years, with inflammatory bowel disease (IBD) is increased, but risk factors for and impact of this are unclear.

Aim: To undertake a systematic literature review of the risk factors for and impact of psychological morbidity in young people with IBD.

Methods: Electronic searches for English-language articles were performed with keywords relating to psychological morbidity according to DSM-IV and subsequent criteria; young people; and IBD in the MEDLINE, PsychInfo, Web of Science and CINAHL databases for studies published from 1994-September 2014.

Results: 1444 studies were identified, of which 30 met the inclusion criteria. The majority measured depression and anxiety symptoms, with a small proportion examining externalising behaviours. Identifiable risk factors for psychological morbidity included: increased disease severity (r^2=0.152, *P* <0.001), lower socioeconomic status (r^2=0.046, *P*<0.001), corticosteroids (*P* ≤0.001), parental stress (r=0.35, *P*<0.001) and older age at diagnosis (r=0.28, *P*=0.0006). Impacts of psychological morbidity in young people with IBD were wide-ranging and included abdominal pain (r=0.33; *P*< 0.001), sleep dysfunction (*P*< 0.05), psychotropic drug use (HR 4.16, 95% CI 2.76-6.27), non-adherence to medication (12.6% reduction), and negative illness perceptions (r= -0.43).

Conclusions: Psychological morbidity affects young people with IBD in a range of ways, highlighting the need for psychological interventions to improve outcomes. Identified risk factors provide an opportunity to develop targeted therapies for a vulnerable group. Further

research is required to examine groups under-represented in this review, such as those with severe IBD and those from ethnic minorities.

INTRODUCTION

Inflammatory Bowel Disease, including both Crohn’s Disease and Ulcerative Colitis affects an estimated 1.5million people in North America, 2.2 million people in Europe and several hundred thousand more worldwide with a globally rising incidence in children and young people (1–3). Around 20-30% of inflammatory bowel disease presents in childhood (4) with a peak onset in adolescence (1) and with a younger age at presentation being a risk factor for poor disease prognosis (5). Young people living with inflammatory bowel disease face a range of issues and challenges that can represent a major psychosocial burden leading to a loss of self-esteem and self-confidence, poorer quality of life, and heightened levels of psychological distress (6). Adolescents with inflammatory bowel disease have been estimated to be at 4.6 fold increased risk of clinically significant symptoms of anxiety or depression than healthy peers (7). Inflammatory bowel disease has also been demonstrated to have a detrimental impact on young people’s education, employment and relationships (8,9). Cognitive behavioural therapy has been demonstrated to improve mood and quality of life in adolescents with IBD and subsyndromal depression (10). European guidelines recommend that patients with inflammatory bowel disease are screened for anxiety, depression and if indicated refer for psychotherapeutic interventions (11,12). A recent worldwide survey of health care professionals caring for inflammatory bowel disease patients perceive that mental health assessment should be standard IBD care (13). However, a defined pathway for referral is available in only 12% of UK adult inflammatory bowel disease centres, to which young people transition from the age of 16, compared to two-thirds in paediatric care (14), and as a result psychological morbidity is frequently untreated in inflammatory bowel disease (15).

Two reviews have examined aspects of psychological functioning and adjustment in young people with inflammatory bowel disease. Greenley et al. (16) examined psychosocial adjustment of young people ($\leq$18 years) with inflammatory bowel disease. The review, which included only studies with a comparison group or those where published normative data was available, found that subjects with inflammatory bowel disease had higher rates of depressive disorders and internalising conditions compared to other chronic conditions such as cystic fibrosis, diabetes and malignancy. Ross et al. (17) found an increased incidence of psychiatric disorders (anxiety and depression) using standard diagnostic interviews in young people ($\leq$18 years) with IBD. However, identifying psychological morbidity in young people with inflammatory bowel disease is difficult due to the overlapping nature of symptoms which may be related to organic disease, adverse effects of medications or due to psychological morbidity (18).

Furthermore, difficulties arise because studies and reviews classify young people according to differing age groups, with studies examining paediatric populations (<16 years), ‘youth’ (<18 years) or ‘adults’ (>18 years). The World Health Organisation defines adolescence as the developmental stage between 10-19 years, and youth as 15-24years. In addition, classification, prevalence and incidence of psychological distress are difficult to define (16,19) due to lack of consistent use of diagnostic criteria of DSM-IV (20) in research settings. In line with World Health Organisation recommendations, this review treats two age groups (adolescence and youth) as a single group aged 10-24years, referred to as young people throughout. This age group is a critical time for young people, when they are learning about their disease, transitioning from children's service provision through to adult care, and from parent-led care to self-management whilst at a life stage characterised by change, exploration, risk-taking and identity development.

Health care professionals managing young people with IBD need to be aware of the possible consequences of psychological morbidity and be adept at identifying those at risk of psychological morbidity. This systematic review therefore aims to synthesize the available evidence regarding the impact of psychological morbidity in young people with inflammatory bowel disease and associated risk factors and to make recommendations regarding future research and service development in this area.

REVIEW CRITERIA AND METHODOLOGY

This systematic review was conducted according to the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) guidelines.

Data Sources and Search Strategy

A systematic literature search was undertaken using four relevant databases, Medline (via Ovid), PsycInfo (via Ovid), Web of Science, and CINAHL aiming to capture all relevant studies across disciplines including psychology, psychiatry, paediatric and adult gastroenterology from 1994 (to correspond to the introduction of the DSM-IV criteria) to 24th of September

2014. Search terms relating to psychological morbidity (“mental disorder”, “psychological health”, “mental health”, “psychological distress”, “mood disorder”, “affective disorder”, “schizophren*”, “psychosis”, “psychotic”, “somatoform disorder”, “eating disorder”, “depress*”, “personality disorder”, “anxiety”), young people (“young people”, “young person”, “young adult”, “youth”, “adolescent”, “adolescence”, “teenager”, “paediatric”, “pediatric”, inflammatory bowel disease (“inflammatory bowel disease”, “IBD”, “Crohn’s”, “Ulcerative Colitis”, “colitis”) were entered and combined, and limited to ‘adolescent’ and ‘young adult’.

Study eligibility and selection criteria

Three authors (A.J.B, G.R, A.J.L) determined study eligibility. Studies were initially screened by the first author; decisions about study inclusion were made independently by all three authors (A.J.B, G.R, A.J.L). Studies were included if (a) published in full and written in English (b) utilised standardized measures of psychological morbidity or defined psychiatric disease by psychotropic drug use (c) used established valid and reliable questionnaires. Studies were excluded if (a) psychological morbidity could not be extricated from the presented data (b) they were case studies or not empirical studies (e.g. narrative reports, reviews), and (c) they were only published in abstract. Additional studies of interest were identified by hand searches of bibliographies and cited references and by consultation with clinical experts in the field.

Data extraction and Quality Assessment

30 studies were included for review (Figure 1; (21)). Of these, 24 were conducted in North America and 6 in Europe. The median number of participants in the studies was 79 (range 20-2144), mean age 14.7 years (range 8-18years) with an inflammatory bowel disease type of 83% Crohn's disease; 16% ulcerative colitis and 1% inflammatory bowel disease unclassified. A formal assessment of study quality was conducted using the GRADE system (22) with 15 (50%) being graded as low and 15 as very low in quality. 28/30 studies reviewed were cohort, cross sectional designs investigating psychological morbidity, psychosocial burden and factors associated with these and related outcomes (see Tables 1, 2 and Supplementary on-line Information: Full Summary of Studies Included).

RESULTS

RISK FACTORS FOR PSYCHOLOGICAL MORBIDITY

Age at Diagnosis. Within this inflammatory bowel disease population, a later age of diagnosis may correlate with increased risk of psychological morbidity. Szigethy et al. (23) found that a diagnosis at an older age correlated with a greater number of depressive symptoms (r=0.28, *P*=0.0006), independent of inflammatory bowel disease duration. Mackner et al. in 2006 (24) found that young people with inflammatory bowel disease diagnosed in adolescence had an increased report of somatic complaints (*P*<0.05) compared to those with childhood onset inflammatory bowel disease. Despite these findings, the use of psychotropic drugs in young people with inflammatory bowel disease were not found to correlate with age at diagnosis (25), nor in various depression subtypes (26).

Socioeconomic Status. Three studies have found a significant relationship between socioeconomic status and depression in young people with IBD (27–29), with two studies finding no association (30,31). Clark et al. (27) found in multivariate model analysis that socioeconomic status was one of the strongest predictors of depressive symptoms in young people with Crohn's disease (r^2=0.046, *P* <0.001). Two further studies used family income as a socioeconomic status measure and found that a family income less than $75000 had higher total Children's Depression Inventory (32) scores than those with >$75000 (*P*= 0.023) (29), and higher depression scores came from lower income families (r= - 0.028) (28). However, from the latter study conclusions are limited as details of family income cut offs are not presented, and a control group of participants with functional gastrointestinal symptoms are included within the analysis of those with inflammatory bowel disease.

Gender. Four studies have examined whether there is a relationship between gender and psychological morbidity in young people with inflammatory bowel disease, with three studies suggesting no association (25,26,33). However, in a larger study, Loftus and colleagues suggest gender may play a role in the young people of psychological morbidity young people with inflammatory bowel disease present with, and this is related to age of the young people with inflammatory bowel disease. Teenage girls (age not further specified) had a two-fold increased risk of anxiety disorders (HR=2.45; 95% CI=1.41-4.25), whereas boys aged <12 years had an increased risk of depression (HR=2.55. 95% CI 1.1.5-5.67) (34).

Ethnicity. The role ethnicity may play is uncertain. All studies in this review report a significant Caucasian predominance in their cohorts. However two studies, with small sample sizes of 50 and 56 participants, did not find an association between ethnicity and psychological morbidity in young people with IBD (30,35).

Inflammatory Bowel Disease Activity and Severity. Several studies have examined the relationship between inflammatory bowel disease severity and depression with a positive association observed in 6 studies (23,27,29,31,36) but no association in 3 (30,33,37). In the study of Clark et al. (27) a positive association was found between measures of disease activity (Paediatric Crohn's Disease Activity Index (38) and erythrocyte sedimentation rate) and depressive symptoms after controlling for predictors, in stepwise regression models ($r^2=0.152$, $P<0.001$). Reed-Knight and colleagues found greater depressive symptoms in the 14% of the cohort with moderate/severe disease activity compared to those with mild or inactive disease activity (36). Furthermore, this study evaluated the relationship between inflammatory markers and depressive symptoms and found a relationship with erythrocyte sedimentation rate ($r = 0.30$, $p < 0.05$) but not C - reactive protein ($r=0.11$, $p= 0.44$). In a small study, disease severity was a significant predictor of self-reported depressive symptoms ($B= 0.122$, SE B 0.044, $P<0.01$), but not parent reported (29), although nearly 80% of participants in this study had inactive or mild disease. Children's Depression Inventory scores did not differ in those with inactive disease compared to those with moderate or severely active disease, nor between those following acute, chronic intermittent or chronic disease courses (23). No control groups was used for comparison however. A pooled measure of disease severity for ulcerative colitis (measured by Clinical Score of Kozarek (39)) and Crohn's disease (measured by Paediatric Crohn's Disease Activity Index (38)) showed significantly increased mean depressive symptoms in the moderate/severe group compared with the inactive group (F (2.88)=4.171, *P*=0.019), and in those receiving systemic steroids (*P*=0.019) (23). In a study based on both self-report and parent-report, young people with severe inflammatory bowel disease symptoms (measured only by self-report visual analogue scales) had greater internalising and externalising (behavioural) problems compared to those with mild disease activity (*P*< 0.01) (31).

Of the studies reporting no relationship with disease severity and psychological morbidity one of these report that patients with mild inflammatory bowel disease diagnosed for $\geq$ 1 year have psychosocial functioning similar to that of controls, and disease severity did not differ in those with or without depressive symptoms (40). However, this study had a small sample size, a Crohn's disease predominant cohort and 93.6% of patients with mild or inactive disease). In a second small study examining predictors of depression in new onset inflammatory bowel disease ($\leq$3months) Burke et al. (37) found that the depressed group had significantly less severe disease than the non-depressed group (*P*=0.006). Finally, Herzog and colleagues examined Children's Depression Inventory scores and found no relationship with inflammatory markers (C - reactive protein) or disease scores (33).

Inflammatory Bowel Disease Duration. No significant correlation has been demonstrated between duration of disease and psychological morbidity in a number of studies (23,30,31,33,41). However, all of these studies include participants with a well-established IBD diagnosis, with a mean duration of disease of 1.2- 5.4 years. Therefore determining the risk that a diagnosis of inflammatory bowel disease may have on psychological morbidity within the first year of diagnosis is uncertain from the studies available. Furthermore, details regarding inflammatory bowel disease diagnosis confirmation is frequently not provided.

Inflammatory Bowel Disease Type. Difference between inflammatory bowel disease type and relationship to psychological morbidity is detailed in 6 studies, with no significant difference reported between ulcerative colitis and Crohn's disease in young people and depressive symptoms (23,30,31,33,42) nor with antidepressant use (25). Difficulty exists in interpreting these findings as studies have not been designed or powered sufficiently to determine effect of inflammatory bowel disease type on depressive/anxiety symptoms, and with Crohn's disease predominant cohorts in 2 studies (23,40).

Corticosteroids. Five studies have examined corticosteroid use and anxiety/depressive symptoms, with four suggesting that corticosteroid use contributes to psychological morbidity (23,27,34,43). Mrakotsky et al. (2012) compared a group of young people receiving high-dose corticosteroids (>30mg/day or 1mg/kg/day for more than 5days) with controls with inflammatory bowel disease but in clinical remission and off systemic steroids for more than 6months. Parental-report of internalizing symptoms in Crohn's disease were greater in the steroid group ($P \leq 0.001$) (43). A further study examining risk factors for depression in young people with inflammatory bowel disease found, after controlling for disease activity, that depressive symptoms were positively associated with steroid dose ($P<0.01$) (27). Szigethy et al. (23) also found that young people receiving steroids were more likely than those without steroids to have clinically significant depressive symptoms with a Children's Depression Inventory score of ≥ 12 (*P*=0.019). In addition when specific symptoms of depression (anhedonia, sleep disturbance, fatigue, decreased appetite) were removed from the Children's Depression Inventory score there was no change in the correlation, suggesting that this finding is not related to disease severity (23). Loftus et al. (34) who also considered anxiety related disorders found that the use of corticosteroids significantly increased the risk of developing anxiety disorders (incidence of 3.04 per 100 patient years vs. 1.32 in controls), but not depression in young people with Crohn's disease. In contrast Reed-Knight and colleagues did not find a relationship between current, but lower oral steroid use (defined as budesonide >3 mg /day and/or prednisone >5mg/day) and Children's Depression Inventory score (36).

Immunosuppressive Drugs. The use of immunosuppressive drugs in young people with inflammatory bowel disease and psychological morbidity has been examined in three studies with no relationship found between the use of anti-TNF drugs, thiopurines and psychological morbidity. A recent study focused on investigating anti-TNF (infliximab) as a predictor of depression in young people with CD (27). Stepwise regression analysis indicated that infliximab use was not significantly associated with depressive symptoms (27). The study excluded those on concurrent antidepressant therapy, those with comorbid psychiatric disorders or being treated with other anti-TNF agents (40/550 excluded), which may limit the generalizability of the findings. In a further study investigating depression subtypes in young people with IBD, treatment with anti-TNF did not differ between the 3 subtypes of depression described (26). Depression in young people with inflammatory bowel disease was sub-divided by latent class analyses into the following subtypes: 1) mild depression, 2) somatic depression – with significant symptoms of depressed affect and motor hypoactivity, and 3) cognitive despair – with highest scores of suicidal ideation and hopelessness. Significant differences between subtypes 1 and 2 were found with biological markers and scores of inflammatory bowel disease activity. Subgroup 3 was associated with a longer duration of IBD diagnosis and presence of a stoma. This study is limited by the small numbers (n=13) in subgroup 3 and heterogeneity in inflammatory bowel disease phenotypes. Virta & Kolho (25) in a Finnish case controlled study of antidepressant use in young people with inflammatory bowel disease, found no significant association between immunosuppressant medication e.g. azathioprine and antidepressant use.

Parental Stress. Four cross-sectional studies (29,37,44,45) and one longitudinal study (46) have found a significant relationship between parental stress or family factors and psychological morbidity. Burke et al. (37) found those whose mothers had depression were significantly more likely to have depressive symptoms compared to those without a history of maternal depression (P=0.03). A larger more recent study found that self-report of internalizing symptoms was associated with parenting stress (r=0.35, P<0.001) and more frequent medically-related situations (r=0.26, P<0.01) as measured by The Paediatric Inventory for Parents (32), but a similar finding was not observed in those with externalising symptoms (45). Significant exclusion criteria were another chronic illness, high risk treatment-associated behavioural and psychiatric symptoms and high dose steroids. Family affective involvement (degree of family interest and involvement with one another) significantly predicted parent-report of young people depressive symptoms, but not self-report (*B*= 4.13, *P*= 0.05) as did family problem solving (*B*= 5.49, *P*< 0.05) (29). The only longitudinal study in this field examined young people receiving an amino-salicylate or thiopurine and depressive symptoms, with measures repeated at 6 months (46). Baseline parenting stress accounted for a significant amount of the variance in depressive symptoms at follow up (r-change=0.53, *P*<0.05) suggesting that parenting stress impacts on young people depressive symptoms in inflammatory bowel disease.

THE IMPACT OF PSYCHOLOGICAL MORBIDITY

Medication Adherence. Understanding factors relating to adherence to medication in young people with inflammatory bowel disease and its relationship to psychological morbidity may help to identify if and when young people with inflammatory bowel disease may benefit from therapeutic and psychological interventions. Of four cross-sectional studies - all without controls – that have examined the relationship between adherence to medication and depressive/anxiety symptoms, three suggest a relationship (47–49). Gray et al. (49) measured adherence by Medication Adherence Measure (50), and found that depression/anxiety symptoms moderated the relationship between Medication Adherence Measure endorsed barriers to adherence (e.g. forgot, refusal) and adherence. Specifically in young people with high levels of anxiety/depressive symptoms, adherence was reduced by 12.6% (*B*= 0.43, *P*<0.001) in contrast to those with lower levels of anxiety/depressive symptoms (adherence reduction of 2%) where increasing other Medication Adherence Measure endorsed barriers to adherence did not affect adherence (49). Hommel et al. (47) examined medication adherence by Medication Adherence Measure, pill counts and thiopurine active metabolite concentrations and found that depressive symptoms showed a weak negative association with adherence measured by thiopurine active metabolite concentrations (r=-0.40, *P*<0.05) and amino-salicylate Medication Adherence Measure adherence (r=-0.56, *P*<0.01). However, pill count adherence scores for 6-mercaptopurine and aminosalicylate medications did not correlate with parent or self-report quality of life (47). Reed-Knight et al. (48) measured adherence with Medication Adherence Measure by self-report and parent-report with externalizing clinical scales measuring attention and conduct problems. Attention and conduct problems showed a negative association with parent and self-report adherence (*B*= -0.038, SE= 0.0017, *P*<0.05). In contrast, Mackner & Wallace (30) found no association with adherence and psychological morbidity when using a standard interview schedule to measure adherence, but biases in this study include a selective outpatient cohort in remission (inactive or mild disease in 94%) and a low response rate.

Physical Symptoms. Abdominal pain may be a feature of both active disease and underlying psychological morbidity. Thus, Srinath et al. (51) found that in depressed young people, inflammatory bowel disease related factors such as weight loss (r= 0.33, P= 0.001), diarrhoea (r= 0.34, P = 0.001), erythrocyte sedimentation rate (r=0.22; P=0.02) were associated with abdominal pain (as measured by the self-report Abdominal Pain Index (52)), but so too were depressive symptoms (r=0.33; P < 0.001). Depression, weight loss, and abdominal tenderness (measured by Paediatric Crohn's Disease Activity Index) were the strongest predictors of pain for young people with Crohn's disease. In ulcerative colitis the role psychological morbidity plays in abdominal pain may be clearer, with only depressive severity predicting pain (51). This suggests that psychological morbidity plays an important role in illness perceptions of young people with inflammatory bowel disease, which is, in turn, important when interpreting self-reported components of well-established disease activity measures.

Health Care Utilization. The relationship between health care contact and psychological morbidity in young people with inflammatory bowel disease has been investigated with conflicting results (35,53). Reigada et al. (53) found anxiety (measured with Screen for Child Anxiety-Related emotional Disorders (54)), and depressive symptoms (measured with Center for Epidemiological Studies depression Scale (55)) did not correlate with an increase in health-care contacts when controlled for current disease activity. In contrast inflammatory bowel disease specific anxiety (defined as worry about impact of symptoms of inflammatory bowel disease in the last two weeks, and an un-validated measure) was associated with greater utilization of medical services (including inpatient admissions) and decreased social functioning compared to those with lower levels of inflammatory bowel disease specific-anxiety. Ondersma et al. (35) found that depressive symptoms correlated with subjective symptoms and disability and also with an increased frequency of health care contact. Details regarding measurement and analysis in the latter study are not provided and limitations exist with the measurement of health care contacts by self-report.

Psychotropic Drugs. A clear, measurable manifestation of psychological morbidity is the use of pharmacological treatments for psychological indications. Two large studies based on national registries in Finland (25) and North America (34) have shown an increased use of antidepressants in young people with inflammatory bowel disease. The most recent of these, based on 3 national Finnish registries (25), examined the use of antidepressants in young people with recent onset inflammatory bowel disease, with a median follow up time from diagnosis of 2.1 years. The cumulative incidence of antidepressant initiations after diagnosis with IBD was 1.2% and 2.4% at 2 and 3 years respectively, compared to 0.9% and 1.0% in age, sex matched healthy controls, with an almost 3-times greater use of antidepressants in inflammatory bowel disease compared to controls up to 3 years from diagnosis (3.2% vs 1.2%, $P=0.031$). Loftus et al. (34) performed a large population study based on medical claims, prescription drug claims, and enrolment data in which they compared the risks of developing psychological morbidity (anxiety and depression) with the incidences of psychotropic medication. After controlling for patient characteristics including comorbidity profiles, health plan types and geographical variation, young people with Crohn's disease were 2-times more likely to receive psychotropic drugs than Crohn's disease-free age, sex and health plan enrolment matched controls. The likelihood of receiving a tricyclic antidepressant in the Crohn's disease group was 4 times greater than controls (HR=4.16, 95% CI=2.76-6.27) (34). This increase in tricyclic antidepressant use may in part be explained by functional bowel symptoms following CD diagnosis, but this was not assessed by the investigators. Of note patients with any mental health disorders or psychotropic medication use before the index date were excluded.

Sleep. The relationship between sleep and psychological morbidity in depressed young people with Crohn's disease has been examined in two recent cross-sectional studies (56,57). Benhayon and colleagues (56) assessed subjective sleep quality, daytime dysfunction, and sleep latency measured by Likert ratings in the Pittsburgh Sleep Quality Index (58). Although sleep disturbances were greater in depressed young people with Crohn's disease (compared to healthy controls without depression) the findings reveal a complex relationship between inflammatory bowel disease activity, psychological morbidity and various aspects of sleep. Multivariate modelling suggests that qualitative measures of sleep (including sleep disturbance, daytime dysfunction, subjective sleep quality, and sleep latency) was predicted by anxiety (r^2=11.0, P=0.001), disease activity (r^2=19.2, P < 0.0001) and abdominal pain (r^2=17.0, P< 0.0001) but not to biomarkers of inflammation (C - reactive protein). In contrast the quantitative measures of sleep disturbance (including sleep duration and habitual sleep efficiency) were predicted by disease activity only (r^2=18.3, P< 0.0001) (56). Pirinen et al. found that the 20% of an inflammatory bowel disease cohort classified as sleep-troubled, reported higher rates of anxiety/depression (P< 0.05) and somatic complaints (P< 0.01) than those without sleep-trouble (57). Mrakotsky et al. (43) reported greater sleep dysfunction in inflammatory bowel disease patients receiving corticosteroids and that this correlated with depressive symptoms. However, the small sample sizes result in poor statistical power in both studies in this field.

Illness Perception. Subjective illness perception and its relationship with psychological morbidity has been investigated in two studies (28,35). In the first study (35), depressive symptoms were measured through negative affectivity and were compared to subjective illness severity (pain, behaviour, fatigue). Negative affectivity correlated significantly with subjective symptoms, and it was estimated that 34% of variance in subjective illness severity was accounted for by negative affectivity, whilst being unrelated to disease activity as measured by erythrocyte sedimentation rate. The more recent study examined illness perception and depressive symptoms in inflammatory bowel disease and a control group of young people with functional gastrointestinal complaints (28). In this study the only independent variable to predict depressive symptoms was whether young people "saw their illness as a problem" (r=-0.43) on the subjective well-being score, suggesting the role illness perceptions may play in psychological morbidity. However, interpretation of these results is limited by the small sample size, the use of non-validated measures of illness perception and subsequent analysis which did not separate inflammatory bowel disease from functional gastrointestinal complaints.

Cognitive Functioning. Cognitive functioning and its relationship to psychological morbidity has been examined in two studies (59,60). Castaneda et al. (59) investigated a small sample of young people with inflammatory bowel disease and compared them to a control group with Juvenile Idiopathic Arthritis, and found no major cognitive deficits in either group. Mild impairments in the verbal memory test were found in inflammatory bowel disease patients compared with controls, but depressive symptoms did not relate to the differences observed. Jones and colleagues (60) examined cognitive and emotional processing by measuring pupillary responses which reflect cognitive and emotional processing, in a small cohort young people with inflammatory bowel disease, with and without depression and compared to healthy controls with and without depression Exaggerated initial pupillary responses to negative emotional words in young people with inflammatory bowel disease with and without depression were observed, but not associated with disease severity or corticosteroid use. These results suggest young people with inflammatory bowel disease experience more negative emotional stimuli compared to healthy controls.

Family Functioning. Family functioning (defined as problem solving, communication, roles, affective responsiveness, affective involvement, and behavior control) has been examined in young people with inflammatory bowel disease with psychological morbidity (measured by parent-report). Odell and colleagues (44) found that greater parent-reported externalizing behaviour in young people accounted for 26% of variance in family functioning, more than parental stress associated with caring for a child with a medical illness (measured by Pediatric Inventory for Parents) (44). In contrast, internalising behaviours (depressive symptoms) in young people were not associated with variance in family functioning. These findings suggesting that parents/care-givers perception of young people with externalising behaviour (behavioural problems) result in an increased disruption to family functioning. This may enable early identification of families in whom targeted psychological interventions may provide the greatest benefit.

Spiritual Well-Being. Spiritual well-being (existential and religious well-being measured by Spiritual Well-Being Scale (61)) and its relationship with psychological morbidity in young people with inflammatory bowel disease and healthy controls was investigated by Cotton et al. (42) with evidence of higher levels of existential well-being was associated with fewer depressive symptoms ($r= -4.8$, $P<0.01$). In a multivariate model of analysis, lower existential well-being contributed 11% of variance of depressive symptoms ($r^2=0.18$), but religious well-being not found to predict depressive symptoms.

CONCLUSIONS

This review has demonstrated evidence that abdominal pain perception, sleep dysfunction, increased use of psychotropic drugs, non-adherence to medication, and negative illness perceptions are likely manifestations of psychological morbidity in young people with IBD. Risk factors for psychological morbidity are likely to include increased disease severity, lower socioeconomic status, use of corticosteroids, family/parental factors and an older age at diagnosis of inflammatory bowel disease. By contrast, there is currently insufficient data regarding gender, ethnicity, inflammatory bowel disease type or duration and psychological morbidity.

The evidence in this field is limited by key methodological and design inconsistencies. Nearly all studies thus far have examined only depression and anxiety, resulting in a significant gap in the literature with regards to other diagnosable psychological conditions. There is wide variation in the assessment methods used to measure and define psychological morbidity and inflammatory bowel disease severity. The studies included recruit predominantly paediatric populations, with none focusing specifically on young people aged between 16 and 24years which of importance due to the increasing prevalence of depression from pre-puberty to post puberty (62). Future studies need a longitudinal design with prospective follow-up to determine causality, with increased representation of young people with severe inflammatory bowel disease requiring surgical interventions, those from ethnic minorities, and extending age of recruitment to 24 years. To determine the full range of possible manifestations of psychological morbidity in young people with inflammatory bowel disease research is needed in health risk behaviours, educational/employment attainment and further work in the areas of illness perceptions, protective factors against psychological morbidity, cognitive functioning and health care utilisation. Such data would directly inform cost-benefit analysis to enable commissioning of psychological services with subsequent evidence with which to increasing the availability of commissioned psychological services for young people within paediatric and adult services.

The findings of this review suggest that psychological morbidity in young people with inflammatory bowel disease may have significant implications for disease management, such as medication adherence, self-report of symptoms of abdominal pain, and illness perceptions. This may pose challenges for inflammatory bowel disease assessment and management in young people, for example with disease severity assessment tools, which assume a direct, causal link between disease activity and symptoms and which are used to guide clinical decisions regarding treatment escalation, continuation or the introduction of immunosuppressive medications. Screening for psychological morbidity should be part of routine clinical practice for young people with inflammatory bowel disease. This is in line with European Crohn's and Colitis Organisation guidelines (11,12). Risk stratification in this vulnerable group might enable identification of subtypes of psychological morbidity and allow for development of individualised interventions.

AUTHORSHIP STATEMENT

Guarantor of the article: A.J.Brooks

Author contributions: AJB reviewed the literature and prepared the manuscript. AJL, AJB, GR, AR, EJP reviewed study eligibility and designed the study. AJB, GR, AJL, BMC prepared the final version of the manuscript.

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TABLES & SUPPLEMENTARY TABLES

Table 1. Summary of Risk Factors for Psychological Morbidity in Young People with Inflammatory Bowel Disease

Identified Risk Factor	Study (reference)	Country	Age (years); mean (SD)	Recruitment Age range (years)	Significant Outcomes
Increased IBD Disease severity	Clark et al 2014 (27)	USA	14.6. (2.6)	9-17	Disease severity (PCDAI, ESR) predictor of depressive symptoms (r^2=0.152, P <0.001)
	Reed-Knight et al 2013 (36)	USA	14.8 (2.8)	11-18	Disease severity in moderate/severe disease associated with increased depressive symptoms and ESR (r= 0.30, *P*< 0.05)
	Schuman et al 2013 (29)	USA	14.8 (1.9)	13-17	Disease severity was a significant predictor of self-reported depressive symptoms (*B*= 0.122, SE *B* 0.044, *P*<0.01)
	Szigethy et al 2004 (23)	USA	14.8 (1.9)	11-17	Disease severity correlates with clinically significant CDI scores (F (2.88)=4.171, *P*=0.019*)*
	Väistö et al 2010 (31)	Finland	15.4 (2.2)	10-18	Disease severity associated with increased parent-report depressive symptoms (*P*< 0.01)
Socioeconomic status	Clark et al 2014 (27)	USA	14.4 (2.6)	9-17	Lower socioeconomic status predictor of depressive symptoms in CD (r^2= 0.046, P <0.001)
	Schuman et al 2013 (29)	USA	15.7 (1.3)	13-17	Lower family income associated with higher depression score (CDI) (*P*= 0.023)
	Gold et al 2000 (28)	USA	13.3 (+/- 3.0)	8-18	Greater depressive symptoms in lower family income (r= -0.028)
Use of corticosteroids	Clark et al 2014 (27)	USA	14.6. (2.6)	9-17	Depressive symptoms positively associated with steroid dose (*P*<0.01)
	Loftus et al 2011 (34)	USA	11.8 (95% CI 11.6-12.0)	NA	Increased risk of developing anxiety disorders in CD (incidence of 3.04 per 100 patient years vs. 1.32 in controls)
	Mrakotsky et al 2013 (43)	USA	13.6 (2.8)	8-17	Parental-report of internalizing symptoms greater in corticosteroid group in CD (*P*<0.001)
	Szigethy et al 2004 (23)	USA	14.8 (1.9)	11-17	Clinically significant depressive symptoms more likely in corticosteroid group (*P*=0.019)
Parental Stress	Burke et al 1994 (37)	USA	14.4. (2.3)	9-17	Maternal history of depression resulted in increased depressive symptoms (*P*=0.03)
	Gray et al 2013 (45)	USA	15.6 (1.36)	13-17	Internalizing symptoms was associated with parenting stress (r=0.35, *P*<0.001)
	Guilfoyle et al 2014 (46)	USA	15.5 (+/- 1.4)	13-17	Parenting stress accounted for variance in depressive symptoms at follow-up (r-change=0.53, *P*<0.05)
	Schuman et al 2013 (29)	USA	15.7 (1.3)	13-17	Family affective involvement (*B*= 4.13, p= 0.05),family problem solving predicted parent-report depressive symptoms (*B*= 5.49, *P*< 0.05)
Older age at IBD diagnosis	Szigethy et al 2004 (23)	USA	14.8 (1.9)	11-17	Older age at diagnosis correlated with a greater number of depressive symptoms (r=0.28, *P*=0.0006)
	Mackner et al 2006 (24)	USA	14.39	11-17	Older age at diagnosis (adolescence vs childhood onset) increased somatic complaints (*P*<0.05)

Abbreviations: Corticosteroids (CS), Crohn's Disease (CD), Erythrocyte sedimentation rate (ESR), Not Available (NA), Paediatric Crohn's Disease Activity Index (PCDAI), Standard Deviation (SD), Standard Error (SE)

Table 2. Summary of Impact of Psychological Morbidity in Young People with Inflammatory Bowel Disease

Identified Impact	**Study (reference)**	**Country**	**Age (years); mean (SD)**	**Recruitment Age range (years)**	**Significant Outcomes**
Abdominal pain perception	Srinath et al 2014 (51)	USA	14.3 (2.4)	9-17	Depression predictor of abdominal pain perception (r= 0.33, *P*< 0.001)
Sleep dysfunction	Benhayon et al 2013	USA	14.4 (2.3)	9-17	Qualitative measures of sleep predicted by anxiety (r^2= 11.0, *P* =0.001)
	Pirinen et al 2014	Finland	15.4 (2.2)	NA	Increased sleep dysfunction in anxiety/depression (*P*< 0.05) and somatic complaints (*P*< 0.01)
Increased use of psychotropic drugs	Loftus et al 2011 (34)	USA	11.8 (95% CI 11.6-12.0)	NA	Increased use of antidepressants in CD; tricyclic use (HR=4.16, 95% CI=2.76-6.27)
	Virta & Kolho 2014 (25)	Finland	NA	6-16	Increased use of antidepressants in IBD (3.2% vs 1.2%, *P*=0.031)
Medication Non-adherence	Gray et al 2012 (49)	USA	15.5 (1.4)	13-17	High levels of anxiety/depressive symptoms; medication adherence reduced by 12.6% (B=0.43, *P*<0.001)
	Hommel et al 2008 (47)	USA	15.7 (1.4)	13-17	Depressive symptoms negatively correlated with self-report medication adherence (r=-0.56, *P*<0.01)
	Reed-Knight et al 2013		14.8 (2.8)	11-18	Attention/conduct problems negatively correlated with parent and self-report adherence (*B*= -0.038, SE= 0.0017, *P*<0.05)
Negative illness perceptions	Gold et al 2000 (28)	USA	13.3 (+/- 3.0)	8-18	Negative illness perception predicted 34% of variance in subjective illness severity
	Ondersma et al 1996 (35)	USA	15.1 (1.3)	11-17	Negative illness perception predictive of depressive symptoms (r=-0.43)

Abbreviations: Confidence Interval (CI), Crohn's Disease (CD), Hazard Ratio (HR), Inflammatory Bowel Disease (IBD), Not Available (NA), Standard Deviation (SD), Standard Error (SE)

Table 3: Supplementary Information: Full Summary of Studies Included

Study and Country	**N (CD/UC/IBDU)** *% given if n not available in study*	**Control group (n)**	**Age; mean (SD)** *Recruitment Age Range (RAR)*	**Exclusion criteria**	**Design**	**Psychological measures** *Parent (P), Young people (YP)*	**Quality of evidence** *(GRADE)*	**Disease related measures (including adherence)**	**Significant outcomes**	
									Impacts	***Risk factors***
Benhayon et al 2013 (USA) (56)	96 (96) *495 1st screening* *187 2nd screening*	19 healthy controls	14.4 (2.3) *RAR:9-17*	None	Cross sectional	P: CDI & CDRS-R YP: PSQI, API, SACRED	⊕⊕◯◯ Low	PCDAI & CRP	• Greater sleep disturbance in depressed CD than healthy controls	
Burke et al 1994 (USA) (37)	36 (21/15/0)	0	11.98 (2.67) *RAR: not available*	Diagnosis <3 months	Cross sectional	P: maternal psychiatric history; A-SADS-L, FILE, FRI YP: Kiddie-SADS-E, FRI	⊕◯◯◯ Very low	LGS		• Depressed YP less severe disease than non-depressed • Mothers of depressed YP display more family conflict and less family cohesion
Castaneda et al 2013 (Finland) (59)	34 (17/16/1)	23 JIA	16.3 (1.7) *RAR:>13*	Coexisting psychiatric disorders	Cross sectional	YP: BDI, WMS-R, WAIS-R, TMT, CVLT	⊕◯◯◯ Very low	PGA, ESR, CRP, FC	• Preservative Repetition Errors greater in IBD but unrelated to DS	
Clark et al 2014 (USA) (27)	153 (153/0/0) *765 1st screening* *499 2nd screening*	0	14.4 (2.6) *RAR: 9-17*	• IFX >2months • Anti-TNF other than IFX • Antidepressants • Psychiatric disorders	Cross sectional	P: CDI-P & K-SADS-PL YP: CDI C & K-SADS-PL	⊕⊕◯◯ Low	PCDAI, ESR		• PCDAI & SES strongest predictors of DS • CS risk factor for DS • IFX use did not predict DS
Cotton et al 2009 (USA) (42)	66 (52/13/2)	88 healthy controls	15.5 (2.1) *RAR: 11-19*	None	Cross sectional	YP: CDI-S, PeadsQL, SWB	⊕⊕◯◯ Low	LGS	• Higher levels of existential well-being associated with fewer DS	• IBD type not predictive of DS
Engstrom 1999 (Sweden) (41)	20 (9/11/0)	20 diabetes 20 CTH	16.5 *RAR: 9-16*	None	Cross sectional	P: Interview, CBCL, Frisk well-being scale	⊕◯◯◯ Very low	None		• Duration of IBD not predictive of DS

		20 healthy controls				C: CAS, Frisk well-being scale, CDI				
Gold et al 2000 (USA) (28)	36 (25/11/0)	26 FGI	13.3 +/-3.0 IBD *RAR: 8-18*	Colectomy	Cross sectional	YP: CDI & CBCL	⊕◯◯◯ Very low	None	- Subjective illness perception correlates with DS	- Higher DS in lower income families
Gray et al 2012 (USA) (49)	79 (80% CD)	0	15.5 (1.4) *RAR: 13-17*	- Other chronic illness CS >1mg/kg/d	Cross sectional	YP: CBCL YSR	⊕⊕◯◯ Low	PCDAI, LCAI & HBI Adherence; MAM	- Anxiety/DS correlate with barriers to adherence	
Gray et al 2013 (USA) (45)	130 (100/30/0)	0	15.64 (1.36) *RAR* : 13-17	- Other chronic illness - CS >1mg/kg/d	Cross sectional	YP: PIP, FAD, CBCL P: CBCL YSR	⊕⊕◯◯ Low	Short PCDAI & LCAI		- Internalizing symptoms associated with parenting stress
Guilfoyle et al 2014 (USA) (46)	93 (74/10/0)	0	15.5 +/- 1.4 *RAR* : 13-17	- Not on 5ASA +/or thiopurine - Comorbid chronic condition	Longitudinal	P: CDI-P, pediatric inventory for parents, Repeated at 6 months	⊕⊕◯◯ Low	PCDAI & LCAI		- Parenting stress accounted for a significant variance in DS
Herzog et al 2013 (Switzerland) (33)	126 (71/55/0)	Normative data	13.4 (3.2) CD *RAR: <16*	- None	Cross sectional	YP: CDI-C, SDQ P: SDQ	⊕⊕◯◯ Low	PCDAI & PUCAI CRP		- CDI-C did not correlate with disease activity, gender, type or duration of IBD
Hommel et al 2008 (USA) (47)	36 (86% CD)	0	15.69 (1.37) *RAR: 13-17*	- Comorbid conditions CS >1mg/kg/d	Cross sectional	PedsQL 4.0, CDI	⊕◯◯◯ Very low	PCDAI & LCAI Adherence: 6TGN, MAM, pill counts	- DS correlate inversely with adherence	

Jones et al 2011 (USA) (60)	23 (14/9/0)	15 IBD – DS 8 IBD + DS 22 healthy controls without DS, 20 with DS	13.5 (2.5) *RAR: 8-17*	• <1 week high dose steroids	Cross sectional	YP; K-SADS-PL, mood & feelings questionnaire	⊕○○○ Very low	PCDAI, PUCAI, ESR, albumin	• IBD demonstrate greater pupillary responses to initial presentation of negative emotional stimuli regardless of DS and disease severity	
Loftus et al 2011 (USA) (34)	2144 (2144/0/0)	10720 CD-free controls	11.8 *95% CI 11.6-12.0* *RAR: not available*	• Enrolment into health plan for >6months	Retrospective cohort study	Data from US nationwide database	⊕⊕○○ Low	None	• YP with CD are twice as likely to receive a psychotropic drug compared with health controls	• Increased risk of anxiety with CS's • Increased age in females risk factor for anxiety • Males <12 years had increased risk of DS
Mackner &Wallace 2005 (USA) (30)	50 (76%/8%/16%)	0	14.69 (1.92) *RAR: 11-17*	• IBD diagnosis >1 year	Cross sectional	P: CBCL & FAD YP: Piers Harris Self-concept scale, CDI, CSI	⊕○○○ Very low	PCDAI Adherence: standard interview	• Adherence did not relate to DS	• No relationship between SES, ethnicity, IBD duration, IBD type or disease activity and DS
Mackner & Crandall 2005 (USA) (40)	50 (76%/8%/16%)	42 healthy controls	14.69 (1.92) *RAR: 11-17*	• IBD diagnosis >1 year	Cross sectional	YP: CBCL YSR, CDI, RCMAS, Piers Harris Self-concept scale, CSI	⊕○○○ Very low	PCDAI & Physicians Global assessment		• No relationship between IBD type, disease activity and DS
Mackner et al 2006 (USA) (24)	50 (76%/8%/16%)	42 healthy controls	14.39 *RAR: 11-17*	• IBD diagnosis >1 year	Cross sectional	P: CBCL, FAD YP: CBCL YSR	⊕○○○ Very low	PCDAI		• Older age at diagnosis associated with increased somatic complaints, independent of IBD duration
Mrakotsky et al 2013 (USA) (43)	76 (30/36/0)	0	13.6 (2.8) *RAR: 8-17*	Steroid group: $\leq$30mg/day or1 mg/kg/day corticosteroid <5days Remission group: off steroids for >6months	Cross sectional	P: CDI-CP, CBCL YP: CDI-C, CBCL YSR	⊕○○○ Very low	PCDAI, CSK Neuro-psychological assessment	• Sleep difficulties greater in CS group	• CS associated with greater internalizing symptoms

Odell et al 2011 (USA) (44)	45 (36/9/0)	0	15.4 (1.32) *RAR: 13-17*	• Other chronic illness CS >1mg/kg/d	Cross sectional	P: PIP, CBCL, FAD YP: CBCL YSR, CDI-C	⊕○○○ Very low	PCDAI, LCAI	• Parent-report of YP externalizing behaviours contributed to more variance in family functioning than parental distress	
Ondersma et al 1996 (USA) (35)	56 (34/22/0)	0	15.1 (1.8) *RAR: 11-17*	• Concomitant illnesses	Cross sectional	YP: RCMAS, CDI, LEC, SIQ, Positive & Negative Affect Schedule	⊕○○○ Very low	FDI, ESR	• NA did not correlate with more frequent health care contacts • NA correlated to subjective illness perception	• No relationship between ethnicity and DS
Pirinen et al 2014 (Finland) (57)	157 (33%/52%/12%)	0	15.4 (2.2) *RAR: not available*	None	Cross sectional	YP: CBCL YSR, SSR	⊕○○○ Very low	None	• Sleep problems greater in IBD YP with anxious/ depressed mood	
Reed-Knight et al 2013 (USA) (48)	85 (64/21/0)	0	14.76 (2.77) *RAR: 11-18*	None	Cross sectional	P: BASC-2	⊕⊕○○ Low	PCDAI, PUCAI *Adherence* P: PMBS YP: MAM, AMBS	• Higher levels of attention and conduct problems negatively associated with adherence	

Reed-Knight et al 2014 (USA) (36)	78 (62/16/0)	564 community sample	13.79 (2.79) *RAR: 8-17.5*	None	Cross sectional	YP: CDI-C	⊕⊕◯◯ Low	abbPCDAI, PUCAI, ESR & CRP Adherence: YP: MAM		• Greater DS in those with more severe disease activity measured clinically and by ESR • No relationship between low dose CS/budesonide use and DS
Reigada et al 2011 (USA) (53)	36 (27/9/0)	0	15.3 (1.67 *RAR: 12-17*	• Any previous bowel resection • IBD< 6 months	Cross sectional	YP: SCARED, CES-D, IBD-specific anxiety scale, IMPACT III	⊕◯◯◯ Very low	Children's somatization inventory	• Anxiety/DS did not correlate with health-care contacts when disease activity controlled for • IBD-specific anxiety associated with greater health care contact	
Schuman et al 2013 (USA) (29)	122 (78.7%/21.3%/0)	0	15.7 (1.3) *RAR: 13-17*	None	Cross sectional	P: FAD, CBCL YP: CDI-C	⊕◯◯◯ Very low	LCAI, PCDAI	• Family affective involvement significantly predicted DS	• Lower family income associated with higher total CDI • Disease severity predictor of DS
Srinath et al 2014 (USA) (51)	163 (120/43/0) *765 1st screening* *217 2nd screening*	0	14.32 (2.36) *RAR: 9-17*	• DSM-IV condition • Antidepressants in <1 month • Substance misuse • Current or <1 year psychotherapy	Cross sectional	P: CDRS, CDI-P YP: API, KSADS-PL, CDI-C, YSR	⊕⊕◯◯ Low	PCDAI, PUCA ESR, CRP, albumin, haematocrit	• DS can predict variance in abdominal pain	
Szigethy et al 2004 (USA) (23)	102 (74/28/0) 25 CDI ≥12 19 K-SADA-PL	0	14.8 (1.9) *RAR: 11-17*	None	Cross sectional	CDI-C & K-SADA-PL	⊕⊕◯◯ Low	PCDAI, CSK, ESR, hematocrit and albumin		• DS correlated with older age at diagnosis • CS's and increased disease severity correlates with clinically significant CDI scores • DS not predicted by IBD type or duration

Szigethy et al 2014 (USA) (26)	226 (75% CD/na/na) 765 1st screening	0	14.3 (SD 2.42) *RAR:9-17*	• DSM-IV condition • Antidepressants in <1 month • Recent suicide attempt • History or substance misuse • Current or <1 year psycho-therapy	Cross sectional	P: CDI-P, CDRS-R YP: CDI-C, CDRS-R, K-SADA-PL, BIPQ, SCARED, IMPACT III	⊕⊕◯◯ Low	PCDAI, PUCAI, API	• 3 sub-types of DS: -1=mild -2=somatic -3=cognitive despair	• No relationship between gender, anti-TNF therapy or age and DS, with no differences between sub-types • Differences in sub-types 1 and 2 in IBD severity and biological markers • Sub-type 3 associated with longer IBD duration and stoma
Väistö et al 2010 (Finland) (31)	160 (33%/52%/12%)	236 healthy controls	15.4 (2.2) *RAR:10-18*	None	Cross sectional	YP: CBCL YSR P: CBCL	⊕⊕◯◯ Low	Visual analogue scale of self-report disease		• Self-report severe disease activity associated with greater DS • No relationship between IBD duration, IBD type or SES and DS
Virta et al 2014 (Finland)	248 (121/127/0)	992 healthy controls	*RAR:6-16*	None	Longitudinal	Scrutiny of 3 national registers.	⊕⊕◯◯ Low			• Greater use of antidepressant use in IBD

Abbreviations: abbPCDAI, Abbreviated Pediatric Crohn’s Disease Activity Index; AMBS, Adolescent medication barriers scale; Anti-TNF, Anti-Tumour necrosis factor; API, Abdominal Pain Index; A-SADS-L, Adult Schedule for Affective and Schizophrenia Lifetime Version; BASC-2, Behaviour Assessment Questionnaire ; BIPQ, Brief Illness Perception Questionnaire; BDI, Beck Depression Inventory; CAS, Child Assessment Schedule; CBCL, Child Behaviour Checklist; CBCL YSR, Child Behaviour Checklist Youth Self-Report; CD, Crohn’s disease; CDIT, Child & Parent CDI Total score; CS, Corticosteroid; CSDS, Clinically Significant Depressive Symptoms; CSI, The Coping Strategies Inventory; CDRS-R, The Children’s Depression Rating Scale-Revised; CDI-C/P, Children’s Depression Inventory-Child/Parent; CDI-S, Children’s Depression Inventory-Short; CES-D, The Center for Epidemiological Studies Depression Scale; CRP, C-Reactive Protein; CSK, Clinical Score of Kozarek; CVLT, The California Verbal learning Test; DS, Depressive symptoms; ESR, Erythrocyte Sedimentation Rate; FAD, McMaster Family Assessment Device; FC, Faecal calprotectin; FDI, Functional Disability Inventory; FGI, Functional Gastrointestinal complaints; FILE, Family Inventory of Life Events; FRI, Family relationship Index; HBI, Harvey Bradshaw Index; IFX, Infliximab; JIA, Juvenile Idiopathic Arthritis; K-SADA-PL, Kiddie-Schedule for Affective Disorders and Schizophrenia-Present and Lifetime Version; Kiddie-SADS, Kiddie-Schedule for Affective Disorders and Schizophrenia Epidemiological Version; IMPAT III, Self-report of health-related quality of life designed for youth with IBD; IBD-U, Inflammatory Bowel Disease-Unclassified; LGS, Lloyd-Still & Green Scale Disease severity scale; LCAI, Lichtiger Colitis Activity Index; LEC, Life Events Checklist; MAM, Medication Adherence Measure; NA, Negative Affectivity; PCDAI, Pediatric Crohn’s Disease Activity Index; PedsQL 4.0, Paediatric Quality of Life Inventory 4.0 Generic Core Scales; PIP, The Pediatric Inventory for Parents; PMBS, Parent Medication Barriers Scale; PSQI, Pittsburg Sleep Quality Index; PTSD, Post Traumatic Stress Disorder; PUCAI, Pediatric Ulcerative Colitis Activity Index; PSQI, Pittsburg Sleep Quality Index; RCMAS, Revised Children’s Manifest Anxiety Scale; SCARED, Screen for Child Anxiety Related Disorders; SCCAI, Simple Clinical Colitis Activity Index; SDQ, Strength and Difficulties Questionnaire; SF12, Short From-12; SIBDQ, Short Inflammatory Bowel Disease Questionnaire ; SIQ, Subjective Illness Questionnaire ; SCAS, Spence Children’s Anxiety scale; SSR, Sleep Self-Report; STATIC, State-Trait Anxiety Inventory for Children; SWB, Spiritual Well-being Scale; 6TGN, 6-Thioguanine Nucleotide; TMT, The Trail Making Test; UC, Ulcerative Colitis; WAIS-R, Wechsler Adult Intelligence Scale Revised; WMS-R Wechsler Memory Scale-Revised.

Chapter 3: Prospective Study of Psychological Morbidity and Illness Perceptions in Young People with Inflammatory Bowel Disease

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Authors: A. J. Brooks, P. Norman, E.J. Peach, A.H. Ryder, A.J. Scott, P. Narula, B.M. Corfe, A.J. Lobo*, G. Rowse*

Addresses:

Author for correspondence

Dr Alenka J. Brooks

Consultant Gastroenterologist

Academic Department of Gastroenterology

Sheffield Teaching Hospitals NHS Foundation Trust

Royal Hallamshire Hospital

Sheffield, S10 2JF

Email:Alenka.brooks@sth.nhs.uk

Professor Paul Norman

Professor of Health Psychology

Department of Psychology

University of Sheffield

Cathedral Court

1 Vicar Lane

Sheffield, S1 2LT

Email: p.norman@sheffield.ac.uk

Ms Emily J Peach

PhD Student

Division for Pharmacy, Practice and Policy

School of Pharmacy

University of Nottingham

Nottingham, NG7 2RD

Email: emily.peach@nottingham.ac.uk

Dr Anna Ryder

Clinical Psychologist

Sheffield Children's Hospital NHS Foundation Trust

Western Bank

Sheffield, S10 2TH

Email: anna.ryder@sch.nhs.uk

Dr Alexander J. Scott

Research Associate

School of Health and Related research (ScHARR)

University of Sheffield

Regent Court

Sheffield

S1 4DA

Email: alex.scott@sheffield.ac.uk

Dr Priya Narula

Consultant Paediatric Gastroenterologist

Sheffield Children's Hospital NHS Foundation Trust

Sheffield, S10 2TH

Email: priya.narula@sch.nhs.uk

Dr Bernard M. Corfe

Molecular Gastroenterology Research Group

Department of Oncology & Metabolism

The Medical School

Beech Hill Road

University of Sheffield

Sheffield, S10 2RX

Email: b.m.corfe@sheffield.ac.uk

Professor Alan J. Lobo

Consultant Gastroenterologist and Professor of Gastroenterology

Sheffield Teaching Hospitals NHS Foundation Trust and University of Sheffield

Academic Department of Gastroenterology

Royal Hallamshire Hospital

Glossop Road

Sheffield

S10 2JF

Email: alan.lobo@sth.nhs.uk

Dr Georgina Rowse

Senior Lecturer and Clinical Psychologist

Clinical Psychology Unit

Department of Psychology

University of Sheffield

Cathedral Court

1 Vicar Lane

Sheffield, S1 2LT

Email: g.rowse@sheffield.ac.uk

Footnotes

*Lobo and Rowse denote joint last authors.

ABSTRACT

Background and Aims: Psychological morbidity is increased in young people with inflammatory bowel disease (IBD). Illness perceptions may be an important factor. This study aimed to describe the prevalence and severity of psychological morbidity and examine relationships between baseline illness perceptions and anxiety, depression and health-related quality of life (HRQoL) at baseline and 12-months later in 16-21-years olds with IBD.

Methods: IBD patients (n = 121) completed measures of anxiety, depression, HRQoL, and illness perceptions (IPQ-R) at baseline and follow-up (n = 100, 83%).

Results: Among the 121 patients at baseline (median age 19.3 years, 40% female, 62% Crohn's disease, 73% in clinical remission), 55% reported elevated symptoms of anxiety/depression and 83% low HRQoL. Negative illness perceptions at baseline were significantly correlated with greater anxiety, depression and lower HRQoL at baseline and follow-up. In regression analysis at baseline, IPQ-R domain of greater perception of a cyclical nature of IBD was an independent predictor of anxiety, whilst a greater perceived emotional impact of IBD was an independent predictor of anxiety, depression and HRQoL. Female gender and clinical relapse were also independent predictors of lower HRQoL. After controlling for baseline measures, clinical risk factors and illness perceptions did not explain additional variance in psychological morbidity at follow-up.

Conclusion: A high prevalence of psychological morbidity, stable over one year, was demonstrated in young people with IBD. Having negative illness perceptions, being female and active disease predicted those at greatest risk of psychological morbidity. Illness perceptions may be an appropriate target for psychological interventions.

Keywords: inflammatory bowel disease, paediatrics, psychological end points

1 Introduction

Inflammatory bowel disease (IBD), including Crohn's disease (CD) and ulcerative colitis (UC), is a chronic relapsing inflammatory disorder of the intestine, increasing in incidence in paediatric populations (1–4), and in particularly in young people (5). Young people who live with IBD face a range of challenges including transitioning from children's to adult services, and from parent-led care to self-management whilst at a life stage characterised by change, exploration, risk-taking and identity development. These challenges can represent a major psychosocial burden leading to a loss of self-esteem and self-confidence, and heightened levels of psychological distress (6). Young people with IBD have been estimated to be at greater than four-fold increased risk of clinically significant symptoms of anxiety or depression than healthy peers (7). A recent study of young people (10-25 years) with IBD demonstrated rates of mild anxiety and depressive symptoms in 35%, with severe symptoms in 12% (8). Moreover, a recent systematic review of risk factors and impact of IBD in young people with IBD highlighted the wide-ranging impact of psychological morbidity, including abdominal pain, sleep dysfunction, use of psychotropic drugs and non-adherence to medication (9).

Given the high levels and wide-ranging impact of psychological morbidity in young people with IBD, it is important to identify factors that may be targeted in interventions to help young people adjust better to living with their condition. The Common Sense Model of Illness (10) proposes that when individuals experience a health threat (i.e. an illness) they form cognitive and emotional representations of the health threat, known collectively as illness perceptions. Illness perceptions are an individual's beliefs regarding their illness across several dimensions (11), and determine their efforts to minimise and/or deal with the health threat and, in turn, are related to clinical and psychological outcomes (12,13). The predictive utility of the Common Sense Model and illness perceptions has been demonstrated across a diverse range of chronic illness and health behaviours, including non-adherence to medication (14), depression (15) and mortality (16). Furthermore, illness perceptions are modifiable through psychological interventions (17,18), and these may be most effective if delivered early.

In adults with IBD, limited cross-sectional research exists examining the relationship between illness perceptions and psychological morbidity and other outcomes (12,19–23). Negative illness perceptions regarding consequences (20,23) and emotional representations (19) have been found to correlate with reduced health-related quality of life (HRQoL), depression and anxiety (12,21) in addition to lower work productivity (23). Most recently, in a larger cross-sectional study in adults with IBD, negative illness perceptions regarding consequences were associated with lower levels of mental and physical health as well as impairment of activity and reduced work activity (22). In addition, a longitudinal study of IBD adult patients found that those with and without arthropathies held significantly different illness perceptions (24), suggesting that symptom or disease-related differences may impact on illness perceptions and, in turn, psychological morbidity. To date, there have been no studies exploring young people's illness perceptions and their relationship with psychological morbidity.

The present study therefore aims to describe the prevalence and severity of psychological morbidity (anxiety, depression HRQoL) over a 12-month period in a UK cohort of young people aged 16-21 years with IBD. The study also aims to examine relationships between clinical risk factors and illness perceptions, assessed at baseline, and psychological morbidity at baseline and 12-month follow-up.

2 Materials and Methods

2.1 Study design

Young people aged 16-21 years, with an established diagnosis of IBD (CD, UC or Inflammatory Bowel Disease Unspecified (IBDU)) completed measures of psychological morbidity (anxiety and depression), HRQoL and illness perceptions. The World Health Organisation defines adolescence as the developmental stage between 10–19 years, and youth as those between 15-24 years. Together, adolescents and youth are referred to as young people. This study examines young people aged 16-21 years.

The inclusion criteria were (1) age 16-21 years at entry to study and (2) diagnosis of IBD defined by current diagnostic criteria (25) for $\geq$3 months in order to allow for perceptions and ideas about their illness following diagnosis to develop. Exclusion criteria included any patient who was unable to give valid written consent, such as a severe learning disability and if unable to speak and read English fluently. Inclusion and exclusion criteria were assessed by the principal investigator (AJB). All patients gave written consent to participate. The study obtained ethics approval from National Research Ethics Service (NRES) Committee North East - Sunderland (14/NE/0024).

2.2. Procedure

Consecutive patients were recruited between March 2014 and March 2015, with follow-up concluded by March 2016. Patients were recruited from two University hospitals (Sheffield

Teaching Hospitals NHS Foundation Trust and Sheffield Children’s Hospitals NHS Foundation Trust). The study was part of a wider research programme examining the experiences of young people transitioning from child to adult healthcare. The two recruitment centres participate in a formal transition process for young people with IBD from paediatric to adult healthcare with transfer occurring between the ages of 16-18 years. This involves medical and nursing health care professionals attending joint IBD clinics alongside an assessment of readiness for transfer in line with current guidelines and international consensus (26,27).

Eligible patients were identified by clinical databases held of young people aged 16-21 years with IBD within each service and invited to participate by letter (from their usual treating consultant) ahead of their scheduled appointment in the IBD service. At their outpatient appointment patients were given the opportunity to enter into the study by a member of their healthcare team. Of 127 patients eligible to participate in the study, 6 (5%) did not wish to take part in the study. Patients were recruited by a member of the research team (AJB and AR) following which participants independently completed the questionnaire pack on hospital or university premises whilst the researcher was available. Completed questionnaire packs were returned in a sealed envelope to the researcher by the participant. Alternatively, patients could chose to complete the questionnaire pack when convenient on paper format and return the questionnaire to a secure university postal address.

At 12-month follow-up, patients were approached at scheduled appointments (by AJB, AR or EP) or by their chosen preference for follow-up (57% returned follow-up data by post, 42% at clinic appointment, 1% via email). If patients failed to respond to the first invitation for 12-

month follow-up they were sent a reminder by their chosen method. Two patients stated they did not wish to participate at the follow-up time point, a further 19 were lost to follow-up during the time period required for completion of the study. At baseline and at 12 months, patients completed measures detailed below alongside demographic measures.

2.3 Measures

2.3.1 Demographic characteristics

Demographic details including age, gender, residential information, educational level, ethnicity and employment status were obtained from the patient.

2.3.2 Clinical characteristics

Clinical information regarding disease classification and severity were collected from electronic and paper medical records at baseline, and included Montreal Classification (28), current and previous medication and surgical history. Disease activity was assessed at both baseline and follow-up. For patients with CD this was defined by physician's global assessment (defined as remission or relapse) and in UC/IBDU by using the criteria of Truelove and Witts (defined as remission or relapse; mild, moderate or severe) (29). C-reactive protein (CRP) was recorded if obtained in routine clinical care within 90 days of recruitment.

2.3.3 Illness Perceptions

The Illness Perception Questionnaire-Revised (IPQ-R) was used to examine illness perceptions. The IPQ-R is a validated questionnaire that has been used extensively in a wide range of chronic conditions (30). Eight key dimensions were measured: *illness identity* (number of symptoms that patients associate with IBD); *time-line chronic* (beliefs regarding chronicity of IBD); *time-line cyclical* (perceived variability in the symptoms of IBD); *consequences* (perceived impact of IBD on the patient's life); *personal control* (perceived effectiveness of controlling IBD by own behaviour); *treatment control* (perceived efficacy of IBD treatments); *emotional representations* (perceived emotional impact of IBD); and *illness coherence* (personal understanding of IBD) (11).

For each dimension, mean scores were computed after recoding inversely formulated items. High scores on the illness identity, time-line chronic, consequences, emotional representations and time-line cyclical dimensions represent strongly held beliefs about the number of symptoms attributed to the illness, the chronicity of the condition, the negative consequences of the illness, the greater emotional response to the illness and the cyclical nature of the condition. High scores on the personal control, treatment control and illness coherence dimensions represent positive beliefs about the controllability of the illness and a personal understanding of the condition. Internal reliability of the subscales of illness perceptions was good with Cronbach's alphas ranging from .77 (personal control) to .92 (emotional representations), with the exception of treatment control (.55).

2.3.4 Anxiety and depression

Anxiety and depression were measured using the Hospital Anxiety and Depression Scale (HADS) (31). Subscale scores were attained by summing the subscale items with higher scores indicating a greater severity (subscale range 0–21) (32). Both measures of depression (alpha

= .82) and anxiety (alpha = .85) were found to have a strong internal consistency. Severity of anxiety and depression was interpreted according to existing literature as 0–7 “normal”, 8–10 “mild severity”, 11–15 “moderate severity”, and 16–21 “severe severity” (31,32).

2.3.5 Health-related Quality of Life (HRQoL)

HRQoL was measured using a disease-specific measure, the IBD Quality of Life Questionnaire (IBDQ) (33). The IBDQ has good psychometric properties (20). The IBDQ contains 32 items rated on 1-7 response scales (range 32-224) in four domains; bowel, systemic, social and emotional functioning. Total scores are used as a measure of HRQoL, with a total score $\geq$209 taken to indicate HRQoL comparable to that of the general population (34).

2.4 Statistical analysis

Data analyses were performed using Statistical Package for the Social Sciences (IBM Corp SPSS Statistics for Windows, Armonk, N.Y., USA). A power analysis demonstrated 96 patients to be sufficient to detect a medium effect size of f^2=0.21 (R^2=.18) in a regression analysis with 13 independent variables at 80% power and alpha set at .05. Descriptive statistics were used to characterise IBD patients, measures of illness perceptions as well as levels of anxiety, depression and quality of life at baseline and 12-month follow-up. Correlations were conducted between the illness perception dimensions and the outcome variables (anxiety, depression, and HRQoL), both cross-sectionally (at baseline) and prospectively (at follow-up). Correlations were also conducted between the demographic and clinical variables and the outcome variables. Hierarchical multiple regression analyses were conducted to assess the ability of illness perceptions to explain variance in each of the outcome variables, both cross-sectionally and prospectively, after controlling for any significant demographic or medical variables.

3 Results

3.1 Patient Characteristics

A total of 121 patients completed baseline questionnaires with 31 (26%) and 90 (74%) recruited from the paediatric centre and adult centre respectively. At baseline, the median age was 19.33 years (range 16-22.7 years) with 62% of patients diagnosed with CD. The majority (88; 73%) were in clinical remission (CD 56; 78%, UC 22; 56%), with 18 (15%) receiving corticosteroids, 78 (64%) on oral immunosuppression, and 43 (36%) receiving anti-tumour necrosis factor (see Table 1). No significant changes were found in these clinical characteristics between baseline and follow-up.

One hundred patients also completed the follow-up questionnaire at 12 months (attrition at follow-up of 17%). No significant differences were identified between patients who completed the follow-up questionnaires compared to those who did not, either in clinical (remission vs relapse *p*= .49, CD vs UC/IBDU *p*= .99, corticosteroids vs no corticosteroids *p*= .45), or demographic details (employment status *p* = .24, ethnicity *p* = .12, gender *p* = .21, age at baseline *p* = .10, age at diagnosis *p* = .72, IBD related flares/admission in last year *p* = .74). Patients who completed the follow-up at 12 months had significantly lower depression scores at baseline (*M* = 3.21, *SD* = 3.38) compared to those who did not (*M* = 5.13, *SD* = 4.30), t(116)

= -2.20, *p* = .03 (CI -3.64 -1.92). No other differences were identified in illness perceptions or in the outcome measures of anxiety or HRQoL between patients who completed the follow-up compared to those who did not.

Twenty-four (20%) transitioned from paediatric to adult services during the follow-up. No significant differences were found between patients who did or did not transition to adult care within the follow-up period for anxiety (*M* = 6.17, *SD* = 5.00 vs. *M* = 6.70, *SD* = 4.30), t(96) = 0.49, *p* = .63, depression (*M* = 3.80, *SD* = 3.63 vs. *M* = 3.03, *SD* = 3.30), t(96) = 0.97, *p* = .34, and HRQoL (*M* = 176.64, *SD* = 40.13 vs. *M* = 167.49, *SD* = 34.39), t(95) = 1.07, *p* = .29, at follow-up. In addition, no significant differences were found between these two groups of patients on any of the illness perception measures.

3.2 Prevalence and Severity of Psychological Morbidity over Time

At baseline, 118 (98%) patients completed the HADS anxiety subscale and HRQoL questions and 117 (97%) completed the HADS depression subscale. Anxiety symptoms were more prevalent than depressive symptoms with 24 (20%, CI = 14% to 28%) reporting mild, 17 (14%, CI = 9% to 22%) moderate and 8 (7%, CI = 3% to 13%) severe symptoms of anxiety with the remaining 69 (58%, CI = 49% to 67%) not reporting any anxiety. Symptoms of depression were; 9 (8%, CI = 4% to 14%) reported mild, 6 (5%, CI = 2% to 11%) moderate and 1 (1%, CI = 0% to 5%) severe symptoms of depression with the remaining 101 (86%, CI = 79% to 91%) not reporting any depression. HRQoL was below the norm for the general population in 98 (83%) patients.

Between baseline and follow-up at 12 months there were no significant changes in the measures of anxiety, depression and HRQoL; baseline anxiety (*M* = 6.70, *SD* = 4.49) and follow-up anxiety (*M* = 6.91, *SD* = 4.49), t(96) = -1.13, *p* = .26, baseline depression (*M* = 3.53, *SD* = 3.60) and follow-up depression (*M* = 3.12, *SD* = 3.76), t(96) = 0.75, *p* = .94, and baseline HRQoL (*M* = 167.34, *SD* = 37.53) and follow-up HRQoL (*M* = 172.17, *SD* = 35.08), t(94) = -0.34, *p* = .73.

3.3 Associations between Demographic/Clinical Risk Factors and Psychological Morbidity

Gender and disease activity affected psychological morbidity at baseline. Females reported significantly higher anxiety than males (*p* = .006) as well as lower HRQoL (*p* = .0005). Higher depression scores were associated with clinical relapse versus remission (*p* = .006), and corticosteroid use versus no corticosteroids (*p* = .004). Poorer HRQoL was associated with an older age at diagnosis of IBD (*p* = .010), older patients (*p* = .007), clinical relapse versus clinical remission (*p* < .001), and corticosteroid use versus no corticosteroids (p = 0.039) (see Supplementary Data; Table 1). At follow-up, significantly higher levels of depressive symptoms were observed in those in clinical relapse versus remission at baseline (*p* = .022). Similarly, lower HRQoL scores at follow-up was found for those in clinical relapse versus remission at baseline (*p* = .022). Significantly lower HRQoL scores at follow-up were also observed among those with a diagnosis of UC versus CD at baseline (*p* = .026), and older age at diagnosis (*p* = .021) (see Supplementary Data; Table 2). Other clinical variables (i.e., receiving biologic therapy, oral immunomodulators or previous surgical resections) were found to have non-significant associations with psychological morbidity at baseline and follow-up.

3.4 Associations between Demographic/Clinical Risk Factors and Illness Perceptions

Gender affected illness perceptions, with more negative illness perceptions in female patients compared to males in relation to time-line cyclical, time-line chronic, treatment control, illness coherence and emotional representations (see Supplementary Data; Table 3). Patients defined as having active disease compared to those in remission had a greater perceived emotional impact of IBD (emotional representations) compared to those in remission (*p* = .04), and lower perception of effectiveness of controlling IBD by own behaviour (personal control) (*p* = .001) (see Supplementary Data; Table 3).

3.5 Associations between Illness Perceptions and Psychological Morbidity

At baseline, all illness perceptions dimensions, with the exception of the perception of a chronic time-line, had significant correlations with psychological morbidity (anxiety, depression and HRQoL) (see Table 2). Prospective correlations were conducted to investigate the relationship between baseline illness perceptions and follow-up psychological morbidity (see Table 2). Perceived negative consequences of IBD (*consequences*) and a greater emotional response to IBD (*emotional representations*) at baseline correlated with follow-up anxiety, depression and HRQoL. In addition, treatment control at baseline correlated with follow-up depression and HRQoL, and personal control at baseline correlated with follow-up HRQoL.

3.5 Regression Analyses Identifying Predictors of Psychological Morbidity

Female gender explained 5% of the variance of anxiety at baseline when entered into the first block of the hierarchical regression analysis, $R^2 = .05$, $F(1,112) = 5.68$, $p = .02$. The inclusion of illness perceptions explained an additional 44% of the variance; $\Delta R^2 = .44$, $F(6,106) = 15.20$, $p < .001$. The variables in the final regression equation explained 49% of the variance in baseline anxiety, $R^2 = .49$, $F(7,106) = 14.45$, $p < .001$. A greater emotional response to IBD (*emotional representations*) and a greater perception of a cyclical nature of IBD (*time-line cyclical*) made significant independent contributions to the final regression model (see Table 3).

Clinical relapse and corticosteroid use explained 8% of the variance in depression at baseline when entered into the first block of the hierarchical regression analysis, $R^2 = .08$, $F(2,111) = 4.81$, $p = .01$; only clinical relapse made a significant independent contribution to the regression model. The inclusion of illness perceptions explained an additional 24% of the variance in depression, $\Delta R^2 = .24$, $F(7,104) = 5.33$, $p < .001$. The variables in the final regression equation explained 32% of the variance in baseline depression, $R^2 = .32$, $F(9,104) = 5.50$, $p < .001$, with only a greater emotional response to IBD (*emotional representations*) identified as a significant independent predictor (see Table 4).

A number of clinical variables (gender, age at diagnosis, clinical relapse, and corticosteroid use) explained 35% of the variance of HRQoL at baseline when entered into the first block of the hierarchical regression analysis, $R^2 = .35$, $F(4,109) = 14.68$, $p < .001$, although only gender and clinical relapse made significant contributions to the regression model. The inclusion of illness perceptions explained an additional 25% of the variance on HRQoL; $\Delta R^2 = .25$, $F(7,102) = 9.04$, $p < .001$. The variables in the final regression equation explained 60% of the variance of baseline HRQoL, $R^2 = .60$, $F(11,102) = 13.84$, $p < .001$. Female gender, clinical relapse and a greater emotional response to IBD (*emotional representations*) made significant independent contributions to the final regression model (see Table 5).

Examining the predictors of psychological morbidity and quality of life at follow-up while controlling for baseline anxiety, depression and HRQoL, revealed that baseline demographics, clinical variables and illness perceptions were unable to explain any additional variance in psychological morbidity and quality of life at follow-up (Supplementary Data; Tables 4-6).

4 Discussion

The current study of young people aged 16-21 years with IBD demonstrated high rates of anxiety/depressive symptoms, with a combined prevalence of (55%). This is greater than the most recently published data in patients between the ages of 10 and 25 years with IBD (47%) (8), and is markedly higher than national UK statistics (19%) reported for 16-24 year olds (35). Of particular concern are high rates of anxiety reported in 42%, compared to 19% rate reported in a recent systematic review for adults with IBD (36), and 28% in 10-25 year olds with IBD (8). The rate of depressive symptoms observed in the current sample was 13%, lower than the 21% rate that has been reported for adults with IBD (36, 38), but much greater than 3% observed in van den Brink data (8). Furthermore, our data show low HRQoL in young people aged 16-21 years with IBD, with 83% scoring lower than that of the general population.

The major finding of this study is the impact of illness perceptions on psychological morbidity. With the exception of the perception of a chronic time-line, all illness perceptions were significantly correlated with psychological morbidity at baseline. In the regression analyses, illness perceptions were able to explain large amounts of variance in anxiety, depression, and HRQoL at baseline, whilst controlling for demographic and clinical variables. In particular, emotional representations (i.e., greater perception of the emotional impact of IBD) was an independent predictor of all measures of psychological morbidity and quality of life at baseline. These data support findings in adult IBD cohorts of illness perceptions (22), but are demonstrated for the first time in a young adult cohort. Prospectively, a greater perception of the emotional impact of IBD as well as the perceived impact of IBD on patients' life at baseline were correlated with increased anxiety and depression and lower HRQoL at follow-up. Greater positive beliefs about personal control (perceived effectiveness of controlling IBD through own behaviour) and the perceived efficacy of IBD treatments at baseline were also correlated with higher HRQoL at follow-up. In addition, lower perceived efficacy of IBD treatments at baseline correlated with increased depression at follow-up. However, despite these significant correlations, illness perceptions were unable to explain additional variance in psychological morbidity and quality of life at follow-up after controlling for baseline morbidity. This may have been due to the lack of change in anxiety, depression and quality of life between baseline and follow-up.

Illness perceptions varied according to disease activity, with a greater perceived emotional impact of IBD observed in disease relapse, and a lower perception of the effectiveness of controlling IBD through patients' own behaviour compared to those in remission. Regression analyses identified clinical relapse and female gender as independent predictors of lower HRQoL at baseline. These findings are in line with previous research indicating a strong relationship between physical disease and psychological morbidity (13,37–39), and the relationship has important clinical implications, as disease control is vital for physical and mental health. Furthermore, the gender differences observed are in line with studies demonstrating adverse mental health outcomes in general population females in this age group (35,40), including suicide surpassing maternal mortality as the leading, global cause of death among girls aged 15-19 years (41). Other IBD studies in adults, children and young people have also demonstrated gender differences, with female patients reporting greater self-report concerns (e.g. socialisation and stigmatization, constraints and uncertainty and loss of body control) compared to men, associated with anxiety (8,42). Furthermore, HRQoL was significantly lower in patients with UC compared to CD at follow-up. This finding is in contrast to other research which has reported no differences in HRQoL between UC and CD (43,44). This may be explained by the significantly greater proportion of UC patients in clinical relapse in the current sample.

Our data support European and American consensus IBD guidelines stating screening is required for depression and anxiety alongside access to psychologists as part of standard IBD services (45–47). Despite this, access to a defined psychologist with an interest in IBD remains low at 12% in adult IBD services in the United Kingdom (48), in contrast to defined access to a psychologist in 67% of paediatric gastroenterology centres (49). The current reactive, rather than preventative, approach to psychological well-being in care of adults with IBD (50) is likely to have a negative consequence on self-management behaviours such as adherence, health risk behaviours and subsequent personal and societal cost through work impairment (22), with young people at the greatest risk (40). A prior Cochrane review suggested that psychological interventions in IBD may of particular benefit in adolescents (51). Evidence regarding the impact of psychological therapies in IBD patients (>16 years) suggests current therapies (in particular cognitive behavioural therapy), may have small short-term beneficial effects on depression scores (52). However, in other chronic diseases evidence regarding interventions based on the Common Sense Model through targeting illness perceptions demonstrate that these are modifiable through psychological interventions (17), and may be most effective if delivered early. For example in asthma, self-report adherence to preventative medication improved with a targeted text message programme using tailored messages based on an individual's illness perceptions (17). In IBD very limited data exists regarding psychological interventions, with one study having demonstrated an improvement in adjustment to IBD (17,53,54). Importantly, the current study has demonstrated that psychological interventions based on illness perceptions should focus on the perceived emotional impact of IBD (*emotional representation*).

The study had important limitations. First, self-report measures were used to assess psychological morbidity, which may be subject to bias. Future studies should consider incorporating a qualified clinician-based diagnostic-interview for confirmation of anxiety and depression (50). Second, disease activity was found to have a negative relationship with illness perceptions and psychological morbidity and, as a result, achieving remission for young people with IBD may be central to improving their psychological wellbeing. Objective methods of disease activity assessment (e.g., faecal calprotectin) or endoscopic assessment of disease activity would strengthen the study findings and should be considered in future studies (50). Limited longitudinal data exists in IBD to determine the impact of disease activity over time on psychological morbidity (55) and, in our cohort, no significant changes in clinical disease activity over 12-month follow-up were observed. Third, like most studies in this area the sample was predominantly Caucasian; therefore the role ethnicity may play in psychological morbidity and illness perceptions remains uncertain (9). Fourth, our recruitment sites included a paediatric centre with a formal transition process for young people with IBD moving to adult healthcare. We did not demonstrate higher rates of psychological morbidity in those who had undergone transition from children's to adult healthcare compared to those who did not. However, future studies should consider psychological morbidity where formal transition arrangements do not exist. Inadequate transition processes are associated with clinic non-attendance and non-adherence with medication, restricted growth potential and an increased likelihood of requiring surgery (56), but the impact on psychological morbidity is unknown. Finally, future studies in this area must consider engagement of participants irrespective of mental health status. We demonstrated that patients with higher depression scores at baseline were less likely to complete follow-up assessment and they may also be less likely to engage with healthcare services.

In conclusion, the high rates of psychological morbidity observed in the current study warrant a systematic approach to screening for psychological morbidity in young people with IBD. Illness perceptions play an important role in psychological morbidity in this age group with a greater perception of the emotional impact of IBD (*emotional representation*) an independent predictor of all measures of psychological morbidity. Early identification and targeted interventions of negative illness perceptions may be crucial in altering key self-management behaviours and health-related outcomes in young people with IBD, and should be a priority for future research and development of targeted psychological interventions.

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Declaration of personal interests

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Author Contributions

Guarantor of the article: AJB

Author contributions: AJB, GR, PN, PN, AJL designed the study. AJB, AR, EJP, GR, PN, PN, AJL, BMC conducted the research. AJB prepared the manuscript. AJB, GR, EJP, AJS, AJL, PN, BMC prepared the final version of the manuscript. All authors approved the final draft prior to submission.

Supplementary Data

Supplementary data are available online.

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Tables

TABLE 1 Demographic and clinical characteristics of patients at baseline

Factor	**N**	**n (%)**
Gender	121	
Male		60 (49.6)
Race	120	
Caucasian		104 (87)
Other		16 (13)
IBD Type	121	
CD		75 (62)
UC		39 (32.2)
IBDU		7 (5.8)
Age at diagnosis (years)	121	14.05 ± 3.44)
Disease duration (months)	121	45 [3-160]
Montreal location at diagnosis	75	
L1		11 (14.7)
L2		14 (18.7)
L3		48 (64)
Isolated upper GI		2 (2.7)
Montreal behaviour at diagnosis	75	
B1		31 (41.3)
B2		19 (25.3)
B3		3 (4)
B1/B2 or B3 & p		8 (10.6)
Perianal		14 (18.7)
Montreal classification of extent (UC/IBDU)	44	
E1		4 (8.7)
E2		18 (39.1)
E3		22 (47.8)
Disease Severity	121	
Clinically active disease		33 (27.3)
CRP	59	6.2 (10.6)
Current smoker		15 (13)
Biologic therapy	121	43 (35.5)
Immunosuppressive medication	121	
Thiopurine		69 (57)
Methotrexate		7 (5.8)
Ciclosporin		2 (1.7)
Corticosteroid		18 (14.9)
Surgery	39	
Abdominal surgery		25 (20.7)
Current stoma		6 (5)
Past stoma		8 (6.6)

Statistics presented as M ± SD, median [range] or N (column %).

CD, Crohn's disease; UC, ulcerative colitis; IBDU, inflammatory bowel disease unclassified

TABLE 2 Correlation of Illness Perceptions with Baseline and Follow-up Psychological Morbidity

	Baseline			Follow-up		
Dimensions	**Anxiety**	**Depression**	**IBDQ**	**Anxiety**	**Depression**	**IBDQ**
Illness identity	.35**	.39**	-.42**	.12	.20	-.16
Time-line chronic	-.01	-.11	-.16	.06	.04	-.07
Consequences	.53**	.44**	-.50**	.38**	.37**	-.35**
Personal control	-.18	-.25**	. 32**	-.17	-.19	.24*
Treatment control	-.22*	-.28**	.34**	-.13	-.21*	.25*
Illness coherence	-.30**	-.22*	.37**	-.14	-.09	.16
Time-line cyclical	.49**	.25**	-.45**	.20	.05	-.12
Emotional representations	.66**	.49**	-.60**	.43**	.38**	-.36**

*Note: * p < .05. **p < .01*

TABLE 3 Summary of Hierarchical Regression Analyses Predicting Baseline Anxiety (N = 121)

Step	**Variable**	**B**	**SE B**	**β**	**95% CIs**
Step 1	Gender	1.93	0.81	0.22*	0.33 to 3.54
Step 2	Gender	-0.15	0.71	-0.02	1.55 to 1.25
	Illness identity	0.07	0.14	0.05	-0.20 to 0.34
	Consequences	0.06	0.63	0.01	-1.19 to 1.32
	Treatment control	-0.42	0.63	-0.05	-1.66 to 0.82
	Illness coherence	0.53	0.44	0.10	-0.34 to 1.40
	Time-line cyclical	1.18	0.44	0.25**	0.32 to 2.05
	Emotional Representations	2.20	0.43	0.56***	1.34 to 3.05

*Note. Step 1 R^2 = 0.05, p = 0.02. Step 2 R^2 = 0.49, p < 0.001. * p <0 .05. **p < 0.01. *** p < 0.001*

TABLE 4 Summary of Hierarchical Regression Analyses Predicting Baseline Depression (N =121)

Step	**Variable**	**B**	**SE B**	**β**	**95% CIs**
Step 1	Clinical relapse	2.01	0.85	0.25*	0.32 to 3.69
	Current steroids	0.60	1.04	0.06	-1.45 to 2.66
Step 2	Clinical relapse	1.04	0.80	0.13	-0.55 to 2.64
	Current steroids	0.93	0.94	0.09	-0.94 to 2.79
	Illness identity	0.13	0.13	0.11	-0.13 to 0.39
	Consequences	0.59	0.60	0.13	-0.60 to 1.78
	Personal control	-0.11	0.53	-0.02	-1.15 to 0.94
	Treatment control	-0.89	0.60	-0.14	-2.08 to 0.31
	Illness coherence	0.26	0.42	0.06	-0.58 to 1.10
	Time-line cyclical	-0.08	0.39	-0.02	-0.85 to 0.69
	Emotional Representations	1.02	0.42	0.31*	0.18 to 1.85

Note. Step 1 $R^2 = 0.08$, $p = 0.10$. *Step 2* $R^2 = 0.32$, $p < 0.001$. * $p < 0.05$

TABLE 5 Summary of Hierarchical Regression Analyses Predicting Baseline HRQoL (N = 121)

Step	Variable	B	SE B	β	95% CIs
Step 1	Gender	-28.49	5.88	-0.38***	-40.15 to -16.83
	Age at diagnosis (years)	-1.03	0.90	-0.09	2.82 to 0.77
	Clinical relapse	-40.84	7.75	-0.48***	-56.19 to -25.49
	Current steroids	1.35	9.16	0.01	-16.81 to 19.51
Step 2	Gender	-13.68	5.49	-0.18*	-24.57 to 2.79
	Age at diagnosis (years)	-0.37	0.77	-0.03	-1.90 to 1.15
	Clinical relapse	-30.18	6.77	-0.36***	-43.61 to 16.75
	Current steroids	0.92	7.58	0.01	14.18 to 15.96
	Illness identity	-1.81	1.03	-0.15	3.86 to 0.23
	Consequences	-5.27	4.93	-0.11	15.05 to 4.50
	Personal control	2.19	4.24	0.04	-6.21 to 10.60
	Treatment control	7.31	4.82	0.11	-2.25 to -16.87
	Illness coherence	0.94	3.34	0.02	-5.68 to 7.55
	Time-line cyclical	-5.11	3.12	-0.13	-11.29 to 1.08
	Emotional Representations	-7.93	3.44	-0.23*	-14.75 to -1.10

Note. Step 1 $R^2 = 0.35$, $p < 0.001$.
Step 2 $R^2 = 0.599$, $p < 0.001$.
** $p < 0.05$. **$p < 0.01$. *** $p < 0.001$*

Supplementary tables

TABLE 1 Significant Clinical Risk Factors for Psychological Morbidity at Baseline

Psychological Morbidity	**Baseline Risk Factors**		***p***
Anxiety	Gender	F 7.85 ± 4.80 vs M 5.58 ± 3.89	t(116) = 2.82, *p* = .006
Depression	Disease Severity	CR 4.97 ±4.13 vs R 2.98 ±3.32	t(116) = 2.77, *p* = .006
	Treatment	CS 5.11 ±4.68 vs no CS 3.25 ±3.32	t(116) = 2.04, *p* = .004
HRQoL	Gender	F 155.47 ± 37.63 vs M 179.21 ±33.74	t(116) = 3.61, *p* = .0005
	Age at diagnosis	Older age at IBD diagnosis	r(1, 116) = -0.24, *p* = .010
	Disease Severity	CR 142.47 ± 39.68 vs R 176.99 ± 32.02	t(116) = 4.91, *p* < .001
	Treatment	CS 150.58 ± 39.49 vs no CS 170.35 ± 36.56	t(116) = 2.08, *p* = .039

Statistics presented as M ± SD

F, Female; M, Male; CR, Clinical Relapse; R, Remission; CS, Corticosteroids; CD

TABLE 2 Significant Clinical Risk Factors for Psychological Morbidity at Follow-up

Psychological Morbidity	**Follow-up Risk Factors**		***p***
Anxiety			
Depression	Disease Severity	CR 4.60 ± 5.39 vs R 2.62 ± 2.32	t(97) = 2.32, *p* = .022
HRQoL	Age at diagnosis	Older age at IBD diagnosis	r(1, 96) = -0.23, *p* = .021
	Disease Severity	CR 159.09 ± 42.07 vs R 176.41 ± 31.68	t(97) = 2.32, *p* = .022
	Disease Type	UC 159.25 ± 39.02 vs CD 177.01 ± 32.73	t(89) = 2.27, *p* = .026

Statistics presented as M ± SD

F, Female; M, Male; CR, Clinical Relapse; R, Remission; CS, Corticosteroids; CD

TABLE 3 Significant Demographic and Clinical Risk Factors and Relationship with Illness Perceptions at Baseline

	Illness Perception Dimensions							
Risk Factors	**Illness Identity**	**Consequences**	**Personal control**	**Emotional representations**	**Treatment control**	**Illness coherence**	**Time-line cyclical**	**Time-line chronic**
Disease Type	CD 7.04 ± 2.76 UC 5.77 ±3.49) *p* = .04	CD 3.21 ± 0.70 UC 2.80 ± 0.93 *p* = .04						
Disease Activity			CR 3.17 ± 0.55 R 3.61 ± 0.65 *p* = 0.001	CR 3.18 ± 1.15 R 2.72 ± 1.07 *p* = .04				
Gender				F 3.18 ± 1.05 M 2.52 ± 1.08 *p* = .0009	F 3.55 ± 0.56 M 3.88 ± 0.51 *p* = .001	F 3.62 ± 0.95 M 4.11 ± 0.75 *p* = .002	F 3.64 ± 0.92 M 3.03 ± 0.85 *p* = .0002	F 4.30 ± 0.63 M 4.04 ± 0.81 *p* = .03

Statistics presented as M ± SD

F, Female; M, Male; CR, Clinical Relapse; R, Remission; CD, Crohn's disease; UC, ulcerative colitis

TABLE 4 Summary of Hierarchical Regression Analyses Predicting Follow-up Anxiety (N = 100)

Step	Variable	B	SE B	β	95% CIs
Step 1	Baseline anxiety	0.64	0.08	0.64*	0.47 to 0.80
Step 2	Baseline anxiety	0.52	0.11	0.52	-2.31 to 3.69
	Consequences	0.46	0.63	0.81	-0.79 to 1.70
	Emotional Representations	0.50	0.50	0.12	-4.39 to 1.49

Note. Step 1 R^2 = .41, p< .001. Step 2 ΔR^2 = .02, p = .24.

TABLE 5 Summary of Hierarchical Regression Analyses Predicting Follow-up Depression (N = 100)

Step	Variable	B	SE B	β	95% CIs
Step 1	Baseline depression	0.73	0.09	0.64*	0.55 to 0.92
Step 2	Baseline depression	0.72	0.10	0.63*	0.53 to 0.91
	Clinical relapse	0.38	0.74	0.44	-1.08 to 1.85
Step 3	Baseline depression	0.59	0.12	0.52*	0.36 to 0.83
	Clinical relapse	0.61	0.75	0.07	-0.90 to 2.11
	Consequences	0.44	0.56	0.09	-0.70 to 1.54
	Treatment control	0.35	0.61	-0.05	-1.57 to 0.87
	Emotional Representations	0.38	0.41	0.11	-0.44 to 1.20

Note. Step 1 $R^2 = .41, p < .001$. *Step 2* $\Delta R^2 = .00, p = .60$. *Step 3* $\Delta R^2 = .03, p = .27$

TABLE 6 Summary of Hierarchical Regression Analyses Predicting Follow-up HRQoL (N = 100)

Step	Variable	B	SE B	β	95% CIs
Step 1	Baseline HRQoL	0.61	0.08	0.62*	0.44 to 0.77
Step 2	Baseline HRQoL	0.60	0.09	0.61	0.42 to 0.79
	IBD diagnosis	-7.22	6.81	-0.09	-20.77 to 6.33
	Age at diagnosis (years)	-1.34	0.92	-0.13	-3.17 to 0.48
	Clinical relapse	6.15	7.43	0.08	-8.62 to 20.92
Step 3	Baseline HRQoL	0.50	0.12	0.51	0.27 to 187.01
	IBD diagnosis	-7.51	7.06	-0.10	-21.57 to 6.55
	Age at diagnosis (years)	-1.55	0.96	-0.15	-3.46 to 0.36
	Clinical relapse	4.80	7.95	0.06	-11.02 to 20.62
	Consequences	-5.31	5.44	-0.12	-16.14 to 5.52
	Personal control	2.85	5.14	0.05	-7.38 to 13.08
	Treatment control	4.33	6.10	0.07	-7.82 to 16.47
	Emotional Representations	0.51	4.12	0.01	-7.69 to 8.71

Note. Step 1 $R^2 = .38$, $p < .001$. *Step 2* $\Delta R^2 = .032$, $p = .22$. *Step 3* $\Delta R^2 = .015$, $p = .71$

CHAPTER 4: The Lived Experience of Young People with Inflammatory Bowel Disease: Understanding Issues of Identity, Isolation, Life Goals and Resilience

ABSTRACT

Background and Aims: Young people living with Inflammatory Bowel Disease (IBD) are at risk of increased psychological morbidity. The aim of this study was to explore the lived experiences of young people to increase understanding regarding the impact of IBD in the context of late adolescence.

Methods: Participants aged 16-21 years were recruited from paediatric and adult IBD centres. Individual semi-structured interviews were conducted, audio-recorded, transcribed verbatim and analysed using interpretative phenomenological analysis.

Results: Fourteen individuals (7 Crohn's disease, 7 Ulcerative colitis) with a mean age of 18.3 years (range 16-21years), 50% female were recruited. Four main themes emerged: 1) Who am I with IBD?, 2) Isolation with IBD identity, 3) Life Reset and 4) Resilience. The experiences of living with IBD were found to be highly individual based on symptoms, healthcare experiences and personal factors. Both the invisibility and visibility of IBD resulted in embarrassment and feeling misunderstood, resulting in isolation. Withdrawal from a wide-range of social interactions was common, with personal, educational and employment aspirations reset. A reframing of adverse experiences, supported by close relationships with family and peers, resulted in a positive outlook, with increased determination and acceptance.

Conclusions: The experiences of IBD in late adolescence are highly individual, but result in isolation and revised life goals. Reframing of adversity with supportive relationships improves resilience. Delivery of developmentally appropriate healthcare with an individualised person-centred holistic approach is required to improve the experiences of young people living with IBD. This has important training and service implications for the IBD multi-disciplinary team.

4.1 INTRODUCTION

Inflammatory Bowel Disease (IBD), including both Crohn's Disease and Ulcerative Colitis, affects approximately 1.5million people in North America, 2.2 million people in Europe with an accelerating incidence in newly industrialised countries (1). Importantly, there is a globally rising incidence of IBD in paediatric populations (2–5), exemplified by recent data demonstrating a dramatic increase in incidence in those aged 10-16 years over a 24 year period in France (6). The peak onset of IBD is between the ages of 15-25 years (2), with approximately 25% of patients diagnosed before the age of 20 years (7). Younger age at presentation is a risk factor for poor prognosis including high relapse rate, penetrating disease and need for repeat surgery (8). Young people who live with IBD face significant challenges with increased use of immunosuppressive medications including biologics (9) and surgery (10–12) compared to adults, combined with transitioning from children's to adult services, and from parent-led care to self-management.

Adolescence is a critical period of development characterised by change, exploration, risk-taking, identity development and a search for meaning (13–15). Living with IBD in adolescence poses additional burdens which can threaten healthy psychosocial development. It has been shown to reduce social functioning (16), negatively impact self-esteem, and result in poorer quality of life and heightened levels of psychological distress (17–19) with an estimated four-fold increase in risk of clinically significant symptoms of anxiety or depression compared to healthy peers (20). Psychological morbidity in adolescents with IBD impacts significantly on physical health including experiences of abdominal pain and sleep dysfunction, and can contribute to the use of psychotropic drugs and non-adherence to medication (21). Living with IBD can also contribute to detrimental outcomes in education, employment and close personal relationships (22,23).

A systematic review of longitudinal studies designed to determine factors which might predict development of psychological morbidity in IBD found that well-being factors such as the degree of gratitude experienced and parenting stress, alongside physical factors such as aggressive disease phenotype and greater comorbidity burden were predictive (24). In addition, age-specific risk was identified with younger people with IBD (aged 13-17years) found to be at increased risk of anxiety and depression, although the review did not specifically examine this age group due to the lack of research in this field. A greater understanding of the factors that contribute to psychological morbidity in young people specifically is vital to reduce its incidence, but importantly to provide evidence-based interventions to ameliorate the impact of psychological morbidity and to improve resilience. Psychological interventions in IBD may be of particular benefit in adolescence compared to adults, due to evidence from a systematic review reporting positive short term benefits of interventions in adolescence but not in adults with IBD (25). More recent research demonstrates that young people who have a greater perception regarding the emotional impact of IBD have high levels of anxiety and depression and lower health related quality of life (19). Improving our understanding of the emotional impact of IBD in young people is central to the development of future interventions.

Qualitative studies provide important insights into the emotional, behavioural and psychological impacts of living with IBD. In adults with IBD, a meta-synthesis of qualitative studies in IBD demonstrated three main themes; the unpredictability of living with IBD, the emotional turmoil of living with IBD and striving to maintain a normal life in managing IBD (26). However, in adolescence there is a lack of research in this field with the majority focusing on specific aspects of the lived experience of IBD such as experiences of surgery (27), living with a stoma (28,29) and young people's response to parental concern (30). Such studies have a wide developmental age range of 11-25 years, with small sample sizes (n=<5) (31,32), focus on either Crohn's disease or Ulcerative Colitis with no studies examining the impact of living with IBD in late adolescence specifically. Despite the heterogeneity of these studies, key themes affecting children and young people are identified; life-disrupting challenges affecting personal, interpersonal, and social systems (32) resulting in vulnerability, diminished control (33) and contradiction regarding their feelings of confidence (34). The importance of importance of family structures and support is described in improving coping in general (31,33,35), and in particular in those undergoing surgery (27) and in living with a stoma (28).

This study aims to address the existing gap in evidence by better understanding the lived experience and impact of IBD in the context of late adolescence. Understanding this will further knowledge regarding the factors contributing to increased psychological morbidity and reduction in quality of life in this developmentally critical period.

4.2 MATERIALS AND METHODS

Qualitative methods were considered most appropriate to address the aim of the study, to gain in-depth insights and understanding into the meaning and interpretation of young people's experiences and views of living with IBD. Interpretative Phenomenological Analysis (IPA) aims to describe participant experience and identify themes across a relatively homogenous group sample (36). Sample size is determined by ongoing analysis and evaluation of transcripts to decide when no further new phenomena are likely to occur. IPA was chosen as the most appropriate method of analysis due to the detailed examination of personal lived experience required. IPA recognises humans as sense-making and does not prescribe a theoretical framework.

Study Design

Eligible patients aged 16-21 years, with an established diagnosis of IBD (Crohn's disease, Ulcerative colitis or Inflammatory Bowel Disease Unspecified (IBDU)) were identified from clinical databases between 2014 - 2015 from a paediatric and adult University Hospital in Northern England. The inclusion criteria were (1) age 16-21 years at entry to study and (2) diagnosis of IBD defined by current diagnostic criteria (37) for at least 3 months, in order to allow for perceptions of illness to have developed following diagnosis. Exclusion criteria included (1) patients who were unable to give written consent, (2) those unable to speak

English fluently due to the interpretative nature of the research methodology requiring verbal fluency in the primary investigator's first language. The study obtained ethical approval from the National Research Ethics Service (NRES) Committee North East - Sunderland (14/NE/0024).

The World Health Organisation defines 'young people' as those aged between 10 and 24 years, with 'adolescence' as the developmental stage between 10–19 years, and 'youth' as between 15-24 years. This broad age range was considered too heterogeneous from a developmental perspective, life circumstance and sexual maturation for a qualitative study examining lived experiences of IBD in young people. As result 'late adolescence' commonly defined as 16-21 years was felt to be an appropriate age range to investigate the lived experiences in the context of adolescence, referred to as 'young people' throughout this study.

Recruitment and Interview Procedure

All eligible patients were sent a letter of study invitation and study information leaflet by letter (from their usual treating IBD consultant physician) before a scheduled appointment in the IBD service. At their scheduled appointment with their treating clinician or a member of their IBD specialist healthcare team, patients were given the opportunity to discuss the study information in line with Good Clinical Practice. Contact details (telephone and email address) of those who patients who expressed an interest to participate in the study were sent to the principal investigator. Subsequently, following which the principal investigator who then contacted the patient via their preferred method of contact. Both verbal and written information was given to the patient with an opportunity to answer further questions about the study at the time or at a further appointment. Patients who confirmed their interest to participate were contacted on a separate occasion by the principal investigator to schedule a date for the face-to-face structured interview. All patients gave written consent prior to the interview. All interviews were conducted face-to-face, on University or NHS premises, in a private interview room and were recorded for transcription.

The interview schedule was developed in line with guidelines recommended for Interpretative Phenomenological Analysis (36), through discussion with the IBD multi-disciplinary team and the research team and consultation of the existent literature. This included asking participants to describe their experiences of: receiving a diagnosis, how the illness impacts on being a young person, on family, friends and social context, identity, feelings about the illness, ways of coping, other people's perceptions of them and their illness (see Supplementary Table 1). A pilot interview was conducted with an IBD patient known to the specialist IBD service in the adult IBD centre to review and refine the interview schedule with regards to timing, style and interview questions.

Research Team and Reflexivity

Personal Characteristics

All interviews were conducted by the principal investigator; a Caucasian female without IBD, whilst undertaking a higher degree (PhD) and working part-time as a Clinical Research Fellow in Gastroenterology in the IBD service at one of the recruiting sites.

Reflexivity

Reflexivity was supported using a research diary to record the principal investigators reflections, ideas and observations (38). A clear audit trail of data collection and analysis processes guided regular discussion of each stage of the analysis with research supervisors and peers undertaking similar research, in line with IPA recommendations to ensure the validity of the research (39).

Data Analysis

Transcripts were analysed in line with current IPA (36) using a personalised systematic approach (see Supplementary Table 2). All participants were allocated pseudonyms for reporting of research findings. Patients were unable to be identified through their study identity numbers alone. The result of the analysis is main (superordinate) themes and their respective sub-themes (subordinate themes). Analysis was undertaken by the principal investigator with independent verification of emergent themes by the last author. Six transcripts were audited by the last author to check that initial themes and ideas were grounded in the data and to ensure that the process of deriving the themes was evidenced.

4.3 RESULTS

Participant Characteristics

Of 17 patients who met the eligibility criteria and who expressed an interest to participate, 14 were recruited to the study with a mean age of 18.3 years (range 16-21 years) with an equal gender split and ethnicity defined as White British by 13 of the participants. Seven were diagnosed with Crohn's disease and seven with ulcerative colitis (see Table 1). The mean duration of the interview was 58 minutes (range 21-90 minutes).

Main Themes

Four main (superordinate themes) emerged from the analysis: 1) *Who am I with IBD*?; 2) *Isolation with IBD identity*; 3) *Life Reset*; and 4) *Resilience*. Within each theme, several sub-themes were identified and described. The following four sections provide an overview of the results categorized by the four main themes and associated sub-themes (see Table 2), included are with illustrative quotes from the participants using pseudonyms.

4.3.1 *Theme 1: Who am I with IBD?*

Participants had highly personal experiences of a diagnosis of IBD. Embarrassing symptoms in combination with feelings of secrecy, denial and judgement often resulted in a sense that diagnosis was delayed or misdiagnosed initially. The complexity of an IBD diagnosis was experienced as overwhelming and confusing due to uncertainties about their future life and identity with IBD.

i. ***Delay to IBD diagnosis***

The profound challenges faced by young people leading to a diagnosis of IBD were defined by the puzzling nature of the symptoms experienced. Participants felt confused *'I can't seem to work it out'* (Sophie, 18 years with Ulcerative colitis) downplayed symptoms, and avoided dealing with symptoms '*left it and left it'* (Mark, 21 years with Ulcerative colitis). Personal denial was compounded by family members lacking in understanding or knowledge of IBD, or downplaying the importance of symptoms when disclosed or observed; '*She was like 'you've* *not got Crohn’s, don’t be silly, you’ve just got constipation’* (Charlotte, 19 years with Crohn’s disease).

In various healthcare settings, symptoms were dismissed, described as normal adolescent behaviours, not believed or attributed to psychological problems; '*It’s all in your head*' (Max, 16 years with Crohn’s disease). This was often in combination with a sense that carers and parents were perceived by health care professionals as being paranoid or overprotective, and participants felt negatively judged. Participants felt that the mislabelling and misdiagnosis of IBD was commonplace, with a sense of shame, regret and guilt regarding delays; ‘*Whereas if they had put me on medication I might not have gone through everything I’d gone through. Because knowing lots of my friends who’ve got Crohn’s, they’re on medication – they’ve had no surgery*’ (Charlotte, 19 years with Crohn’s disease).

ii. One size does not fit all

The experience of a diagnosis of IBD and living with IBD was highly personal and unique. Young people expressed deep frustration at specialist health care professionals treating them as a uniform and pre-defined group, with a lack of understanding of the individuality of experiences: *‘everyone gets tarred with the same brush. You’ve got this, so that affects you. But no, I think everyone’s body is different’* (Mark, 21 years with Ulcerative Colitis). There was a wide variation of feelings in reaction to a diagnosis of IBD. Some experienced a sense of indifference and a delayed reaction; ‘*I don’t remember sort of having this big moment where it sort of hit me – I suppose I didn’t quite – I understood that I had Crohn’s but I didn’t understand how it would affect the next 10 years’* (Harry, aged 19 with Crohn’s disease). For many there was a sense of relief, but for others a sense of shock, denial and feeling overwhelmed were prominent: *'I just wanted to pretend it wasn't real'* (Sally, 16 years with Crohn's disease). Other young people felt worried about the emotional response of their parents *'I was upset that my mum was upset, but my mum felt like it was her fault* (Gemma, 18 years with Ulcerative Colitis). For some young people a diagnosis of IBD was experienced through physical trauma due to the use of medical interventions such as nasogastric tubes which had a known symbolism of IBD; *'I told my mum that I already knew that I'd got Crohn's, and then I woke up with a pipe it was like so depressing. Like to change and to know I'm never going to get better from it'* (Max, 16 years with Crohn's disease). Others knew when they woke up after surgery that they had changed due to the presence of a stoma bag; '*…yeah, I woke up with a stoma bag and it was just – I don't know, it was just the start of a horrible journey'* (Charlotte, 19 years with Crohn's disease).

iii. Uncertainty and permanency

The permanence of IBD was understood early by participants; '*knew it would be there forever'* (Mark, 21 years with Ulcerative Colitis*),* but the emotions related to a chronic disease diagnosis differed due to the uncertainty of IBD perceived by young people; *'puzzled by the impact'* (Jacob, 18 years with Crohn's disease). The puzzlement and self-doubt felt by participants regarding the severity and implications of IBD on their lives led to anxiety about the future; *'I think I was just trying to think what that meant – how could I cope, what level of the spectrum was I on, will I get better with drugs, will I have to have the surgery?'* (Helen, 20 years with Ulcerative Colitis). These questions extended to wider aspects of life such as how would IBD affect their future with regards to relationships, children, employment and education;

> *'At the time my worries were more like missing school and things, because it was getting towards year 9 and 10 when it was getting really bad and I kept missing quite a few days, so. Those were the days I was starting GCSEs which was quite worrying'* (James, aged 21 with Crohn's disease).

Participants sought external help to try and address these questions, such as peer support from various sources including online IBD forums, social media stories and pictures from celebrities and patterns of IBD observed in friends and family with IBD. Whilst for some participant's other patients individual's stories on social media were powerful and useful in increasing confidence; *'they make me feel better about myself; like I look at them and they're my inspiration'* (Sally, aged 16 years with Crohn's disease), for others it felt overwhelming seeing the complexity and severity of IBD.

4.3.2. *Theme 2: Isolation with IBD Identity*

Highly personal and individual experiences of both the invisibility and visibility of IBD led to a sense of isolation driven by a fear of stigma. Participants often perceived a lack of compassion from others, feeling misunderstood. Avoidance, concealment and withdrawal compounded feelings of isolation.

i. 'Losing myself'

A diagnosis of IBD forced a new identity; *'I didn't want that to be who I was' (Helen, aged 20 with Ulcerative Colitis)*, in which participants perceived they would be judged as unattractive and negatively by others due to the embarrassing nature of the symptoms; '*I'm so scared about telling people; maybe they'll think 'oh, she's a right freak*' (Sally, 16 with Crohn's disease). Participants felt a loss of self-confidence due to the embarrassing nature of IBD and felt this changed their ability to relate to themselves and others; '*I used to sit at the back of class and be like – I'm an outgoing person, but I daren't – I didn't want people to talk to me because – they couldn't see it, but I felt so conscious about having it, because it made noises'* (Charlotte, 19 with Crohn's disease). Frustration was felt at the drugs that manage the disease and give control, yet also give side-effects which young people felt powerless to manage; '*It just gives you like a fat head, the steroids did. Like swollen – that's the worst thing the steroids did, about the whole thing'* (Mark 21 years with Ulcerative Colitis). A sense of loss for life prior to IBD was experienced: '*I want it to be how I used to be and it changes everything again'* (Alex, 16 years with Crohn's disease).

ii. ***Withdrawal and concealment***

Young people were fearful of stigma related to both the visibility and invisibility of IBD. This led to withdrawal from friends, family and peers in social situations in order to reduce the risk of disclosure. Participants were fearful of disclosing a diagnosis of IBD to their peers, keen to avoid reactions of pity, feeling different to others and of social and emotional rejection; *'Like, if I'm going to make friends, I want to make friends because they like me, not because I've got Crohn's'* (Max, 16 years with Crohn's disease). Most participants employed strategies to make visible aspects of IBD invisible such as skipping meals to reduce noises and risk of visible symptoms, avoiding and managing social situations to avoid the perceived visible embarrassing symptoms of IBD;

> *'And then I think a couple of weeks later or something I got some suppositories, which I hated, absolutely hate – they were the worst things – and I didn't want to put them in and I had to go into the toilet every night and do it and I was just so embarrassed'* (Sophie aged 18 years with Ulcerative Colitis).

Others tried to carry on with concealment and downplaying symptoms and limitations to fit in with peers;

> '*I think 'ok, I'm going to go, get up today, do things and just – you do pretend you haven't got IBD, you do pretend 'oh, I haven't got to go to the loo' and everything, and you just try to soldier on, but it just want' working'* (Helen, aged 20 with Ulcerative Colitis).

Fear of being judged for their inability to participate fully in education, sport and social activities, resulted in the seemingly easier choice to simply withdraw; '*I was sort of feeling down all the time and I didn't really want to go out of anything, didn't really want to go to school or anything'* (Alex, 16 years with Crohn's disease). The loss of social experiences was devastating for many frequently relating to the impact of self-imposed or medically recommended food restrictions; *'Keeping a relationship with friends was quite hard, because with parties and stuff there's always food out and like at that point I couldn't go to certain parties.'* (Max, aged 16 with Crohn's disease). However, concealment of the illness and their feelings around their new identity gave participants a sense of ownership over their illness; *'I just really feel like it's my problem and I didn't want anyone to know about it, I just wanted to deal with it' (Sophie, aged 18 with Ulcerative Colitis)* with pride in the stoicism required to '*soldier on'* (Anna, 19 years with Ulcerative colitis). Recognition of the adverse impact of withdrawal was clear to others; *'I think it's hard, but I think I make it really hard for myself'* (Sally, 16 years with Crohn's disease).

iii. Invisibility

There was both an active component to the invisibility experienced resulting in a significant impact on life choices for young people such as the type of university accommodation lived in; *'unable to live with others'* (Gemma, aged 18 with Ulcerative Colitis) and resulting in feeling *'locked inside'* (Zena, aged 19 with Crohn's disease). Many participants made themselves invisible in order to cope; *'I spent a lot of time in my room by myself, so I didn't have a clue what everyone else was doing. But now when I talk to them about it I can see that it upset them as well.'* (Anna, aged 19 with Crohn's disease). This invisibility was often employed to protect those around them from the impact of IBD; '*I don't want anyone to feel upset or feel sorry for me, so I need to get on with it myself really.'* (Max, aged 16 with Crohn's disease).

The invisibility of certain IBD symptoms, in particular fatigue was profoundly challenging for young people; *'It's just when you feel drained it's more mental, the fact that you think you can't do it because you feel empty and no more battery life really.'* (Jacob, aged 18 with Crohn's disease). This had significant implications for social, education and employment settings; *'it took 2 years of life, cause I was that tired'* (James, aged 21 with Crohn's disease). A perception of a lack of empathy and understanding from others was felt regarding the invisibility of profound fatigue; '*So if they point something out to me I'll just be like, yes, I'm not just lazy; I genuinely have a reason for sleeping. But I don't tend to tell people.'* (Zena, aged 19 with

Crohn's disease). Frustration was expressed that those around them did not understand the complexity of IBD due to the apparent invisibility of illness;

> '*I don't think people realise how bad it can make you feel as well – health wise, because you can look fine, you can be really well outside, but inside you can be in a lot of pain. And getting my friends to understand that as well is hard, because they see me great, and I might not be feeling great, and I might not have been well last night you know, that's hard'* (Charlotte, aged 19 with Crohn's disease).

4.3.4 Theme 3: Life Reset

Participants sought control over aspects of their identity with IBD. This led to a temporary or permanent scaling back of current and future aspirations and goals.

i. Control

Young people experienced a lengthy, fluid and dynamic process of experiential learning to develop their own IBD specific knowledge and sense of control; *'I think I'm still learning now but over the last 2 years I've learned an awful lot about it, but I think what other people have told me has been absolute rubbish about it'* (Mark, 21 years with Crohn's disease). Participants had a strong sense of needing to control their IBD; *'I'm one of them people that's like 'no, I will rule Crohn's!'* (Charlotte, aged 19 with Crohn's disease). This resulted in a variety of and changing methods in which control over IBD was sought, such as at diagnosis a belief in medicines was strong; '*overall, the medication and stuff, I know what to take, I know when to take it, I know why I'm taking it and stuff like that'* (Zena, aged 19 with Crohn's disease). Over time the relationship with food was a way in which young people experimented in gaining control over IBD; such as skipping meals, testing specialised diets, eating specific foods or simply not eating; *'I was pretty devastated, because all the foods that I used to have I can't have anymore'* (Alex, aged 16 with Crohn's disease). Other aspects of control were sought through reducing health risk behaviours such as alcohol and smoking, all of which compounded isolation;

> *'I mean it's not necessarily a bad thing that you're not drinking, but it can feel as though sometimes you think 'oh, I'll have a coke' and that, rather than drinking a beer, it just feels a bit bad, it could leave you out from doing so.'* (Jacob, 18 years with Crohn's disease).

Over time a set of individualised knowledge was assimilated by young people to control their IBD; *'I think you have to have a period for yourself to find out what works for you'* (Anna, aged 19 years with Ulcerative Colitis), with a sense of ownership of their IBD; *'So it's just controlling myself and what I want to do, and understanding what's best for me to do'* (Gemma, aged 18 years with Crohn's Disease).

ii. Scaling back

The inability to predict how IBD was going to affect them in the future led to an underlying sense of uncertainty for their own life as a whole; '*But what's hard now is that they think I've got scars and now I'm better, whereas I'm not, I'm still battling the same disease that gave me these scars that gave me this disease, and I could potentially be facing more'* (Charlotte, aged 19 with Crohn's disease). Participants felt frustrated and sometimes resigned to aspirations for their own lives being reset by a diagnosis of IBD;

> ‘*Yes, before I was wanting to go into the army or the navy, but the roles I wanted to do in there now I can’t do because of Crohn’s disease. I can still go into it; I just can’t do the things I wanted to do’* (Alex, aged 16 with Crohn’s disease).

Young people left opportunities due to fear of letting employers down;

> *‘And then I just got ill and I just had to leave and I had a few months and I just didn’t go back there, because I wasn’t sure – I didn’t want to let anybody down by someone employing me and being ‘oh, she gets ill a lot and we can’t rely on her,’* (Helen, aged 20 years with Ulcerative Colitis).

This affected other domains of life from education and career aspirations, social relationships, intimate relationships and future family hopes; *‘I want to be like that eventually, and I want to have kids and stuff. But they might end up having Crohn’s disease as well, so I’m not sure how I’ll deal with it’* (Alex, aged 16 with Crohn’s disease). Social and leisure activities such as travel and sport were often affected;

> ‘*Well, I used to do rugby before I got Crohn’s and I had to have my operation…..I was starting to get ill and become more tired was the point where my rugby training started to pick up and do more fitness, so I sort of couldn’t keep up anymore.’* (James, aged 21 years with Crohn’s disease).

For some acceptance of limitations of living with IBD was reached: *‘I wasn’t free from symptoms, but they weren’t always absolutely terrible – they were manageable and I could still go out and do – not whatever I wanted, but a lot of things’* (Anna, 19 years with Ulcerative colitis).

iii. 'Forced to grow up'

The additional and new responsibility of looking after themselves coupled with the sense of isolation led many young people to feel that they had entered an accelerated period of growing-up; ‘*I know my limits, and that’s another part about how I feel about teenagers with Crohn’s; you’re forced to grow up more than your friends*’ (Charlotte, aged 19 with Crohn’s disease). Participants experienced a subjective sense of feeling older than they should; *‘You’ve got to make a decision, and then you’ve got to make a decision with Crohn’s* (Max, 16 years with Crohn’s disease). For some this felt like being a parent to their IBD with new responsibilities being thrust upon them;

> *‘I always think about the come-back, even when I’m just out with my friends and we’re out for something to eat, I have to think about what I’m eating, will it make me ill. It stops me doing a lot of stuff, but then again I still do a lot of stuff, do you get me?’* (Alex, aged 16 with Crohn’s disease).

4.3.4 Theme 4: Resilience

Some young people were able to reframe the adversity experienced associate with IBD through support from close relationships with family and peers. This resulted in a positive outlook, coupled with self-compassion and increased determination for the future.

i. *Reframing IBD*

Many of the participants were over time, able to reflect and reframe the adversity associated with IBD; ‘*grow to understand it’s not your fault’* (Gemma, 18 years with Ulcerative colitis). A range of strategies were used by young people to help them manage stress including relaxation techniques (e.g. breathing exercises and caring for pets), support for anxiety and depressive symptoms through psychological interventions (e.g. antidepressants) and celebrity role models; '*Yes, that helped quite a lot, that I know someone – and Steve Redgrave has got it – big sportsmen have got it so I wasn't too bothered but obviously it did worry me a little bit; the consequences of it'* (Mark, aged 21 years with Ulcerative Colitis). This helped to foster a positive outlook, increase acceptance of their situation and, for some, an ability to adapt and develop new perspectives on their life with IBD; '*I mean, I'm so much better than what I was which is fantastic and because of that I feel I can cope right now, because I know where I've come from'* (Helen, 20 years with Ulcerative colitis).

ii. ***Openness and belonging***

Openness in personal relationships were pivotal to enable young people with IBD to live well alongside IBD; *'So I guess I'm hoping if, is say if, when I do have another flare up, because I've been more open about it, I'll be in a better place to deal with it';* (Anna, aged 19 years with Ulcerative Colitis). Many recognised the risks of not being open to others regarding their experiences of living with IBD; *'Just being open with it and not push it to the back of your mind, because then it just gets worse'* (Alex, aged 16 years with Crohn's disease). Friendship and trust was central to a sense of belonging and confidence in disclosure of IBD to friends was enabled though trusting relationships; *'I don't openly say – unless I really trust someone, or know someone'* (Gemma, aged 18 years with Ulcerative Colitis). Humour was often utilised by participants to help them communicate with friends and family about their IBD;

> ‘*I don’t know, because most of my friends knew and just laughed, but I was like really awkward because all my friends were laughing and I couldn’t help laughing as well, so we got in a bit of trouble sometimes in assemblies, when everyone was laughing, it was because of my stomach going off’* (James, aged 21 years with Crohn’s disease).

IBD itself was felt by some to have strengthened their close relationships, particularly with parents and carers, such as a bringing of family together, increased affection, a deeper sense of belonging and gratitude; ‘*But I mean, family have always been there for me and hopefully always will be, because they’ve always been supportive of me and I always try and see them as much as you can.’ (Jacob, aged 18 with Crohn’s disease).*

iii. *Self-compassion*

Many participants felt lucky often with a sense that their illness and circumstances could be worse. This resulted in a positive outlook to living with IBD;

> *‘It used to be that IBD was the be all and end all. It was what I was and I just thought of myself as being ill, whereas now I – I don’t know, it’s really cheesy, but like more of a complete person, it’s just a small part of me. But that could be because it’s under control now and I’ve learned how to deal with it when I am ill, so it’s more like I’m in control of it rather than it’s in control of me’* (Anna, aged 19 years with Ulcerative Colitis).

Viewing the positive aspects of IBD was common, with participants full of pride for their achievements and determination despite the adversity they had lived through and continued to live with; ‘*you’re different from everyone else, it makes you who you are so don’t be scared* *about telling people about it'* (Sally, 16 years with Crohn's disease). Hope for the future was abundant in young people's view of the future: '*The world is my oyster it doesn't hold me back'* (Anna, 19 years with Ulcerative colitis).

4.5 DISCUSSION

The present study of young people living with IBD in late adolescence demonstrated highly individual experiences based on symptoms, healthcare experiences and personal factors. Both the invisibility and visibility of IBD resulted in a sense of isolation and feeling misunderstood. This led to a withdrawal from a wide-range of social interactions. Future goals and aspirations were scaled back as a result of the emotional response to a diagnosis of IBD. Yet adverse experiences related to IBD also enabled development of resilience. This was aided by open and close relationships with family and friends fostering a positive outlook, acceptance and increased determination.

Young people's responses to a diagnosis of IBD were found to be highly individual and included a combination of relief, denial, indifference and traumatic experiences symbolised by particular medical interventions and surgery. A strong view was portrayed by the young people's accounts regarding the importance of time, experience and support in making sense of a diagnosis of IBD. Young people experienced their new IBD identity as profoundly isolating, often feeling distant or misunderstood. A fear of consequences of disclosure of IBD to others was found, as described in other chronic health conditions (40). Isolation was driven by a fear of stigma from both the visibility and the invisibility of IBD and resulted in withdrawal from a wide range of social, educational and employment experiences. This is in line with other studies proposing illness stigma and social functioning as targets of intervention for improving emotional adjustment in young people with IBD (43).

It was clear that young people wanted to be viewed and managed by health care professionals as individuals with a unique experience of IBD, rather than a homogenous group with a chronic illness. Young people with IBD felt their symptoms are dismissed or mislabelled, sometimes as somatoform or psychiatric disorders by health care professionals prior to a diagnosis of IBD which is previously described in case reports (41). Recent studies have demonstrated a median diagnostic delay in paediatric healthcare of >10.8 months in Crohn’s disease and >6.6 months in Ulcerative colitis/IBD-U (42). This has significant implications for the individual with IBD and the costs of healthcare, with a 2.5-times higher rate of strictures/internal fistulae in Crohn’s disease and growth impairment (42). Our findings illustrate some of the factors which may contribute to the diagnostic delay for young people with IBD including difficulty communicating and being dismissed by health care professionals regarding complex, atypical and embarrassing symptoms. Enabling a person centred approach in the delivery of developmentally appropriate healthcare (43) from the first contact in the healthcare system may improve the frequent delays to diagnosis of IBD in young people.

Life with IBD was reset for young people in this study. The pressure of living with the uncertainty of a relapsing and remitting condition, the unpredictability of symptoms, and the difficulties with IBD being misunderstood by others led to young people’s need to control IBD wherever possible. Scaling back of current and future life aspirations was commonplace across multiple life domains, including in education, career aspirations, hobbies and leisure activities and in future hopes for close relationships and having a family. Yet despite this, young people displayed an abundance of resilience and hope for the future. Adversity related to IBD was viewed as resilience-forming, enabled by an openness in close relationships leading to acceptance and self-compassion. Other studies in young people with IBD have also demonstrated the importance of family structures and support networks in improving coping generally (31,33,35), and in particular in those undergoing surgery (27) and in living with a stoma (28). Resilience and self-efficacy has been shown to be useful predictors of readiness for transition to adult services in IBD (44), important to health outcomes into adulthood.

The findings of the current study have important clinical and service implications for healthcare providers but also for social, education and employment settings. Firstly, healthcare providers in the community, paediatric and in adult settings require bespoke education and training to improve the delivery of person centred care for young people with IBD, currently lacking in education programmes (45,46). Secondly, specific action is required to address the delay to a diagnosis of IBD highlighted in this study which increases the psychological burden for young people. Clear and accessible urgent referral pathways are needed for the non-specialist provider to improve access for young people with suspected IBD. Thirdly, the findings of this study support the recommendation from European and American consensus IBD guidelines stating screening is required for depression and anxiety alongside access to psychologists as part of standard IBD service (9,47). The use of validated questionnaires to assess risk of developing anxiety and/or depression and assessment of body image concerns (47) to enable delivery of early interventions could be easily delivered in a digital era to inform clinical consultations. However, this study demonstrates that young people's experiences and psychological needs are broader than anxiety and depression and cannot be fully assessed by screening questionnaires. IBD services require healthcare staff trained in the broader psychological needs of young people to enable identification of indicators demonstrating difficulties in living with IBD. The complexity of young people's experiences demonstrated in this study highlights the need for provision of explicit psychological support services within the core IBD team. Finally, to improve the experiences of young people being investigated for and living with IBD, delivery of developmentally appropriate healthcare with an individualised person-centred holistic approach is required. This requires co-production of IBD services in line with national recommendations for transition care where co-production with young people and their families is strongly recommended (48).

The study also have implications for future research. Improving resilience for young people may have important long term implications into adulthood. Studies are needed to identify factors associated with resilience in young people with IBD to enable development of validated scoring systems to measure resilience (49). Identifying young people most in need of novel interventions to promote the development of resilience is needed, followed by development, testing and validating of such interventions. Further research is required to determine the outcomes and cost-effectiveness of various well-being and psychological interventions. In addition, this study highlights the need for further research evaluating the impact of embedding psychology provision within IBD services and community services. Finally, research is need to evaluate the outcomes of co-produced communication training to empower young people with IBD and improve the healthcare literacy required to navigate complex health care systems, education and employment settings.

The present study has some limitations that should be noted. In particular, the study was conducted within a single university centre, although it was strengthened by participant recruitment from both the paediatric and adult services. From previous studies in this field, young people with higher depression scores have been shown to be less likely to complete follow-up assessments (19). Therefore selection bias may have occurred unintentionally in this study with potential participants experiencing poor mental health less likely to attend for interviews. In addition the cohort included predominantly Caucasian participants, and therefore lived experiences of IBD may differ in other cultures, education and cultural contexts. For example in a study of adults from South Asian origin, living with IBD resulted in increased stigma, an increased use of alternative therapies and complexities due to frequent need to travel (50). It is also noteworthy that this study did not consider sexual relationships explicitly, this should be an area for further research in the impact of IBD in young people. Research in this area has shown that sexual dysfunction in IBD is common with wide ranging impact (51). Finally, whilst this study did not exclude participants with IBD unclassified (IBDU), no patients with IBDU were recruited. Young people may experience increased stress due to lack of a definitive diagnosis of an IBD type.

4.6 CONCLUSION

This study highlights the individuality and variation of experiences for young people living with IBD in late adolescence. The experiences often result in isolation and revised life goals. Reframing of adversity with supportive relationships improves resilience. Psychological screening and development of interventions to improve resilience and reduce psychological morbidity are required in late adolescence. Delivery of developmentally appropriate healthcare, co-produced by young people living with IBD would enable improvements in the healthcare and wider life experiences of young people living with IBD.

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TABLES & SUPPLEMENTARY TABLES

TABLE 1: Demographics of Participants

Study ID (Pseudonym)	Sex	Age (years)	Ethnicity	IBD type
Sally	Female	16	White	CD
Sophie	Female	18	White	UC
Gemma	Female	18	White	UC
Anna	Female	19	White	UC
Zena	Female	19	Asian British	CD
Charlotte	Female	19	White	CD
Helen	Female	20	White	UC
Lewis	Male	16	White	CD
Alex	Male	16	White	CD
Max	Male	16	White	CD
Jacob	Male	18	White	CD
Harry	Male	19	White	CD
Mark	Male	21	White	UC
James	Male	21	White	CD

CD, Crohn’s disease; UC, ulcerative colitis

TABLE 2. Main themes and sub themes in young people living with IBD

1. Who am I with IBD?	Delay to IBD diagnosis One size does not fit all Uncertainty and permanency
2. Isolation with IBD identity	‘Losing myself’ Withdrawal and concealment Invisibility
3. Life Reset	Control Scaling back ‘Forced to grow up'
4. Resilience	Reframing IBD Openness and belonging Self-compassion

Supplementary Table 1: Interview Schedule

Main Questions	**Sub Questions**	**Possible Prompts**
Can you tell me a little bit about your first experiences of IBD?	What did you or your family first notice?	Symptoms experiences
	Would you mind telling me a bit about your experience of being diagnosed with IBD?	
	How did you feel about being diagnosed with IBD?	What it meant? Any expectations or worries?
	Have you told anyone about having IBD?	
	Could you tell me about the reaction of people around you /what other people thought to you being diagnosed with IBD?	Friends Partners Family
	How would you describe your experience of getting to know and understand IBD, your treatment, your doctor, the health professionals and the system they work in?	
Could you tell me more about how living with IBD is, as a young person/from the perspective of a young person?	How you feel about yourself?	
	Relationships?	Forming and maintaining relationships with friends, partners, family Short-term/long-term relationships Love

		Sex
	Your socialising?	Going out with friends Drinking/drugs Travelling Leisure & sport
	Education and employment?	School; exams, subjects College & university Choice of career)
You have told me about […summarise diagnosis and living with IBD experiences…] could you now tell me a little about your ways of coping with living with IBD?	How has it been coping with living with IBD?	
	What ways, if any, have you found to cope with living with IBD?	
	Do you have particular strategies or tips that you feel helps you cope?	
	How, if at all, have your family and friends supported you through living with IBD?	
	Do you feel you can talk to people about your experience of IBD	Physical symptoms Hopes and worries Friend, partner, family
	Have you used any face to face or social medial support networks directly related to IBD or other related conditions during your time living with IBD? What have you thought about these?	

You have told me about […summarise coping with IBD…] could you now tell me about other people's reaction to you and your IBD?	Could you tell me about how you feel your family & family members see you and how they think about your IBD?	
	How do you feel your IBD has been for other members of your family?	Siblings, parents, grandparents
	Could you tell me about your experiences of talking about your IBD with other people outside your family?	Friends, girlfriends/boyfriends/partners, school, college, university, employers)
We have spent a bit of time thinking about how things have been and how things are now, I wonder if you could tell me any thoughts you have about how living with IBD will be for you in the future?	Hopes/worries?	
	Leaving home/living independently	
	Relationships Your family, having a family of your own	
	Education/career	

Supplementary Table 2: Step-wise approach to analysis of transcripts for Interpretative Phenomenological Analysis

Steps	Description	Researcher Team Member Involved in step
1	Transcript checked for accuracy whilst listening to audio-recording.	AJB
2	Transcript read several times and simple descriptive comments made while reading and listening to the transcript in order to reveal content. Preliminary notes kept in the left margin.	AJB
3	Emerging codes and early themes recorded in the right margin.	AJB
4	Written content formatted into a table to facilitate annotation process.	AJB
5	Process repeated a second and third time to note linguistic (use of language, laughter and voice tone) and conceptual (questions and interpretations of the text) comments.	AJB
	Steps 1-5 repeated for all transcripts.	AJB
6	Themes considered at participant level, and later at group level.	AJB
7	Various techniques employed to search for connections across themes including; abstraction (grouping similar themes), polarisation (focusing on differences between themes) and numeration (looking at frequencies of themes).	AJB
8	Themes organised by the researcher and following supervision meetings into clusters to identity preliminary main (superordinate) and sub-themes (subordinate) themes by grouping quotes and initial codes from tables produced in Step 4.	AJB & GR
9	Peer supervision with a colleague conducting IPA research undertaken with audit of one of the transcripts to ensure initial codes and subsequent themes and ideas grounded in the data and to	AJB

	ensure that the process of deriving the themes was evidenced.	
10	Key quotations illustrating a theme were noted throughout.	AJB
11	Participant quotes colour coded to allow assessment of how representative each theme was. Changes made to a theme checked against the original data to confirm a grounding of themes and their selection.	AJB & GR
12	Themes reviewed for clusters and transcripts reread to confirm or dispute themes and overall robustness of the final representation.	AJB
13	Independent verification of emergent themes.	GR
14	A final list of main (superordinate) themes and their respective subordinate theme was produced.	AJB
15	Reflexivity was supported through a reflexive diary to record the researcher’s reflection, ideas and observations.	AJB

Chapter 5: Structured Transition from child to adult services: Characterising Experiences of young people with Inflammatory Bowel Disease

ABSTRACT

Background and Aims: Young people with inflammatory bowel disease (IBD) transitioning from paediatric to adult services have specific health care needs and understanding their experiences is essential for improving structured transition interventions. The aim of this study was to explore the experiences of young people with IBD in a structured transition programme.

Methods: Two groups were recruited; (i) pre-transfer (6-12 months prior to transfer) from a single paediatric centre with a structured transition programme to a linked adult service, (ii) post-transfer (6-12 months post transfer). Individual semi-structured interviews were conducted. Interviews were audio-recorded, transcribed verbatim and analysed using interpretative phenomenological analysis (IPA).

Results: A total of 19 participants with a median age of 16.7 years (range 16-18 years) were interviewed, 14 with Crohn's disease, five with Ulcerative Colitis. The pre-transfer group consisted of nine participants, six of whom subsequently transferred to a linked adult centre. Of the 10 participants in the post-transfer group, five were receiving adult healthcare in the linked transition centre. Interviews were conducted at a median of 6 months (range 6-12 months) pre- or post-transfer to adult healthcare. Four main themes were reported: 1) Hopeful for change, but living in the present: 2) Stuck in the middle; 3) My turn; and 4) Starting over again. Young people find the transition process hopeful and empowering, but the dependency on caregivers to support this journey highlights vulnerabilities and an accelerated entry into adulthood. Despite a structured transition programme, young people can feel passive and lack personal control. Person-centred developmentally appropriate care and communication was key to young people feeling empowered and fitting in to adult healthcare.

Conclusions: Young people require an individualised, developmentally appropriate and flexible approach from healthcare providers in a structured transition programme to enable empowerment, independence and a sense fitting in to adult healthcare to develop. Further work is needed to understand the additional benefit of virtual communication tools and education programmes to improve self-efficacy.

5.1 INTRODUCTION

Inflammatory Bowel Disease (IBD), including both Crohn's Disease (CD) and Ulcerative Colitis (UC) has a globally rising incidence in paediatric populations (1–4), particularly in young people (5). The peak onset of IBD is in adolescence (1), with approximately 25% diagnosed before the age of 20 years (6). The World Health Organisation defines 'adolescence' as the developmental stage between 10–19 years, 'youth' as between 15-24 years and 'young people' as those aged between 10 and 24 years. Adolescence and young adulthood is recognised as a distinct developmental stage and a critical period of development characterised by change, exploration, risk-taking (7), identity development and a search for meaning (8–10). A diagnosis of a chronic disease such as IBD, poses a threat to normal psychosocial and psychological development in adolescence and early adulthood (11). In IBD patients, detrimental outcomes are described in psychological well-being , education, employment and close personal relationships (12–14). The specific needs of young people with chronic health conditions have been recognised, with the recommendation to deliver developmentally appropriate healthcare (15). Developmentally appropriate healthcare is a set of conceptual dimensions and include the need to recognise biopsychosocial development, acknowledge young people as a distinct group, making adjustments as the young person develops and empowering young people through health education and health promotion (16).

During this complicated period of adolescence, young people with chronic diseases transition from child to adult healthcare services. Transition is a complex healthcare intervention (17), defined as ‘the purposeful planned movement and preparation of adolescents and young people with chronic health conditions from child to adult-orientated healthcare systems’ (18). In the United Kingdom, and western countries transfer to adult healthcare as part of a structured transition programme takes place from the age of 16 years, with the transition process starting from the age of 12 years. There is evidence that inadequate transition for young people with other medical conditions including diabetes (19) and, congenital heart disease (20,21) is associated with adverse outcomes in adulthood such delay in psychosocial development as well as worsening control of long term conditions with serious adverse outcomes (22). In IBD specifically there is limited research in transition outcomes, but previous data suggests that adult services are not well placed to support young people with IBD through the life changes they experience from adolescence to adulthood (23). The economic consequences of inadequate transition to adult healthcare are likely to be costly, with a recent evaluation of the economic impact of structured transition demonstrating higher treatment costs in those who did not undergo structured transition (24). Inadequate transition processes are associated with clinic non-attendance, non-adherence with medication, restricted growth potential and an increased likelihood of requiring surgery (25), and hospitalisation (26). Adult gastroenterologists report that the barriers to successful transition include inadequate preparation of young people for the management of an adult service, a lack of financial resources, clinical time and inadequate training in both paediatric and adult hospital based healthcare providers (27).

National guidelines in the United Kingdom set out overarching principles of transition care which include the need to be developmentally appropriate, person-centred and to involve young people in service design, delivery and evaluation (28). National and international gastroenterology and IBD guidelines in transition care (22,29) recommend structured transition programmes, but due to insufficient research in IBD specifically are unable to recommend a particular transition model. Structured transition programmes follow a broad set of principles to deliver multidisciplinary programmes with the aim of improving health-related quality of life, self-efficacy, knowledge, satisfaction and vocational readiness (30–32). In IBD specifically structured transition programmes have demonstrated improved outcomes with lower rates of surgery two years following transfer, lower in-patient admissions, improved drug adherence and growth targets compared to those who were not part of a transition programme (25). More recent retrospective studies have demonstrated the benefits of a transition programme in reduction of pre- and post-transfer hospitalisation and flare-ups (33), and higher disease remission rates in Crohn’s disease (34). Importantly, a comprehensive 5-year research programme investigated which components of structured transition programmes were most associated with improved long-term outcomes in young people with chronic health conditions. The three most important components were appropriate parent involvement, promotion of health self-efficacy and meeting the adult team before transfer with a personalised clinical approach once in adult healthcare (35) .

In chronic conditions in general, evidence exists from mixed-methods studies that young people often do not experience key components of a structured transition programme (36). However, in IBD there remains limited research in the experiences of young people transitioning to adult healthcare. In a retrospective online questionnaire based study post-transition, young people reported positive themes regarding adult services which included independence, autonomy and trust, while negative themes included initial discomfort and confusing logistics (37). Mixed patient and professional focus groups highlighted concerns regarding loss of relationships with paediatric healthcare professionals and a perception of poorer quality care from adult providers (38). A mixed-methods study using thematic analysis and validated assessments of self-efficacy in 20 transitioned young people with IBD focussing on developing a transition intervention found key themes including ‘individualised and multifaceted’ and the need for support in the shift in responsibility (39). A Delphi exercise which included young people with IBD found their three perceived most important items for successful transition to be decision making regarding IBD, independent communication and patient satisfaction (40). In summary there are no in depth qualitative studies examining the lived experiences of a structured transition programme, with all studies to date using either questionnaire based assessment or mixed patient and professional groups.

This study aims to address the existing gap in qualitative research to understand the lived experience of young people with IBD in a structured transition programme moving from children's to adult healthcare services. The insights gained from this study will further the existing knowledge based regarding factors which contribute to successful transition experiences in young people with IBD and inform improvements in services through new insights.

5.2 MATERIALS AND METHODS

Qualitative methods were considered most appropriate to address the aims of the study, to gain in-depth insights and understanding into the meaning and interpretation of young people's experiences of structured transition from child to adult healthcare for IBD. Qualitative research is critical to understanding the individual experiencing a complex intervention such as transition, and therefore can identify factors that influence successful transition outcomes (41). Interpretative Phenomenological Analysis (IPA) aims to describe participant experience and identify themes across a group sample (42). It was chosen as the most appropriate method of analysis due to the detailed examination of personal lived experience required. IPA recognises humans as sense-making and does not prescribe a theoretical framework.

Study Design

Eligible patients aged 16-18 years, with an established diagnosis of IBD (Crohn’s disease, Ulcerative colitis or Inflammatory Bowel Disease Unspecified (IBDU)) were identified from transition databases between 2014 - 2015 from paediatric and adult University Hospitals in Northern England. These two recruitment centres participate in a formal structured transition process for young people with IBD from paediatric to adult healthcare with transfer occurring between the ages of 16-18 years. This involves medical and nursing health care professionals attending joint IBD clinics between both services, alongside an assessment of readiness for transfer in line with current guidelines and international consensus (43). Due to patient preferences, some patients transferred to other adult centres including regional district hospitals.

Inclusion criteria were (i) age 16-18 years at entry to study and (ii) diagnosis of IBD defined by current diagnostic criteria (44) for at least >12 months, in order to allow for perceptions and ideas about their illness following diagnosis to develop and transition programme to be experienced (iii) eligible participants from the paediatric centre were required to have planned transfer to an adult centre in approximately 6-12 months’ time and be currently part of the local structured transition programme (iv) eligible participants from the adult centres were required to be approximately 6-12 months post-transfer to an adult centre and have undergone a structured transition programme from the paediatric centre. Exclusion criteria included (i) patients who were unable to give written consent, (ii) those unable to speak English fluently due to the interpretative nature of the research methodology requiring verbal fluency in the primary investigator’s first language (42). The study obtained ethical approval from the National Research Ethics Service (NRES) Committee North East - Sunderland (14/NE/0024), February 2014.

It was felt that a study of the lived experiences pre- and post-transition to adult healthcare would be best explored within relatively recent transition experiences and as result the recruitment age was 16-18 years to reduce heterogeneity of the study sample from a developmental, life circumstance and maturation perspective. For the purposes of this study the age range of 16-18 years will be referred to as ‘young people’ throughout.

Recruitment and Interview Procedure

All eligible patients were sent a letter of invitation and study information leaflet (from their usual treating IBD consultant physician) before a scheduled appointment in the IBD service. At their scheduled appointment with their treating clinician or a member of their IBD specialist healthcare team, patients had the opportunity to discuss the study information in line with Good Clinical Practice (45). Contact details (telephone and email address) of those who expressed an interest to participate were sent to the principal investigator (AJB), who then made contact via the preferred method to provide further information and answer further questions. Patients who confirmed their interest to participate were then contacted to schedule a date for interview. All participants provided written consent prior to the interview. All interviews were conducted face-to-face, on University or hospital premises, in a private interview room, and were recorded for transcription.

The interview schedule was developed in line with guidelines recommended for Interpretative Phenomenological Analysis (42), through discussion with the IBD multi-disciplinary team and the research team and consultation of the existent literature. This included asking participants to describe their experiences of preparing for transition, relationships with staff, timing decisions, social support, resilience factors, transfer of responsibility, self-management and the impacts of transition on being a young person, on family, friends and social context (see Supplementary Table 1 & 2).

Research Team and Reflexivity

Personal Characteristics

All interviews were conducted by the principal investigator; a Caucasian female without IBD, whilst undertaking a higher degree (PhD) and working part-time as a Clinical Research Fellow within the IBD service (not part of the transition healthcare team), at one of the recruiting sites.

Reflexivity

Reflexivity was supported using a research diary to record the principal investigator's reflections, ideas and observations (46). A clear audit trail of data collection and analysis processes guided regular discussion of each stage of the analysis with research supervisors and peers undertaking similar research, in line with IPA recommendations, to ensure the validity of the research (47).

Data Analysis

Transcripts were analysed in line with current IPA guidance (42) using a personalised systematic approach (see Supplementary Table 2), with main (superordinate) themes and their respective sub-themes (subordinate themes) emerging. All participants were allocated pseudonyms to ensure confidentiality in the reporting of research findings. Analysis was undertaken by the principal investigator with independent verification of emergent themes by the last author (GR). Six transcripts were audited by the last author to check that initial themes and ideas were grounded in the data and to ensure that the process of deriving the themes was evidenced.

5.3 RESULTS

Participant Characteristics

Of the 19 participants, 14 had a diagnosis of Crohn's disease and five had Ulcerative Colitis. The median age of participants was 16.7 years (range 16-18 years). Of the nine participants in the pre-transition group, six transferred to a linked adult centre (see Table 2). Of 10 participants in the post-transition group, five participants had transferred to the linked transition centre, and five to other hospitals. Interviews were conducted at a median of 6 months (range 6-12 months) before or following transfer to an adult service (see Table 2). The mean length of interviews was 24 minutes (range 17-35 min).

Main Themes

Four main (superordinate themes) emerged from the analysis: 1) Excited for change*, but living in the present;* 2) *Stuck in the Middle;* 3) *'My Turn';* and 4) S*tarting over again.* Within each theme, several sub-themes (subordinate themes) were identified and described. The following four sections provide a narrative overview of the results (see Table 2), with illustrative anonymised quotes.

5.3.1 Theme 1: Hopeful for change, but living in the present

Participants experienced hope and a sense of excitement prior to transfer to an adult healthcare setting. The young people felt hopeful they would "fit in" more in adult healthcare and that IBD would have a reduced impact on their lives. Despite the positive outlook, young people expressed feeling daunted, "child-like" and wedded to their familiar healthcare setting where they have a strong sense of belonging. The strong relationships formed during childhood with the paediatric health care team enabled a sense of stability whilst living alongside IBD, which was emotional to depart from.

i. 'Daunting, but nothing I couldn't handle' Milo, aged 18

Although some young people felt anxious ahead of transition: "*I suppose I'm dreading it because there's so much to – that you've got to take in"* (Adele, aged 17), most felt they had the skills to be able to manage; "*Eventually I'll be the one making all the decisions. Um, it's a bit daunting. But I think I will be able to handle it"* (Callum, aged 16). A sense of indifference was expressed regarding the move; "*Same thing will always happen, yes, medications, yes; nothing's really going to change apart from the people and the nurses*" (Cristina, aged 16). This was framed as the need to live in the present, despite being aware of transition:

> *Ha, I haven't, I haven't even thought about it* [transition] *to be honest. I'm excited for it, but it's not a priority at the minute; just I'm here now, so I've got to think about being here and not thinking about the other* (Max, aged 17).

Following transition, many felt they had handled the process well: “*The move, it’s been alright, like it’s not really – I’m alright with like moving and stuff, it’s not phased me at all”* (Kate, aged 17).

ii. Belonging

A strong and trusting relationship with the paediatric IBD team enabled the young people to feel a sense of belonging: “*It’s like you’re going to see a friend”* (Sunita, aged 18). They described feeling as though they had grown up alongside a healthcare team:

> *All of the doctors make you feel like they know you; like even if they might not know me, even if they might just know my name, but like my consultant actually knows me – like a teacher, you have that relationship with a teacher and they get to know you over that period of time* (Max, aged 17).

This strength of relationships underpinned a strong confidence in the healthcare system; *“They just made sure you got the highest level of care that could be provided”* (Adele, aged 17) and resulted in participants not feeling isolated whilst living with IBD; “*I’d never feel like I was alone and I had to go through it on my own, like they’d always be there for you” (*Sally, aged 17). The role of the IBD Specialist nurse in the paediatric team was central to participants’ perception of strong and nurturing relationships with the healthcare team; “I *feel like they care about how I’m feeling and how everything’s going, which is nice”* (Sam, aged 16). This support was crucial to transition preparation; “*Yes, she’s sort of the one consistent person who we’ve seen again and again and again, and she’s nice, and caring, which is nice. Just sort of like the supervisor of everyone who is in my situation I guess”* (Milo, aged 18). The trust in the IBD specialist nurse was pivotal in enabling a platform for young people to prepare for transition;

> *You go on with your normal life, have another appointment, but I think in terms of preparation for it, it's the nurses. The nurses prepare you for it; I think they make sure everything is up to check and things like that* (Sunita, aged 18).

Holistic communication and time to talk to the IBD Specialist nurse about personal fears related to transition, helped reduce participants' anxiety: "*Yes, before I was quite scared, but then they talked it through with me and then, yes, I was fine after that"* (Kate, aged 17).

iii. Hopeful about fitting-in

Despite the fear of letting go of significant relationships with their paediatric team, young people felt hopeful regarding relationships with their future new adult team; "*I've not really been here long, but I think everyone is really genuine and I think they'll give the same support as they did at the* [children's hospital]*"* (Kate, aged 17), realistic about the time for this to develop; "*so that relationship will probably develop, it just obviously takes more time because I've had to start over again*" (Adele, aged 17). The impact of healthcare on their lives was an important consideration for participants, who were hopeful that transfer to adult healthcare would lessen the impact of IBD on their lives; "*I mean, that's probably the only reason why I want to be there, just so I don't have to sit around for 4 hours with a tube in my arm"* (Max, aged 17). Organisation of systems in adult healthcare were also viewed positively; "*it's just more organised and straight forward and stuff like that, which kind of* *helps me cope I suppose"* (Jessie, aged 18). The adult environment was perceived as more developmentally appropriate by young people;

> *I'm actually excited because I won't be surrounded by little toddler kids and stuff like that, because it's hard to talk to a toddler. Their parents are quite nice, but it's not like – I'm not expecting there to be like lots of teenagers, but it would be like a little bit better if people are older, if you know what I mean? So I'm excited.* (Cristina, aged 16).

5.3.2 Theme 2: Stuck in the Middle

Participants described a feeling of passivity and lack of control around decision making with regards to the specifics of the transition process. For example young people gave consideration to the needs of their parents/carers in their choice of adult centre for transition, taking into consideration the impact of time and financial burden of travelling for healthcare. Variable perception of personal control during the transition process could for some result in a sense of indifference, being stuck both in the middle of healthcare professionals and their complex systems whilst also in stuck in the middle of childhood and adulthood. Participant's perception of their developing skills associated with adulthood was variable.

i. ***"Up the road is fine"*** (Max, aged 17)

Young people portrayed a sense of apathy and indifference regarding specific transition decisions, such as the choice of adult centre: "*I could decide which one I want to go to, so I* *had a decision; which hospital would be most convenient, and that they're all pretty much the same"* (David, aged 16). The goal of remaining well from an IBD perspective was often the main priority: "*I wasn't really fussed, again, as long as there was a hospital I could go to where if I am not feeling well they will make me better, and that's close enough"* (Milo, aged 18). The young people took into consideration the impact on their parents and carers as important factors in the choice of site for transfer;

> *I guess it's like there won't be as much pressure on my mum or my dad to fetch me places, and I mean, when I was in hospital, they spent a lot of money coming here every day just to see me, so I think that will put my mind at rest because I know they won't be as stressed and they'll be able to relax a bit.* (Callum, 16 years).

Impact on other aspects of life, such as education, were was also considered in choices for adult healthcare for IBD; *"It will help me in education wise, because if I'm going to [hospital] it's not that far, so I'm not going to be – we're not going to be as long travelling, so I'm not going to miss much time of"'* (Kitty, aged 16).

Parent and carers generally supported the young people as they made choices about adult centres for transition. Some parents made decisions for the young people; "*My parents kind of took the lead but I was happy with their decision*" (William, aged 18), whilst others were supported by their parents to make their own decision:

> *Um, well, she helped me decide about what hospital to go to; she spoke to me about it and – I don't know, she just – I'm not sure – she doesn't tell me what to do but she – I can't think of things like on the spot.* (Lizzy, aged 16).

Family experiences of healthcare settings were important narratives for young people to influence their choices: "*Oh, well, I didn't choose, my mum did. Because I think she – it think it's where – my mum and dad go there, so, somewhere easy like where we all go"* (Kitty, aged 16). Other factors outside of the family were also described: "*I know – my next door neighbour works in there, so, she said it's nice, well, as hospitals go, it's nice".* (Beth, aged 16).

ii. Variable sense of control

Some of the young people experienced a sense of agency within the transition process which felt positive;

> *We had a discussion about it and it was kind of my choice of when I wanted to move and he gave me a choice about my medication as well. He gave me a lot of choice and I think it would be the right time as well anyway* (Kate, aged 17).

There was a sense that during transition young people were, for the first time, asked their views. This was experienced as a shift in responsibility away from parents and carers;

> *Yes, I actually got asked if I wanted to move, which is why I – it's quite a big thing for me because I never get asked, do you know what I mean – it feels better to be asked than just told 'you're moving now'* (Cristina, aged 16).

Intentional delays to the transition process were common and were seen positively in context of education; "*They've done it quite well, because they wanted to wait until after my GCSEs so there's no stress about it"* (Anthony, aged 16). Other delays to transition were viewed clearly as being in the young person's best interests such as management of active IBD; "*they make sure your health is stable before they even think about transition, that's why it takes so long"* (Sunita, aged 18). The pace of transition was also regarded positively by some; "*I don't feel uncomfortable with the way that he's like putting me into it; it is very subtle, and it is a very slow process"* (Max, aged 17). In contrast, for others, there was frustration at not understanding when a transfer to the adult hospital was going to occur; "*Because it's like – it's not happening yet, like I'm not being – now they're like talking about what's happening instead of actually doing it"* (Callum, 16 years). Delays to transfer were not clearly always communicated to young people clearly; *"I'm not sure, it kept getting postponed and we were all over the place to be fair we were all over the place"* (Jessie, aged 18). Others felt confused by the process and hoped for signposting about next steps; "*I don't really know when I'm transitioning, it's confusing but I'm sure I'll – someone will explain it to me when I get there"* (Cristina, aged 16). This led to sense that it was unclear who was leading the transition process; "*I've kind of been passed about a bit so I'm not really sure who's in charge of it"* (Adele, aged 17). The lack of clarity led to young people feeling out of control; "*I wanted to take control of things myself and not rely on Mum, because they were still contacting my mum all the time for things"* (Jessie, aged 18). A paternalistic approach was experienced by some; *"I've always had a say but not really much of a say, like the doctors always just decided when I was younger"* (Isla, aged 16).

iii. Inevitability of transition

Feeling settled and not wanting to leave children's services, whilst appreciating the inevitability of the move was commonplace; "*Just got – well, I don't really want to get settled,* *but I have got settled if you know what I mean? You have to do it anyway, don't you, so just get on with it"* (Beth, aged 16). The preparation for transfer to adult care occurred early on in many of the young people's IBD care, including, for some, at the time of diagnosis. This was a time when there was a lot of new information to process:

> *I didn't really take note* [transition]*, because it was just like another thing piled on top of everything else. But it made me think I wasn't going to be here as long as I have been, because I'm older than a lot of the other patients and I thought, like, I wouldn't – I'd go there quicker than it has taken'.* (Max, aged 17).

For many of the young people transfer to adult care felt too early: "*I think it's too soon; I think I should be at least 17, because when I found out that I was having a transition I think I just turned 16 in January, so it was quite soon"* (David, aged 16).

Others felt the timing was right for them: "*Yes, it was in-between stuff so it was alright, so it didn't have to do that - rather than say education or have time out of stuff"* (James, aged 17) and that the transfer to adult care was tailored to their needs: "*It's alright, they said they want to fit it around me, so if I don't want to go yet, they're not going to push me to leave, but they said I have got to go when I'm 18"* (Max, aged 17). Some felt there was a duality of processes, moving healthcare and education at the same time which was helpful; *"I think it was the right time, because I'm moving from high school to college as well, so it was like a move from the children's to the adults unit"* (Kate, aged 17).

5.3.3 Theme 3: My Turn

The transition process for young people with IBD can be experienced as a symbolic period, associated with a perception of having to enter adulthood prematurely. As a result, young people can feel as though they do not possess sufficient adult life-skills to manage their IBD independently, resulting in anxiety and a cycle where they feel acutely aware of dependency on parental/carer support. Adult healthcare is perceived as busy and a less-person centred setting compared to paediatric centres. Despite these feelings, young people can gain a sense of empowerment, with a developing independence throughout the process of transition.

i. "I'm growing up, very fast" (Beth, aged 16)

Transition felt a symbolic period, representing entry into adulthood; *"I just remember them* [paediatric IBD team] *all saying goodbye to me and it made me really upset, because I was like 'I've gone from being a child now to being an adult' "* (Sally, aged 17). There was a shift away from the family unit where young people came to appointments, including for treatments and infusions alone; "*I feel more grown up, because I'm not having mum behind me all the time" (*Anthony, aged 16). The transition period focussed young people on the impending need for increasing independence;

> *Oh, yes, it makes me feel like I've got to grow up, a lot! It makes me feel like I've got to be a lot smarter and more – I've got to give a lot more attention to detail because whenever I'm sat with my mum and dad in the room I kind of zone out and I let them talk to mum and then I'll ask mum later what they said, whereas when I get up there I think I've got to actually listen and make a decision for myself' (*Max, aged 17)*.*

Participants in general did not feel ready to take on what they perceived as "grown-up" skills; "*Don't class myself as a grown-up"* (Anneka, aged 16), nor did they want to grow-up sooner than necessary; *"I don't know – I don't want to be grown-up, grown-up, just kind of in the middle"* (Sam, aged 16). Young people perceived pressure and described feeling as though they had inadequate skills to manage transition; "*Scared, I'm not – I'm a very – not independent, un-independent, if that's a word?"* (Kitty, aged 16).

ii. Fear of isolation

The young people voiced fears of feeling and being alone within adult healthcare settings, perceiving adult healthcare as busier; "*you're sort of limited to how much time you get before you get lost in the mix of everybody else"* (Adele, aged 17), with healthcare professions less likely to have good communication skills; "*Well, I'm scared at the adult hospital they won't really talk, because they're all adults and they'll do their own thing and not really talk to others"* (Sam, aged 16) and individual differences in doctors; "*I just imagine adult hospitals being quite morbid – like old doctors and like moaning a lot of the time. They just want to get you in and out straight away" (*Max, aged 17). Such fears were often based on family experiences of healthcare, or popular culture; *"Just stereotypes, isn't it? When you think of a hospital for adults, it's like a scary place where bad things happen. Ha. Films. Ha, yes, films and books and television" (*Max, aged 17).

Specific fears around being alone in adult healthcare settings related to inpatient hospital admissions; *"And sleeping in the hospitals, because you know, older people. So you can go* *from being the oldest in the hospital to being the youngest"* (Sunita, aged 18). Some of the young people felt anxious about the experience due to their younger age compared to other patients, and to family not being able to stay with them;

> *If I end up being admitted, like the age of people in there, because I think they'll all be quite old and I'll be the youngest and it will be really weird, because I've never been in a room with a load of old people, and then mum won't be able to stay either, so I will be a bit all on my own, won't I?'* (Beth, aged 16).

Participants feared feeling different to other patients in adult healthcare settings; *"I was a bit nervous, because it's like older people that's going to be here, and I thought obviously I'm the youngest when I'm having my treatment and everything, but everyone is really nice so yes"* (Kate, aged 17).

iii. Conscious dependency on parents/carers

Parent/carer support was described as essential by young people both in general and specific aspects of support required for successful transition to and whilst in adult services. Young people wanted this support to continue within adult healthcare at their pace; "*Yes, I think eventually, I'll be the one to be making all the decisions and things, but for now I'd like to keep it how it is, ha"* (Kate, aged 17). Participants often needed ongoing emotional support from parents/carers to manage anxiety; "*Just tell me to stop stressing all the time, because I stress a lot"* (Isla, aged 16 post transition) and their physical presence was important in reducing anxiety in interactions with healthcare professionals; "*Um, it makes – I prefer her coming with me, it makes me feel better, even if she just sits outside, it's just because if I need* *her to come in, if I don't know something then she'll know it"* (Lizzy, aged 16). Despite being the focus of consultations, young people tended to trust their parents/carers to act as their advocates; "*So they know best, they'll – who's in charge? Yes, I am in charge but I may as well not be, if that makes sense"* (Milo, aged 18). Developing the skills displayed by parents/carers to successfully manage IBD felt daunting; *"She's always on top of it. I still need looking after at the end of the day, but I know what's going on"* (Sam, aged 16). But for some this support could feel overprotective; "*Happy that she's concerned and she cares. Sometimes she's a bit over the top, but mums are, aren't they?"* (Beth, aged 16).

Through the process of transition participants felt their independence had increased significantly, but practical support for IBD management was still needed from parents/carers:

> *Ha, no, my mum plays a big part in that obviously. She'll make sure that my prescriptions – that I've got my prescription, all I've got to do is make sure I've got enough tablets to last while she gets my prescription, but my mum's probably key in it, so I kind of should take more responsibility I suppose, but it is my mum that plays a big part in that, mum is probably key'* (Adele, aged 17).

Some of the young people lacked confidence in their ability to successfully order medications; "*Because when you're talking to them it's just like you know what you're going to say, but when it's ordering prescriptions and stuff, I might get it wrong"* (Kate, aged 17*)* and with ongoing support their compliance was maintained;

> *It sounds really bad but my granny still has to put my pills out in the morning, and she still goes and gets my prescription- that's not changed, because I think if I had to go get my medication myself, I'd probably forget it' (*Sally, aged 17).

iv. Under the spotlight

Communication by healthcare professionals during the transition process had a significant impact on the experiences and feelings of the young people. Subtle differences in communication styles with adult healthcare professionals made young people feel like they were growing-up; *"Everything is about the same, but they talk to you more like an adult in adult care. And they treat you different, like – I don't know – like, not like a kid"* (Isla, aged 16). For some this process was an additional pressure, feeling forced to take responsibility after years of parents/carers holding this role;

> *Um, at the adult's hospital the doctors are very much like 'we want you to be the one we're talking to, we don't want to deal with parents.' And I kind of don't like that, because you know, all my life it has been parents and when I first got my diagnosis I didn't ask the question 'what's the name of my disease?' Or the details; I just wanted to get better. Because that's what is important to me, so yes, I kind of like having my parents – and then maybe as time passes I probably will be happy without them, but I don't like the sort of pressure to make it all about me'* (Milo, aged 18).

Some felt they were expected to communicate at a more adult level that they were not prepared for; *"but it's just talking, because I feel a bit better if someone helps me chose, because obviously I'm still a kid, isn't it? I might be 16, but I still feel like a 5 year old!"* (Cristina, aged 16). They feared getting it wrong and the implications of being able to communicate effectively; "*Well, again, it has been my mum ringing up when things have gone wrong. Ha, rather than me, because I do get pretty nervous on the phone, but it's just me trying to take more responsibility I suppose*" (Adele, aged 17 post-transition), with some suggesting virtual methods of communication would be beneficial in improving communication with healthcare professionals; "*I wish you could do it online, I'm fine with that, but I kind of – I don't like the thought of ringing places"* (Anneka, aged 16 pre-transition).

5.3.4 Theme 4: Starting over again

Participants felt frustration at having to understand and get to know another healthcare system. Adult healthcare felt more impersonal, but with the perception of more efficiency and confidence in treatment options. The process of transition to adult healthcare was empowering for young people in terms of their IBD self-management and wider life-skills. Empowerment was enabled through subtle changes in communication from health care professionals, and resulted in young people feeling a sense of belonging within the adult healthcare setting.

i. Empowered through transition

Overall the transition process was felt to be empowering; "*Actually, it's very like, it gives you responsibility, and that's what you need now, because of college and University and things like that, and it makes you feel like – it empowers you more to make the right decisions!"* (Cristina, aged 16). Through the process of transition participants moved away from the family unit managing their IBD, to autonomous decision-making; "*She leaves it up to me, to do it, and says, like, if they do another endoscopy, she'll advise me, but she'll leave it to me"* (Beth, aged 16). The acceleration in acquisition of skills required for transition was interpreted positively by some, with wider benefits;

> *Um, I think it improves your communication skills and time-management and organisation and all that kind of stuff, because it's important to actually schedule appointments so that I don't miss school or that kind of thing. But um, once again, it's more personal responsibility; it's been me making the decisions as opposed to my parents.* (William, aged 18).

Despite feeling under the spotlight during transition, key components of the transition experience led to participants feeling increasingly empowered. Communication styles differed in during transition and in adult healthcare settings leading to empowerment; "*There'd be a lot – like they'll treat me – they'll ask questions to me, instead of my mum most of the times, so I feel like I'll be able to have more of an input in"* (Callum, aged 16). The content of discussions differed in adult settings; "*It's like complex and they speak to you in like different type of context"* (James, aged 17). This led to a feeling of control and increased personal responsibility regarding factors such as medication adherence; "*Well, my mum used* *to remind me about my tablets, and now it's not really that anymore, I just know to take them"* (Sam, aged 16) and travelling to appointments alone; "*Um, just because I get calls now instead of my mum, I bring myself here, I do everything independently now"* (Jessie, aged 18).

ii. Same yet different

Following transfer to adult healthcare participants reflect that adult healthcare feels subtly different to experiences of paediatric healthcare; "*Yes, but in a way they're sort of the same, because they're both just as friendly, but it's still quite different"* (Sally, aged 17). Adult settings are perceived as serious due to the change in physical environment;

> *I think it's just being in the main adult hospital, it's a lot bigger, there's a lot more stuff going on. It's a little bit more sort of impersonal in a way, and the rooms aren't all flowery with butterflies on the walls like they are in the children's. It feels a lot more like you're there to be treated, in a way"'* (William, aged 18).

Adult healthcare settings were seen as impersonal, busy; *"They've got so many other patients as well, you sometimes can get missed off the list and missed off the system"* (Adele, aged 17) and sterile; "*It feels kind of like a production line, in that you go in and it's like you have your turn and you see the person and then you go out again. And you don't really know – you don't really recognise anyone, ever"* (Milo, aged 18). This included experiences of wider adult hospital services; *"Because in like pharmacy and stuff, they're a bit more formal, like 'you do this, now you do this' and there's no sort of personal touch, but that's ok, that's not a worry"* (William, aged 18). Despite these feelings, participants accepted the differences as part of their new healthcare system; *"That's it really, because they're there to do the same* *job, aren't they, they just treat you differently, they treat you more like grown up, if you know what I mean, I don't really know what the word is"* (Beth, aged 16).

Positive differences in adult healthcare were perceived by some young people including efficiency; "*but they did seem to be more on the ball at the children's hospital"* (Adele, aged 17) and feeling more organised; "*Like, just – it's just more organised and straight forward and stuff like that, which kind of helps me cope I suppose"* (Jessie, aged 18). This resulted in an increased confidence in their IBD care; "*it's made me feel a bit more confident, in that I'm getting better treatment now that I'm older"* (Isla, aged 16). The changing environment of adult healthcare settings was mostly appreciated by participants; "*But in here it's peaceful and they chat about like life with you, where as in the children's hospital they'd play games with you"* (Sally, aged 17). The type of interactions with healthcare staff participants were key to the differences they perceived in the settings; '*It's more mature here and like – I don't know, it's just better'* (Jessie, aged 18) but some required support to understand conversations; "*I'm alright with it, it's just a few little bits I need a bit of help understanding, apart from that it's alright"* (James, aged 17). Young people developed an appreciation of the time it takes for relationships with healthcare staff in the adult healthcare setting to develop; "*Yes, over time, yes, being as you go more often, start actually knowing people, knowing your doctor, knowing the different people in the teams and stuff like that"* James, aged 17).

iii. “I’ve fitted in here now” (Sally, aged 17)

Frustration about having to understand and navigate a new healthcare system was experienced through the transition process; *“This again, going through it all over again”* (Kate, aged 17). Metaphors of moving from primary to secondary school, or moving house, were helpful for participants in making sense of their experiences of healthcare transition; “*it just seems like we’re moving a bit further down the road – like you’ve just moved down the road to a new house; it’s all pretty much the same area, if that makes sense*?” (David, aged 16). Most participants felt as though they had “*fitted in*” to their new healthcare setting and were hopeful for the future; “*I haven’t got any worries anymore; I’ve fitted in here now, so I think looking at the future it might be quite good and at ease, but who knows, I might be wrong”* (Sally, aged 17). Reflecting on their transition process, young people had a sense of overcoming their fears; “*Because it feels like a very small thing, like a small moment in my life now. Yes, it was a big – it felt huge at the time”* (Milo, aged 18). Personal factors relating to a sense of “fitting in” were frequently due to increased personal maturity; “*So, it’s probably just down to myself really, like I said, at the children’s hospital I was a bit difficult when I was there, so I should have listened more and tried to take things into my own hands a bit, but it’s obviously still fairly new at the adults hospital, so that relationship will probably develop, it just obviously takes more time because I’ve had to start over again”* (Adele, aged 17). The process of maturing was often subconscious; “*But I don’t really feel much, it’s just sort of like a natural – like I didn’t decide to get more involved, it just sort of happened*’ (Milo, aged 18).

5.4 DISCUSSION

This qualitative study of 16-18 year old young people living with IBD provides in-depth insights and new understanding of the experiences of a structured transition programme from paediatric to adult healthcare. A strong sense of safety and trust within paediatric healthcare is felt by the young people, perceiving and experiencing adult healthcare as busy and impersonal. Young people wanted to feel that they "fit in" as they made the transition from children's to adult's healthcare services. Many of the participants described their anxiety related to their own perception of a lack of maturity and feeling of readiness for the transition process. Participants felt an accelerated entry into adulthood due to an awareness of the ongoing dependency on parents/carers which enabled them to feel supported. The young people described a variable sense of control through the transition process, which often lacked clarity around decision-making. Ultimately, the young people described the transition process as empowering and encouraged them to take increasing responsibility for their health. Person-centred developmentally appropriate communication from healthcare providers in both paediatric and adult healthcare was key to enabling self-efficacy to develop.

Hope is a key feature of this study. There were frustrations about learning about a new healthcare system, but young people maintained hope that moving to adult healthcare would result in a reduced impact of IBD on their lives and that of their caregivers. They hoped to "fit in" more than in a paediatric settings, sensing that they have outgrown these services. Finally they were hopeful that they would develop a new independence. But their hope is tempered by feelings of indifference, and anxiety regarding their lack of self-efficacy and self-management skills. Self-management is defined as the interaction of health behaviours and related processes that patients engage in, in order to care for a chronic disease, often not mastered until after 18 years of age (48). In this study, we have demonstrated that the young people often had a sense of premature entry into adulthood as a direct result of healthcare transition. This may be compounded by the pressure experienced during other key life transitions such as social, education and employment that all young people experience in late adolescence. Self-efficacy is the ability to monitor symptoms and report them to health care professionals, manage medication and handle disease flare-ups. Some young people in this study felt they did not possess these skills, contributing to a feeling of inadequacy and anxiety regarding transfer to adult healthcare. European guidelines on transition care state decision making and self-efficacy are critical skills for successful transition (29). A recent systematic review of transition interventions found improvements in HRQoL, self-efficacy, self-management and patient satisfaction with interventions (49).

The young people describe a variable lack of control around decisions within the transition process, often feeling passive or out of control and as though key decisions around timing, site of transfer and process are made for them rather than with them. These findings have been replicated in cystic fibrosis (50), cerebral palsy (51) and in other studies of IBD where 54% of participants did not feel adequately prepared for transition (52), with a call for a ‘road map to care’ (53). This is also in spite of national IBD standards stating protocols should be in place which clearly define the local transition service and the personnel responsible (54). In this study, this lack of clarity and personal control the young people feel results in frustration and uncertainty about their role in transition and overall their future managing their IBD in an adult healthcare setting. Within the transition process, young people described the importance of prioritising what is important to them within wider transition process decisions (including social aspects of their lives, impact on their education, and the time and cost of travelling), rather than a focus on standardised processes and health outcomes. Young people describe a need for continued support from caregivers as they move into an adult healthcare setting. The transition away from the whole family unit managing a young person's IBD to the young person taking on this role independently is person-specific and unpredictable, and is frequently not fully completed within the transition process. Healthcare professionals should consider fully the young person's view of their self-efficacy skills in guiding developmentally appropriate decision making.

The strong relationships within the paediatric health care team, in particular the holistic approach of key professionals such as the IBD nurse specialists is an integral part of many young people's sense of trust and stability. The process of transition is disruptive to this key relationship which is often where an assessment of transition readiness, psychosocial screening and health risk behaviours takes place. Studies in IBD suggest that these more sensitive areas such as health risk behaviours are only discussed with 8% of young people prior to transfer to adult healthcare (52). Recent data has demonstrated that higher numbers of IBD nurse specialists in a service was strongly associated with patients having confidence in self-management and reporting high-quality care (55). The new relationships with healthcare professionals in an adult setting take time to build, but are crucial to successful transition with young people and caregivers (52). Previous studies have demonstrated that person-centred continuity of care is a key in reducing the 'not lost to follow-up' rate following transition (56,57). Despite the challenges experienced, young people in this study report a sense of personal growth and empowerment through healthcare transition, with acquisition of wider life-skills and an increasing personal responsibility for their IBD.

The findings of this study have important clinical and service implications for healthcare providers in IBD. The overarching finding of this study is the importance of flexibility in all aspects of the design and delivery of a developmentally appropriate approach to a structured transition programme for young people with IBD, which can build upon and enable their hopes for the future. Practical aspects in the delivery of such a flexible, personalised service include not only structured developmental assessments, but also the view of the individual regarding their own perception of readiness for adult healthcare and adulthood more generally. Robust processes around developmental assessment within a structured programme would promote a more individualised approach to transition, thereby increasing the flexibility around the timeline of transition and empowering young people for their transition to adult healthcare at a time that is right for them. Currently relatively rigid structures exist regarding the timing of transition and inter-organisation collaborative work is required to reduce these barriers. Tools to assess transition readiness are recommended by the American Academy of Paediatrics (53) and in the United Kingdom (22), with most assessing knowledge of disease through self-efficacy (58). However, uptake of developmental assessment is poor with only 23% of paediatric providers incorporating them in the transition process (59).

Secondly, empowerment of young people through generic and disease specific transition information and education programmes would be helpful to young people. IBD specific-education programmes to improve self-management and self-efficacy would help prepare young people for successful transition, but require an individualised approach (60). Thirdly, the young people in this study have described the need to minimise the impact of healthcare on their lives and that of their care-givers, therefore healthcare delivery should focus on meeting the concerns and specific developmental needs of the individual. This may require a bespoke approach to consultations for young people to improve accessibility, such as flexibility in timing, longer appointments, alternative locations and mode of appointments. Young people have been found to prefer e-mail rather than telephone communication between visits (61), and health care providers should be responsive to these newer ways of engaging with services whilst minimising impact on personal lives. Finally, it is clear from this study that the style of communication and the developing relationships with adult healthcare professional team is vital to empowerment and independence for the individual transitioning. Providing continuity of care is vital in the post-transition period and should be complemented by ongoing developmental assessment and responsive to individual biopsychosocial needs. This study highlights the importance of the IBD nurse specialist in both the pre and post-transition period in delivering holistic care. Their role is vital in supporting young people in transitioning away from the family focussed delivery of healthcare, to that of the autonomous individual. Consideration should be given by healthcare providers regarding how continuity of care from the IBD specialist nurse and other members of the IBD team can be safeguarded and consolidated in the post-transfer period of young people with IBD.

This study raises important research questions in a hugely under investigated area. Key components of structured transition programmes have been defined in chronic health conditions (35), with this work adding to the literature in IBD specifically. A methodological approach to testing interventions within a structured transition programme would strengthen the evidence base significantly. Young people in this study were keen for communication methods other than face-to-face consultations with healthcare professionals, and research to investigate whether digital platforms enhance experiences and outcomes related to transition are important for future innovation. However, health inequalities may limit the accessibility and impact of these interventions. Health literacy defined as "the degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions" (62) may be an important aspect of transition outcomes. Further research is required to determine whether disease specific educational programmes can improve self-management and self-efficacy taking into account health literacy of young people and their parents/carers. Previously our research group has shown that those who had undergone transition from children's to adult healthcare compared to those who had not yet transferred did not have increased psychological morbidity (63). Future studies should investigate the relationship of transition experiences and psychological morbidity including well-being, education and employment opportunities both where formal transition arrangements exist and where they do not. Finally, in the United Kingdom the NHS Long-term plan aims to improve integration across public health, healthcare, education and social care (64). Research is needed to understand the potential benefits, risks and views of young people and their families of integrated care including the role of the generalist within specialist complex conditions such as IBD.

A limitation of this study is that it was conducted within a single university centre. However, it was strengthened by including participants who made the transition to a range of different adult healthcare centres regionally. Future qualitative studies may be enhanced by design of linked transition interviews with the same participant's pre- and post- transfer. This sample was predominantly Caucasian, therefore the role ethnicity and cultural context may play in transition experiences remains uncertain (65). Finally, this study did not include experiences of young people with additional needs and IBD such as visual or hearing impairment.

5.6 CONCLUSION

The findings of this study provides key new insights and understanding into the lived experience of young people with IBD transitioning from children's to adult healthcare services. This new evidence contributes to the existing evidence base to inform improvements in services. Young people desire an individualised, developmentally appropriate and flexible approach from healthcare providers in a structured transition programme to enable empowerment, independence and a sense fitting in to adult healthcare to develop. The delivery of developmentally appropriate healthcare during and post-transfer to adult healthcare through flexible and accessible services is critical to this. Further work is needed in young people specifically to understand the additional benefits of interventions such as virtual communication tools and education programmes to improve self-efficacy.

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TABLES & SUPPLEMENTARY TABLES

TABLE 1. Demographics of participants in structured transition programme (n=19)

Study ID (Pseudonym)	Sex	Age (years)	Ethnicity	IBD type	Pre or post transfer to adult centre	Transfer to linked adult centre
Kitty	Female	16	White	CD	Pre transfer	No
Lizzy	Female	16	White	UC	Pre transfer	Yes
Cristina	Female	16	White	CD	Pre transfer	Yes
Beth	Female	16	White	CD	Pre transfer	Yes
Anneka	Female	16	White	UC	Pre transfer	No
Callum	Male	16	White	UC	Pre transfer	No
Sam	Male	16	White	CD	Pre transfer	No
David	Male	16	White	CD	Pre transfer	Yes
Anthony	Male	16	White	CD	Pre transfer	No
Isla	Female	16	White	UC	Post transfer	No
Max	Male	17	White	CD	Pre transfer	Yes
Sally	Female	17	White	CD	Post transfer	Yes
Kate	Female	17	White	CD	Post transfer	Yes
Adele	Female	17	White	CD	Post transfer	No
James	Male	17	White	CD	Post transfer	No
Sunita	Female	18	Asian British	CD	Post transfer	Yes
Jessie	Male	18	White	UC	Post transfer	Yes
Milo	Male	18	White	CD	Post transfer	Yes
William	Male	18	White	CD	Post transfer	Yes

CD, Crohn's disease; UC, ulcerative colitis

TABLE 2. Main and sub-themes of structured transition to adult healthcare centre (n=19)

Main themes	Sub-themes
1. Excited for change, but living in the present	i. “Daunting, but nothing I couldn’t handle” ii. Belonging iii. Hopeful about future in adult healthcare
2. Stuck in the middle	i. “Up the road is fine” ii. Variable sense of control iii. Inevitability of transition
3. My turn	i. “I’m growing up, very fast” ii. Fear of isolation iii. Conscious dependency on parents/carers iv. Under the spotlight
4. Starting over again	i. Empowered through transition ii. Same yet different iii. “I’ve fitted in here now”

Supplementary Table 1: Interview Schedule

Main Questions	Sub Questions	Possible Prompts
Can you tell me a little bit about your first experiences of IBD?	What did you or your family first notice?	Symptoms experiences
	Would you mind telling me a bit about your experience of being diagnosed with IBD?	
	How did you feel about being diagnosed with IBD?	What it meant? Any expectations or worries?
	Have you told anyone about having IBD?	
	Could you tell me about the reaction of people around you /what other people thought to you being diagnosed with IBD?	Friends Partners Family
	How would you describe your experience of getting to know and understand IBD, your treatment, your doctor, the health professionals and the system they work in?	
Could you tell me more about moving from being looked after by a children's hospital for your IBD to an adult hospital, I wonder if you could tell me a little bit about how that has been for you?	How did you feel about the transfer?	
	What have you noticed that is the same or different across the hospitals/teams?	

	How have you felt about the timing?	
	How have you felt about decisions that have been made with regards to transition?	
	How, if at all, has moving hospitals made a difference to you or your life?	
	Have your experiences made a difference to how you feel about yourself, or you're IBD?	
Could you tell me about the relationships with staff at both hospitals?	How do you feel about the relationships you have had with staff at the Children's hospital?	Doctors, nurses, other
	How, do your relationships with staff in the adult hospital feel the same or different to those at the Children's hospital? What do you think about this?	
	In what ways could your relationships with staff at either hospital be better?	
Could you tell me more about how decisions have been made about your IBD before, during and after transition?	Can you tell me about who makes decisions about your IBD now? How do you feel about this?	
	Has who makes the decisions about your IBD changed over the course of transition?	
	How have you felt about getting more involved with managing your IBD?	Self-medicating Booking appointments Speaking to specialist nurse
You have told me about […summarise transition experiences…] could you now tell me about your ways of coping with transition?	What ways, if any, have you found to cope with your experiences of transition?	

	Has anybody supported you through transition?	Friends Family
	Have you had any support from face to face or social medial support networks directly related to IBD or other related conditions during your transition with IBD? How have you found this?	
	Is there anything else important about these issues that you would like to tell me?	

Supplementary Table 2:

Step-wise approach to analysis of transcripts for Interpretative Phenomenological Analysis

Steps	**Description**	**Researcher Team Member Involved in step**
1	Transcript checked for accuracy whilst listening to audio-recording.	AJB
2	Transcript read several times and simple descriptive comments made while reading and listening to the transcript in order to reveal content. Preliminary notes kept in the left margin.	AJB
3	Emerging codes and early themes recorded in the right margin.	AJB
4	Written content formatted into a table to facilitate annotation process.	AJB
5	Process repeated a second and third time to note linguistic (use of language, laughter and voice tone) and conceptual (questions and interpretations of the text) comments.	AJB
	Steps 1-5 repeated for all transcripts.	AJB
6	Themes considered at participant level, and later at group level.	
7	Various techniques employed to search for connections across themes including; abstraction (grouping similar themes), polarisation (focusing on differences between themes) and numeration (looking at frequencies of themes).	AJB
8	Themes organised by the researcher and following supervision meetings into clusters to identity preliminary main (superordinate) and sub-themes (subordinate) themes by grouping quotes and initial codes from tables produced in Step 4.	AJB & GR
9	Peer supervision with a colleague conducting IPA research undertaken with audit of one of the	AJB

	transcripts to ensure initial codes and subsequent themes and ideas grounded in the data and to ensure that the process of deriving the themes was evidenced.	
10	Key quotations illustrating a theme were noted throughout.	AJB
11	Participant quotes colour coded to allow assessment of how representative each theme was. Changes made to a theme checked against the original data to confirm a grounding of themes and their selection.	AJB & GR
12	Themes reviewed for clusters and transcripts reread to confirm or dispute themes and overall robustness of the final representation.	AJB
13	Independent verification of emergent themes.	GR
14	A final list of main (superordinate) themes and their respective subordinate theme was produced.	AJB
15	Reflexivity was supported through a reflexive diary to record the researcher’s reflection, ideas and observations.	AJB

CHAPTER 6. General Discussion

This discussion chapter provides a summary of how each paper addressed and fulfilled the aims of the research, and adds to new knowledge within the field. The research findings are then considered in the context of future research and clinical implications.

6.1 Background summary

Young people living with Inflammatory Bowel Disease (IBD) face significant challenges in adolescence, with greater risk of poor psychological well-being (depression, anxiety and quality of life) compared to those without IBD. IBD has the potential to have adverse outcomes on relationships, educational and employment opportunities for young people. It is also during adolescence that young people transition from children's services into adult IBD healthcare services. This has important implications for chronic disease management throughout adulthood. In particular for IBD, this is an important area for research as the prevalence is rising worldwide, with an associated increase in complexity of both disease and treatments with important economic implications. Healthcare costs over a lifetime in IBD are similar to that of major diseases such as heart disease and cancer.

However, young person specific research in IBD is extremely limited in general with a significant gap in knowledge regarding understanding of the impact of IBD on identity and transition experiences of young people. Whilst there is some data on the prevalence of psychological morbidity from paediatric research, this is limited to cross-sectional studies. Research regarding the risk factors for the development of psychological morbidity is sparse.

Given the potential for poor health outcomes related to psychological morbidity, the research conducted for this thesis has aimed to further understanding into psychological well-being and experiences of young people living with IBD, and the impact of transition from paediatric to adult healthcare systems.

6.2 Overview of thesis findings

The overarching aim was met through four studies to address the gap in knowledge regarding the experiences and psychological well-being of young people aged 16-21 years living with IBD. Papers 1 and 2 examined psychological morbidity in young people with IBD and the relationship with illness perceptions and identification of risk factors for psychological morbidity. Paper 3 provided rich, in-depth insights into the lived experiences of young people with IBD. Paper 4 provided more specific focus of their experiences of transitioning to adult services.

The research specifically sought to: (i) identify the risk factors and manifestations of psychological morbidity in young people with IBD within the existing literature base, (ii) investigate the illness perceptions of young people with IBD over time and factors that predict psychological distress through a longitudinal observational study, (iii) understand experiences and challenges of young people growing up with IBD in late adolescence, and (iv) specifically during the time of transition from child to adult services. An overarching summary of these studies is provided in the next section of this chapter.

Paper 1: Systematic Review: Psychological Morbidity in Young People with Inflammatory Bowel Disease - Risk Factors and Impacts (1)

Paper 1 was a systematic review of the scientific literature concerning the impact of psychological morbidity in young people with IBD and associated risk factors. Data synthesis showed that the manifestations of psychological morbidity in young people with IBD included sleep dysfunction, increased use of psychotropic drugs, non-adherence to medication, abdominal pain and negative illness perceptions. Risk factors for psychological morbidity in young people with IBD consisted of two main groups; (i) IBD related factors, which were increased disease severity, use of corticosteroids and older age at diagnosis, noting the heterogeneous methods of disease severity assessment and (ii) non-IBD related risk factors, which included lower socioeconomic status and family/parental factors.

An important recommendation from Paper 1 was for future research to include longitudinal studies in young people with psychological morbidity. This paper also supports guidelines suggesting routine psychological screening in IBD, but suggests a focus on risk stratification and interventions to reduce the impact of psychological morbidity in young people.

Paper 2: Prospective Study of Psychological Morbidity and Illness Perceptions in Young People with Inflammatory Bowel Disease (2)

The aim of the research for Paper 2 was to address research recommendations in Paper 1. This was therefore a longitudinal study of psychological morbidity in young people. The first aim of this study was to determine the prevalence and severity of psychological morbidity in young people aged 16 - 21 years with IBD. The prevalence of anxiety and depressive symptoms in young people with IBD aged 16 - 21 years was higher than previously described, with low Health Related Quality of Life (HRQoL). There was no change in these symptoms at follow-up at 12 months, and in a sub-group this remained stable over the transition period to adult healthcare.

The second aim was to investigate the relationship between risk factors and illness perceptions with psychological morbidity over a 12 month period. The risk factors for psychological morbidity were found to be clinical relapse (defined by physician's global assessment) and female gender. Illness perceptions (comprising of eight key domains) played an important role, with nearly all domains associated significantly with psychological morbidity, demonstrated here for the first time in young people with IBD. The most important domain within illness perceptions was found to be emotional representations (the perception of the emotional impact of IBD), with a greater perceived impact being associated with increased psychological morbidity. Illness perceptions were impacted by IBD disease activity.

Paper 3: The Lived Experience of Young People with Inflammatory Bowel Disease: Understanding Issues of Identity, Isolation, Life Goals and Resilience

The aim of this study was to understand the lived experience and impact of IBD in late adolescence. The findings of the longitudinal study described in Paper 2 illustrated the breadth of psychological distress in young people with IBD, however the mean scores of screening tools for symptoms of anxiety, depression and HRQoL did not allow for an understanding of individualised experiences. The study carried out for Paper 3 provided novel insights into the experiences of young people with IBD based on symptoms, healthcare experiences and personal factors. Young people described profoundly embarrassing symptoms leading to secrecy, denial, stigma and a fear of judgement. Delays in diagnosis were common and multifactorial. Once made, diagnosis was often experienced as overwhelming, with uncertainty about future identity being a strong theme. Isolation was a key feature with highly personal and individual experiences of IBD, with both invisible and visible aspects of IBD contributing to isolation. Young people felt misunderstood and perceived a lack of compassion from others. This study found that young people sought control over aspects of their identity with IBD, which led to a reset of aspirations and goals.

Finally, an important finding of this study was resilience whereby some young people were able to positively reframe the adversity experienced with IBD, through support from close relationships with family and peers. This resulted in a positive outlook, with self-compassion and increased determination for the future. The findings of this study provide evidence to support the importance of an individualised and compassionate approach to developmentally appropriate healthcare services for young people. Delivering care underpinned by such principles may improve experiences of healthcare and contribute to improved self-efficacy and resilience.

Paper 4: Structured Transition from Child To Adult Services: Characterising Experiences of Young People with Inflammatory Bowel Disease

This research aimed to improve the understanding of the lived experiences of young people with IBD transitioning from child to adult services, within a structured transition programme. The structured transition programme included key components described in national guidelines for transition in IBD (3). Importantly, the aim of this study was to investigate the experiences of a transition programme, rather than to evaluate this specific transition programme.

The main findings of this study were that young people expressed hopefulness regarding transfer to an adult healthcare setting. However, transition was also daunting, and the strong relationships formed with the paediatric healthcare team were difficult to leave. Young people described a sense of a lack of control regarding the specifics of transition, often considering the practical needs of their parents/carers as they made choices about their care. There is an ongoing dependency on caregivers during transition and after transfer that is important to young people. Participants described varied perceptions of personal control, with a sense of indifference, being stuck in the middle of healthcare professionals and complex healthcare systems, whilst also in stuck in between childhood and adulthood. Despite this, young people in this study felt a sense of empowerment, with a developing independence throughout the process of transition, set against the perception of having to enter adulthood earlier than their peers.

The key findings of this study illustrated the importance of an individualised approach to healthcare transition for young people with IBD. Offering a process that is flexible, individualised and developmentally appropriate promotes empowerment, independence and may have a positive impact on psychological well-being.

6.3 Strengths

The overarching strength of this body of research is the focus on young people living with IBD and the unique focus on their psychological well-being and experiences of living with IBD. The inter-related set of qualitative and quantitative methods used in this thesis of young people with IBD under the care of child services, adult services and across the transition between these services brings new insights to this under researched area. The use of these methods provides a richer understanding of young people's experiences of living with IBD and the transition from child to adult services, in addition to important triangulation of findings from the quantitative studies which adds to the overall validity of the findings (4).

Paper 1 was the first published systematic review specifically examining the impacts and risk factors for psychological morbidity in young people with IBD (1). The review has provided future investigators in this field with an overview of key areas for further research due to the synthesis of available data in the area. Since publication it has been cited 83 times, including in national guidelines (3). The longitudinal research methods described in Paper 2, designed to assess psychological morbidity and relationship with illness perceptions and other clinical variables in young people aged 16-21 years over a 12 month period, is novel (2) and has been cited 19 times since publication. This study demonstrated for the first time that emotional representations were an independent predictor of all measures of psychological morbidity in young people. The detailed assessment of clinical variables in this study is a key strength, with the identification of impact of disease activity on illness perceptions and corticosteroid use associated with higher depression scores. The high retention (83%) of young people at the follow-up interval at 12 months is also a strength of this study. Further work is required to understand this high retention rate for future studies. This may relate to the motivation of young people with IBD to be involved in research, or the positive engagement of the research and clinical teams involved in this study with the cohort of young people.

The qualitative studies of young people's experiences of living with IBD and of transition to adult healthcare provide new insights into the multi-factorial challenges that young people with IBD face. Interpretative phenomenological analysis (IPA) focuses on how individuals "perceive and make sense of their lived experiences of illness" (5), with qualitative research recognised as the appropriate method through which to gain rich, in-depth insights into experience that cannot be gained using quantitative methods (6). This rich data and the identified themes are important considerations as healthcare providers develop young-person friendly services. To date, Papers 3 & 4 represent the first qualitative studies using IPA methodology in IBD patients in late adolescence specifically. This adds new insights into the existing evidence base which consists of only a handful of IPA based studies in adults (7–9).

In IPA, the researcher's background and own experiences are an active component in the analysis, influencing the interpretation of the participants' accounts and the derivation of themes (10). A continuous process of reflection and discussion with the research team is a key part of the analysis which I undertook in the design, conduct and analysis. My role as both an IBD Clinical Research Fellow and investigator within these studies may be both a weakness and a strength. I am likely to have pre-existing beliefs about the challenges young people face in general whilst living with IBD, and may have had compassion in specific aspects due to the experiences I have had as a clinician. My pre-existing knowledge and position within the department may have subtly affected the views expressed by participants during the interviews and it may be that my role facilitated the participants to feel at ease and elicited a richness of data. I am unable to fully evaluate the impact of my role as both an IBD physician and researcher from the patient's perspective. However, I believe the outcome of the research studies is unlikely to have differed significantly with a non-clinical investigator.

6.4 Limitations

The findings of the papers should be considered in context of the limitations. Firstly, all four papers aimed to consider age categorically, in line with World Health Organisation recommendations on the age categories of adolescence (11) and the basis that adolescence can be seen as a distinct, developmental period (12). However, developmental changes are unlikely to occur in a discrete manner and therefore consideration could have been given to the developmental stages of the young people included in the original research studies (Papers 2-4). The use of assessments of pubertal development and/or assessment of self-efficacy or transition readiness may have been helpful. The role of inflammation and its relationship with psychological morbidity is vital to this field given the research in both animal models (13,14) and emerging data in longitudinal observational studies (15–17) . In Paper 2 the evaluation of disease activity could have been strengthened by more objective measures of disease activity.

Further insights regarding the impact of IBD on psychological morbidity prevalence might have been strengthened by a control group in Paper 2. Including an age-matched control group of young people without a chronic disease would have provided a valuable comparison regarding the rates of anxiety and depressive symptoms with our without IBD. A control group in this study would not have strengthened the study with regards to illness perceptions, where this is specific to individuals with a health condition. Paper 2 used validated self-report questionnaires to assess psychological morbidity (anxiety/depression) (2), but this could be strengthened by formal diagnostic evaluation in line with diagnostic schedules (18). Comparisons with other studies regarding prevalence and severity of symptoms related to anxiety and depression is challenging given the wide variation in the assessment methods used to measure and define psychological morbidity and in assessing inflammatory bowel disease severity.

Participants in all the studies were from a predominantly White British ethnic background, (87% Caucasian in Paper 2). This is likely to underrepresent other ethnicities with recent estimates suggesting 35% of IBD is in those from non-Caucasian backgrounds (19) . Therefore the results may not be generalizable to young people with IBD from more diverse ethnic backgrounds. This is an important consideration given the increase incidence of IBD in racial and ethnic minorities worldwide (20), and the disparity in access to healthcare described (21). In adults with IBD from a South Asian origin, a recent qualitative study has illustrated the additional challenges individuals face in living with IBD in particular related to increased stigma, use of alternative therapies and challenges of frequent need to travel (22). Studies in other chronic health conditions such as diabetes have demonstrated that cultural differences and a lack of support from social networks and family members were important barriers to interventions related to a healthy diet (23). In addition consideration of socio-economic status would strengthen the results of the original work in Papers 2-4, given the findings of Paper 1 demonstrating lower socio-economic status as a risk factor for psychological morbidity in young people with IBD (1).

Finally, this body of work would have been strengthened overall by the development of an expert patient panel to ensure the voices of young people were heard throughout the research planning stages and delivery of the project. This was not undertaken beyond the period of the grant funding due to financial constraints for this research programme. However, during the funded time of the research (24 months), a steering group was assembled and met twice yearly to shape the research programme. This included the immediate research team, IBD specialist nurses and medical transition leads from adult and paediatric teams. Importantly, two expert service users aged 16-21 years with experience of both child and adult healthcare with IBD were members of this steering group, alongside a senior member of the national charity funding this programme of research.

6.5 Implications for future research

i. Proposed focus on adolescent focussed research in IBD

To date, adolescence has not been taken into consideration from a physical, biological and experiential perspective within IBD research design. This represents a substantial gap in the existing evidence base to inform service design in IBD care for young people. The lack of attention to this developmental age category within global health, social policy and research worldwide is well described, with clear opportunities for addressing these to reduce inequalities for adolescence and improve health into adulthood (24).

The age of participants included in the searches for the systematic review (Paper 1) needed to be extended from a minimum age of 16 years to a lower limit of 10 years of age. This was because there was no identifiable IBD specific research in the field of psychological morbidity in late adolescence (1). The studies included in the systematic review recruited from predominantly paediatric populations, with a mean age of 14.7 years (range 8-18 years) (1). As a result of the findings in Paper 1 we recommend that there should be a focus on research specifically in young people up to the age of 24 years in line with WHO recommendations (11).

There are a number of barriers to clinical research related to service configuration between paediatric and adult healthcare services. These include funding, governance procedures, site specific approval processes in addition to the need to involve patients and families from both paediatric and adult healthcare (25). In order to address the gap in research with young people in adolescence these barriers must be addressed. In this research programme we addressed one of the barriers by developing a research steering group which included clinicians and academics from both paediatric and adult backgrounds. This complemented the well-established strong integration of clinical teams through the joint delivery of a longstanding structured transition programme. We recommended attention at a national level for a research strategy to enable integration to develop and enhance recruitment in adolescent research. This is in keeping with recommendations for the NHS plan for 0 - 25 years (26).

Future studies in this field should be powered sufficiently to allow for sub-analysis of early, middle and late adolescence with consideration given to pubertal status and developmental assessment depending on the nature of the study. Studies in this thesis focussed on late adolescence in particular, due to the paucity of research in this field due to frequent age based exclusion from both paediatric and adult IBD studies. In Paper 3 the experiences of young people at diagnosis were central to how they made sense of their IBD. Investigating how developmental stage and/or age affects identity, self-efficacy and resilience will be crucial in developing IBD services to provide developmentally appropriate IBD focused care and education. Multicentre trials to enhance recruitment and meet minimum sample sizes are likely to be required.

ii. Standardising measurement of psychological morbidity and disease activity endpoints in future IBD research

The results of the systematic review (Paper 1) demonstrated heterogeneity in study design in the assessment of psychological morbidity and the poor quality of existing literature in IBD variables in particular assessment of disease severity (1). Future studies might consider design of trials in young people that more objectively confirm IBD disease activity despite the challenges this poses. A more accurate assessment of clinical disease activity either through end points of endoscopic or histological remission might further understanding of the impact of deep remission on psychological well-being (27) and healthcare utilisation. However, such an approach could lead to limitations in recruitment particular from harder to reach groups. One strategy to study these end points might be to consider routine assessment of psychological morbidity in drug trials, whilst ensuring specific recruitment for adolescents in trial designs. Co-designing acceptable end points with young people could address such issues and provide input into future trial design.

In the assessment of psychological well-being we identified significant variation in the self-report validated tools used for assessment, with variation according to whether studies are conducted in paediatric or adult healthcare. In the research conducted for Paper 2 the validated tool was the Hospital Anxiety and Depression scale (28) due to its predominate use in hospital settings where the research was conducted. However, in primary care and psychological services other validated self-report tools are used routinely (29,30). In summary, psychological adolescent research is an emerging field in IBD and consideration should be given to a core-set of end points in order to address heterogeneity (31). The use of agreed uniform screening tools, with comparable cut offs, could facilitate this, and there would be potential for this approach to be applied across clinical disciplines beyond IBD to assess psychological morbidity (32). Robust patient and public involvement would be important in defining these end points in terms of patient acceptability.

iii. Understanding the experiences and prevalence of wider psychological morbidity in young people with IBD

The systematic review (Paper 1) demonstrated that nearly all literature in this field examines depression and anxiety symptoms, resulting in a gap in the literature with regards to other psychological morbidity or co-existing conditions in keeping with current diagnostic schedules (33) . As a result of findings from this thesis we propose that further research is needed to establish the impact and prevalence of other psychological morbidity in young people with IBD, such as post-traumatic stress disorder (PTSD) (34). PTSD has been recently examined in a qualitative study in patients with medical trauma related to IBD (including medical procedures, surgery and disease uncertainty), highlighting the importance of trust and communication with the healthcare team and possible risk factors (35). This is a key area for further research in young people with IBD.

The findings of the research conducted for Paper 3 illustrated the restrictions that IBD causes young people to experience when living with IBD, particularly related to eating and food (key aspects of social interactions). This is another under researched area. A recent systematic review suggests a possible association between IBD and eating disorders, demonstrating that most are female and young (aged 10-44 years) (36). A further limitation of the research in this thesis is that it did not consider the impact of neurodiversity in the context of young people's experiences or in prevalence and risk factors for psychological morbidity. It is estimated that approximately 5% of children have a diagnosis of autism spectrum disorder (ASD) and Attention Deficit Hyperactivity Disorder (ADHD) respectively in the United Kingdom. High levels of psychological morbidity are described in association with both ASD and ADHD (37,38) alongside premature mortality and increase annual health expenditure (39). Social communication difficulties might affect how children and young people present and manage chronic health conditions such as IBD and contribute to delays in diagnosis. We recommend a focus of research in this group specifically to tailor and develop IBD services to meet individual needs.

iv. Designing psychological interventions centred on illness perceptions

The longitudinal research conducted for Paper 2 has for the first time described the relationship between illness perceptions and psychological morbidity in a cohort of young people with IBD (2). The relationship between psychological well-being and IBD has previously been demonstrated in adult studies, where induction of remission is associated with an improvement in psychological well-being (40), and antidepressants appear to have a beneficial effect on IBD disease course (41,42). This suggests that improving psychological morbidity should be an important focus for future IBD research. Recent psychological intervention studies (43) are a step in the right direction and show promising results. However, data to support the use of psychological interventions in IBD in general is limited, with the strongest evidence in adolescents all be it in only two eligible studies (44).

The findings of this research suggest that illness perceptions may provide the basis for future targeted psychological interventions for young people with IBD in order to improve adjustment to living with IBD. In other chronic diseases such as ischaemic heart disease (45) and diabetes (46), there is evidence to demonstrate that illness perceptions are modifiable through psychological interventions. There is an urgent need for preliminary trials to evaluate the effectiveness of psychological interventions in young people with IBD, and results of this thesis suggest particular attention should be given to illness perception based interventions. Future drug trials could consider the use of comparative arms with and without a psychological intervention focussed on illness perceptions to determine how such interventions might impact on therapeutic responses and long term outcomes (47).

v. Designing prospective longitudinal research in young people with IBD and psychological morbidity

Longitudinal observational studies are required to develop the understanding of psychological morbidity in young people. Consideration should be given to designing studies that evaluate this from diagnosis and study children and young people into early adulthood. Current technology with the use of virtual research platforms could enable recruitment and retention. Further studies are required with longer follow-up periods and multicentre collaborations to increase sample sizes and allow for additional analysis of IBD related and non-IBD related factors to determine causality to psychological morbidity. Epidemiological studies designed to understand how various other psychological factors such as resilience, gratitude and parenting stress might help predict the development of psychological morbidity would be of value (28). Attention is required to assess the potential importance of IBD related factors such as disease duration, type, treatments and disease phenotype which may affect risk stratification and intervention targets in psychological morbidity (48).

vi. Designing research to improve the understanding of the impact of psychological morbidity in young people with IBD

Papers 1 and 3 have demonstrated the far reaching impacts of psychological morbidity on young people with IBD. In Paper 1 there was insufficient data to determine the relationship between psychological morbidity and health care utilization. In recent research in adults with IBD, those with higher rates of depression and anxiety over a 12 month follow-up period had significantly greater use of healthcare utilization including more outpatient appointments and investigations (16). Similar results in appropriately designed studies of adolescents with IBD would help inform cost-benefit analyses to inform appropriate commissioning of integrated psychological services.

Paper 3 has demonstrated clearly the nature in which young people with IBD feel their life is reset, with a change in expectations for their future goals. IBD has been demonstrated to affect employment in terms of reduced work productivity (49), but little is known as to whether experiences of living with IBD lead to temporary or permanent alteration in life goals. There is therefore a need for further research to enhance understanding into the wider impact of psychological morbidity, and potential limitations on a young person’s life, as a result of living with IBD.

vii. Research into factors promoting resilience and self-efficacy

One of the key findings of the research (Paper 3) was that in many young people, the adversity related to IBD led to the development of resilience. Furthermore, openness in close relationships led to acceptance and self-compassion. Research into the process of transition (Paper 4) showed how individualised care can lead to a sense of empowerment and increase independence (self-efficacy) of young people with IBD.

Little is known about any positive impact of living with IBD in young people. Existential well-has previously been described in one study (50). A more recent qualitative study of young people with IBD identified key components of post-traumatic growth (51) which included spiritual change, support, cognitive re-shaping (learning to identify and dispute irrational or maladaptive thoughts), externalised behaviours (emotion dysregulation problems and impulsivity) and future orientated thinking (52). In adult IBD research, the concept of post-traumatic growth has been investigated in one study, with a positive association demonstrated with increased acceptance (53).

Resilience allows acceptance, adaptation and young people to flourish despite adversity, and is described as a modifiable characteristic (71). Research in adults with IBD has demonstrated that increased resilience promotes both physical activity and increases HRQoL (54). In young people, resilience in combination with self-efficacy have been shown to be useful predictors of readiness for transition to adult services (55). In contrast, low resilience as measured by validated scores such as the Connor-Davidson Resilience Scale (56) is a predictor of poor adjustment and disease management (57), anxiety (58) and is associated with increased surgery, disease activity and low HRQoL in (59). This research to date demonstrates the importance of further research to understand how to develop and promote resilience in young people with IBD.

Promoting resilience is an example of proactive IBD care (60), and recent early studies have shown promising results to suggest it is modifiable in IBD cohorts. Pilot data with a behavioural intervention in patients with Crohn's disease in remission without a previous psychological morbidity (anxiety, depression, substance misuse) has shown to increase resilience and HRQoL when compared to treatment as usual (61). In a larger trial of a resilience intervention programme developed specifically for IBD patients (GRITT), a reduction in steroid and opiate use and decreased hospitalisations was observed over a 12 month follow-up period (62). Similar studies are urgently needed in this area of positive psychological and behavioural intervention in adolescence where it may have the greatest impact, but should also be studied in adults with IBD.

6.6 Clinical Implications

Findings of Paper 1, 2, and 3 support existing literature in paediatrics and adult IBD studies that the burden of psychological morbidity is high in young people. These findings support the evidence base from adult studies, notably a recent large population registry in Sweden where suicide attempts were more common in IBD compared to the general population, as was new psychiatric morbidity within the first year of diagnosis or amongst people affected by extra-intestinal manifestations of IBD (63). Findings of the research outlined in Paper 3 of this thesis illustrate clearly the profound experiences of isolation, withdrawal and a reset of life expectations in young people with IBD. Young people in Paper 3 described how the period of adjustment is most significant following a diagnosis of IBD. Depression and anxiety may be the manifestation of some of the early feelings associated with developing a chronic condition, but further work in needed in this area to help determine when interventions would be most useful.

Paper 2 has demonstrated that how a young person thinks and feels about their illness (illness perceptions) are likely to be important in the development of psychological morbidity. Paper 1 has illustrated how abdominal pain perception is associated with psychological morbidity in IBD. A recent longitudinal study in adult IBD patients demonstrates the bi-directional nature of the gut-brain axis, with those in remission but with high anxiety scores associated with later need for steroids or flare of IBD activity (17). This supports the recommendations in Paper 3 of an individualised approach to IBD care with interventions to improve resilience and increase access to social support. Whilst this may be provided in the form of behavioural or psychological interventions, some of this care can be incorporated into existing systems of IBD care (64) and in line with the findings in Paper 3 and 4 may be of most importance at diagnosis and at times of healthcare transition. The following sections describe clinical recommendations based on the findings of this thesis and the wider context described above.

i. Implementation of screening for psychological morbidity in standard IBD Care

The results from Papers 1, 2 and 3 support current international guidelines in paediatric (65,66) and adult patients (67–69) to be screened for psychological morbidity as part of standard IBD care. Findings from this research suggest that this is of particular importance in adolescence, yet this is not currently incorporated into standard practice in community or hospital based healthcare in the United Kingdom (70). Studies in adults with IBD have shown that psychological screening is well accepted by patients, and can be used to risk stratify those most at need of psychological interventions (71). Similar findings have been demonstrated in a single study of 12 - 22 year olds with one of three chronic disease (including diabetes, IBD and cystic fibrosis), where the Patient Health Questionnaire (PHQ-9) (29) was used. This study demonstrated easy completion for patients without disruption to clinic flow for services (72). The findings of the research in Paper 4 suggest that young people transitioning to adult healthcare value the use of remote contact with their IBD care team. This requires further development by IBD care providers. In summary, health care providers must consider how best to standardise the use of psychological assessment tools into routine IBD care, and consider the use of technological interventions to aid this at low cost (73), and meet the preferences of young people.

ii. Recommendation for psychological services in an IBD integrated care model

Whilst incorporating screening tools into routine IBD services are recommended strongly, it is imperative to consider how best to deliver appropriate psychological services for young people with psychological morbidity. Findings from this body of work support the recommendations made in the IBD Standards where all children should have a defined access or a pathway for referral to a paediatric psychologist (74). Increasing the availability of commissioned psychological services which meet the needs of all young people with IBD, including those aged over 16 years and managed in adult services is vital to reduce the of impact of psychological morbidity in IBD into adulthood. In the United Kingdom provision of psychology services in adult healthcare is poor with only 2% of services with sufficient psychologists to meet the IBD National Standards (75).

The findings of this thesis support a key recommendation that training and support of the IBD healthcare team in basic psychological knowledge should be a core component of IBD care. Our findings suggest that integration of psychologists into IBD teams is vital not only as a key member of the IBD multi-disciplinary team, but importantly to improve the knowledge of the core IBD team of the uniquely inter-related biopsychosocial aspects of IBD (76). Clinical psychologists should play a vital role in teaching and providing of expert support for the immediate IBD healthcare team. By empowering staff with the knowledge to understand the manifestations of psychological distress, staff are more likely to be able to ensure that patients feel validated and more in control of their options. Patient activation (having the knowledge, skills, and confidence to effectively manage one's care) has in an adult cohort of IBD patients been associated with improved patient outcomes and clinical remission (77). This work could be supported by community based healthcare providers who have significant expertise in this area, but would require specialist input to bespoke the programmes. Furthermore commissioning of integrated services may facilitate the use of psychotropic drugs such as antidepressants directly by the IBD team, where strong relationships may increase acceptability to patients and improve adherence. This is of particular importance in young people with IBD who were twice as likely to discontinue antidepressants within 1 month compared to those aged 40-60 years (78).

A systematic review of IBD care standards from both a healthcare provider and patient perspective, endorsed an interdisciplinary coordinated structure, concluded that integrated care model was cost effective (71). In a study utilizing semi-structured interviews with IBD specialists, a consensus was reached that the ideal model involved “sharing collective expertise in a formalized manner” with interactions between subspecialty providers (such as gastroenterologist and psychologist) being of the highest importance (79). Another recent systematic review also concluded that an integrated care model incorporating a healthcare team that included a psychologist was the optimum model and reduces hospital admissions, IBD surgery, comorbidities, and both direct and indirect costs (80). Integrated care offers an ideal framework to meet patients biopsychosocial needs (81) with recent prospective trial of integrated psychological care for IBD demonstrating significant cost savings (82). Provision of integrated care models may reduce costs overall by reducing unplanned healthcare attendances (83).

However, integrated care beyond the multi-disciplinary IBD team is also important to consider. In the United Kingdom this integration is to be delivered by “Integrated Care Systems” with the goal of overcoming barriers in physical and mental healthcare services, local authorities, primary care and wider public health including education and housing recently formalised in the 2022 Health and Care Act. This is currently being evaluated as a national research programme in children and young people in the United Kingdom, with early findings reporting key challenges which need to be overcome before integration can succeed (84), including high-quality research and the importance of strong relationships between professional groups.

iii. Compassionate Care in Young People with IBD

The findings of Papers 3 and 4 illustrate the importance of components of compassionate healthcare care within both child and adult IBD services. An individualised approach to care is key. The presence of compassion in healthcare enables young people with IBD to make sense of their IBD diagnosis and their transition between healthcare systems. The qualitative studies in this thesis detail a number of areas where young people report valuing aspects of compassionate care including understanding, empathising, helping and attending (85).

Compassionate leadership in healthcare systems has been shown in numerous trials to improve health outcomes and positive clinical outcomes (86), including in a recently validated measure of compassionate leadership in end of life care (87). However, key barriers have been described in the delivery of compassionate care which include suboptimal training environments and a lack of time and resources (86). Ensuring IBD services are compassionate is vital, as current IBD care models result in individuals with IBD maintaining a lifelong relationship with their medical team. Findings from both Paper 3 and 4 demonstrate that when young people feel they have little control over the system they are currently in or transitioning to, this results in emotional distress.

iv. Delivering developmentally appropriate care in IBD care

The research findings outlined in Paper 4 demonstrated the importance of developmentally appropriate care in young people with IBD transitioning from paediatric to adult healthcare services. The importance of key components of this approach was also described in Paper 3 and 4, with both papers emphasise the importance to young people of a flexible and individualised approach to IBD healthcare, with young people valuing and feeling in control of their care and aspects of healthcare transition.

Developmentally appropriate healthcare focuses on the biopsychosocial development of the individual, recognising the changing needs of young people and the role of the healthcare team in addressing and supporting the individual and is a priority in national policy (26,88). The recommendations arising from Paper 4 are that IBD services within paediatric and adult healthcare teams should formally recognise developmental stage in context of service design, provision and training, and undertake regular developmental assessments (89). Findings from Paper 3 and 4 demonstrate that IBD services for young people require key components to ensure they are developmentally appropriate. These include increased accessibility to services to meet the young person's needs rather than that of the healthcare system. Flexible and longer appointment times help to ensure that young people can be seen with and without their parents and carers (90,91). Consistency in members of the IBD healthcare team promotes a person-centred therapeutic relationship. These consistent relationships must be maintained within the IBD healthcare team where possible, with particular importance at times of life and healthcare transitions. The IBD specialist nurses play an important role in this, where a trusting relationship allows psychosocial concerns to be addressed routinely.

Our results have demonstrated that a change in communication style from healthcare professionals to use person-centred, age appropriate language during transition can lead to empowerment and independence. Education programmes for the IBD healthcare teams is vital in ensuring a comprehensive approach to the delivery of developmentally appropriate healthcare. Finally, enabling delivery of developmentally appropriate healthcare within an integrated care model including primary care may improve access to timely assessment and reduce the delay to diagnosis of IBD in young people.

v. Early diagnosis to reduce psychological morbidity in young people with IBD

In Paper 3 young people described experiences leading to a delay in diagnosis of IBD which may contribute to emotional distress. Some of the delay relates to young people reporting a perception that symptoms were minimised or dismissed by healthcare professionals. Improving access to early testing through the use of faecal calprotectin, a highly specific and sensitive biomarker (92). The International Organization for Inflammatory Bowel Disease recently developed a tool to identify early Crohn's disease consisting of a questionnaire based tool with a 97% negative predictive value, which increased to 100% when used in combination with faecal calprotectin (>250ng/g) (93). Service providers and commissioners should consider the implementation of validated screening systems within an integrated care model with primary care for young people presenting with psychological symptoms alongside gastrointestinal symptoms. The development of such pathways is important to maintaining a trusting relationship with community healthcare providers. In the context of truly integrated healthcare models, protecting and strengthening the relationship patients with chronic disease have with community care providers is vital.

vi. Empowerment of young people with IBD

Paper 3 demonstrated the view of young people that time, specialist knowledge and support was needed to help make sense of a diagnosis of IBD. In Paper 4 young people transitioning through healthcare systems often felt passive and lacking in control over their healthcare. Taken together these results emphasize the importance of patient empowerment in IBD care of young people. Empowering people with IBD to have an active role in planning, development, delivery, and review of their healthcare services is likely to empower them to live well with their condition. Education programmes designed to promote empowerment and self-management skills to enable young people to make informed choices about their care are central to a successful integrated IBD care model. Disease specific education programmes in IBD have demonstrated improvements in IBD specific skills as measured by psycho-pedagogic scores in prospective evaluation over 12 months (94), suggesting that disease specific education may be important in promoting coping and compliance. Supported online self-management for symptoms such as pain, urgency and incontinence are currently under evaluation as part of the IBD-BOOST randomised controlled trail (95). If found to be effective such interventions alongside education programmes may offer healthcare providers alternative models to the current provision of care.

The NHS Long Term Plan sets out how patients will have more control over their health with shared decision making, personalised care and support planning, patient choice and patient activation (26). Personalised care recognises that people are experts in their own lives and chronic health conditions. Paper 3 and 4 have emphasized the importance of setting of goals for young people with IBD, regular review based on developmental stage. This is line with national recommendations for a personalised care plan in IBD (74). However, studies suggest that in IBD that there can be a disconnect between physician set goals and patient goals. A large European survey in 2010-2011 found that 53% of people with IBD were not able to tell their specialist something that was important to them (96). Qualitative research is vital to ensuring the experiences of young people with IBD bridge this gap. Such findings should be central to the development of education programmes for healthcare professionals and patients alongside tools to empower such as personalised care plans and digital health passports.

6.6 Conclusion

In conclusion this thesis has met the overarching aim of beginning to address the gap in knowledge regarding the experiences and psychological well-being of young people living with IBD. The systematic review demonstrated a lack of research in young people with IBD specifically, and a need for longitudinal research to investigate causality in psychological morbidity. We demonstrated wide ranging manifestations of psychological morbidity, alongside a number of IBD and non-IBD related risk factors for psychological morbidity. To address this gap in knowledge and study design, we undertook a prospective study of psychological morbidity and illness perceptions in young people aged 16 – 21 years. This demonstrated a high level of psychological distress in young people with IBD, with important relationships with illness perceptions and disease related factors described. The qualitative studies in this thesis have furthered the existing evidence base regarding the experiences and challenges of young people with IBD and specifically during the time of transition from child to adult services. Findings from these studies illustrate the highly individual experiences of young people, often resulting in isolation and revised life goals. Delivering individualized and developmentally appropriate care promotes empowerment, independence and resilience in young people with IBD.

The findings from this thesis address a substantial gap in knowledge in the well-being and experience of young people with IBD. Papers from this thesis have demonstrated new findings and have demonstrated wider impact through citations and incorporation into national and international guidelines. Importantly this body of work was undertaken prior to the COVID-19 pandemic, and it is unclear how this may have further affected the psychological well-being of young people with IBD.

Important recommendations for further research and clinical practice arise from the findings of this thesis. A future focus on adolescent research in IBD in general is required to advance this field. In context of psychological morbidity, we propose this be underpinned by a core-set of outcome measures to reduce heterogeneity and promote joint paediatric and adult research collaborations. Focus should be given to designing and testing psychological interventions based on illness perceptions and furthering knowledge regarding factors which promote resilience and self-efficacy. The clinical implications arising from this thesis support the recommended use of screening tools to identify psychological morbidity, but to focus their use initially in young people perhaps through the use of technology. Integration of clinical psychologists within IBD teams across paediatric and adult healthcare commissioning barriers is important within adolescent care in general, but vital in context of life and healthcare transitions. IBD teams need to be facilitated through time, education, psychological support, management structures and processes to deliver and maintain compassionate, individualised and developmentally appropriate care for young people with IBD. Delivery of developmentally appropriate healthcare with an individualised person-centred holistic approach is vital to improving the experiences and empowerment of young people living with IBD.

6.7 References

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APPENDICES

APPENDIX 1

Publications from Thesis

1. Brooks AJ, Norman P, Peach EJ, Ryder A4, Scott AJ, Narula P, Corfe BM, Lobo AJ, Rowse G. Prospective Study of Psychological Morbidity and Illness Perceptions in Young People with Inflammatory Bowel Disease. J Crohns Colitis 2019; 14;13(8):1003-1011. doi: 10.1093/ecco-jcc/jjz028. (cited 15)

2. Brooks AJ, Rowse G, Ryder A, Peach EJ, Corfe, BM, Lobo AJ. Systematic review: psychological morbidity in young people with inflammatory bowel disease – risk factors and impacts. Aliment Pharmcol Ther 2016; DOI: 10.1111/apt.13645. (cited 78)

Publications related but not directly from thesis

1. Johnson LE, Lee MJ, Turner-Moore T, Grinsted Tate LR, Brooks AJ, Tattersall RS, et al. Systematic Review of Factors Affecting Transition Readiness Skills in Patients with Inflammatory Bowel Disease. J Crohns Colitis. 2021;15(6):1049–59.

2. Hoogkamer AB, Brooks AJ, Rowse G, Lobo AJ. Predicting the development of psychological morbidity in inflammatory bowel disease: A systematic review. Frontline Gastroenterology. BMJ Publishing Group; 2020. p. 10.1136/flgastro-2019–101353.

3. Brooks AJ, Smith PJ, Cohen R, Collins P, Douds A, Forbes V, Gaya DR, Johnston BT, McKiernan PJ, Murray CD, Sebastian S, Smith M, Whitley L, Williams, Russell RK, McCartney SA, Lindsay JO. UK guideline on transition of adolescent and young

persons with chronic digestive diseases from paediatric to adult care. Gut 2017; pii: gutjnl-2016-313000. doi: 0.1136/gutjnl-2016-313000. (cited 72)

4. Brooks AJ, Smith PJ, Lindsay JO. Monitoring Adolescents and Young People with Inflammatory Bowel Disease during Transition to Adult Healthcare. Frontline Gastroenterology 2017; 0:1–8. doi:10.1136/flgastro-2016-100747. (cited 8)

Abstracts & Letters

1. Brooks AJ, Rowse R, Peach EJ, Ryder A, Narula P, Corfe BM, Norman P, Lobo AJ. Frequency of Health Risk Behaviours in Young People with Inflammatory Bowel Disease. Gut 2016.

2. Brooks AJ, Rowse G, Ryder A, Narula P, Corfe BM, Norman P, Lobo AJ. "I can cope right now, because I know where I have come from"; A Qualitative Exploration of the Lived Experience of Young Adults with Inflammatory Bowel Disease. Gut 2015; 64: A85-A86.

3. Brooks A, Tattersall R. Crohn's disease in adolescents and young adults: an important omission. BMJ 2014; doi: https://doi.org/10.1136/bmj.g6670.

APPENDIX 2

Ethical Approval

NRES Committee North East - Sunderland
Room 002
TEDCO Business Centre
Viking Business Park
Jarrow
Tyne & Wear
NE32 3DT
Telephone: 0191 4283563

30 January 2014

Dr Alenka Brooks
Clinical Research Fellow Gastroenterology
Sheffield Teaching Hospitals NHS Foundation Trust
Department of Gastroenterology, P39
Royal Hallamshire Hospital
Sheffield
S10 2JF

Dear Dr Brooks

Study title:	**Young People with Inflammatory Bowel Disease: their relationship with their disease, identity and illness perceptions**
REC reference:	**14/NE/0024**
Protocol number:	**R/136123-11-1**
IRAS project ID:	**141793**

Thank you for your email of 28 January 2014, responding to the Proportionate Review Sub-Committee's request for changes to the documentation for the above study.

The revised documentation has been reviewed and approved by the sub-committee.

We plan to publish your research summary wording for the above study on the NRES website, together with your contact details, unless you expressly withhold permission to do so. Publication will be no earlier than three months from the date of this favourable opinion letter. Should you wish to provide a substitute contact point, require further information, or wish to withhold permission to publish, please contact the REC Manager Mrs Helen M Wilson, nrescommittee.northeast-sunderland@nhs.net.

Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a **favourable ethical opinion** for the above research on the basis described in the application form, protocol and supporting documentation as revised.

Ethical review of research sites

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

Conditions of the favourable opinion

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

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

Management permission ("R&D approval") should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements.

Guidance on applying for NHS permission for research is available in the Integrated Research Application System or at http://www.rdforum.nhs.uk.

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

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

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

Registration of Clinical Trials

All clinical trials (defined as the first four categories on the IRAS filter page) must be registered on a publically accessible database within 6 weeks of recruitment of the first participant (for medical device studies, within the timeline determined by the current registration and publication trees).

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

To ensure transparency in research, we strongly recommend that all research is registered but for non clinical trials this is not currently mandatory.

If a sponsor wishes to contest the need for registration they should contact Catherine Blewett (catherineblewett@nhs.net), the HRA does not, however, expect exceptions to be made. Guidance on where to register is provided within IRAS.

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

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

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

You are invited to give your view of the service that you have received from the National Research Ethics Service and the application procedure. If you wish to make your views known please use the feedback form available on the website.

Further information is available at National Research Ethics Service website

14/NE/0024 Please quote this number on all correspondence

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

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

Mr Paddy Stevenson
Chair
Email: nrescommittee.northeast-sunderland@nhs.net
Copy to:
Dr Jim Lithgow, Sheffield Teaching Hospitals NHS Foundation Trust
Dr Dipak Patel, Sheffield Teaching Hospitals NHS Foundation Trust

NHS Governance

10 Feb 2014

Dr Alenka Brooks
Clinical Research Fellow Gastroenterology
Sheffield Teaching Hospitals NHS Foundation Trust
Department of Gastroenterology, P39
Royal Hallamshire Hospital
Sheffield
S10 2JF

Dear Dr Brooks,

Project Authorisation
NHS Permission for Research to Commence

STH ref:	STH18172	
NIHR CSP ref:	141793	
REC ref:	14/NE/0024	
MHRA ref	CTA No: NA	EudraCT No: NA
Study title:	Young People with Inflammatory Bowel Disease: their relationship with their disease, identity and illness	
Chief Investigator:	Dr Alenka Brooks, Sheffield Teaching Hospitals NHS FT	
Principal Investigator:	Dr Alan Lobo, Sheffield Teaching Hospitals NHS FT	
Sponsor:	Sheffield Teaching Hospitals NHS FT	
Funder:	Crohn's and Colitis UK	
NIHR TARGET FPFV RECRUITMENT DATE	17th April 2014	

APPENDIX 3

Qualitative Patient Invitation Letter

Department Of Psychology
Clinical Psychology Unit

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

Clinical Psychology Unit
Department of Psychology
University of Sheffield
Western Bank
Sheffield S10 2TN UK
Telephone: 0114 2226635
Fax: 0114 2226610

[Patient Name]

[Patient Address]

[Date]

Dear [Patient Name]

We are writing to you to invite you to consider taking part in a research study.

The research is funded by the charity Crohn's and Colitis UK and is titled ***Young People with Inflammatory Bowel Disease (IBD): their relationship with their disease, identity and illness perceptions*** and has been approved by the xxxx NHS REC Ethics Committee. The research is being jointly conducted by the University of Sheffield, Sheffield Children's Hospital NHS Foundation Trust and Sheffield Teaching Hospitals NHS Foundation Trust.

Taking part in the study would involve an interview to talk about their experience of living with Inflammatory Bowel Disease. We would also ask you to complete a number of well established questionnaires about your IBD. We enclosed a copy of the patient information sheet for you to read more about the study. If you do decide that you are interested in taking part in the study, you can discuss this in more detail with your doctor at your forthcoming clinical appointment.

If you require any further details ahead of your clinical appointment with your doctor regarding the project or your potential participation in the research please do not hesitate to get in contact with us.

Yours sincerely

[Signature & Name of Treating Consultant]

Research Team Contact Details:

Dr Alenka Brooks	**Dr Georgina Rowse**	**Prof Alan Lobo**	**Dr Priya Narula**
Department of Gastroenterology, P39 Royal Hallamshire Hospital Sheffield S10 2JF	*Senior Lecturer in Clinical Psychology* Clinical Psychology Unit Department of Psychology Western Bank University of Sheffield S10 2TN	*Professor of Gastroenterology* Department of Gastroenterology, P39 Royal Hallamshire Hospital Sheffield S10 2JF	*Consultant Paediatric Gastroenterologist* Sheffield Children's Hospital Western Bank Sheffield S10 2TH

Invitation Letter date of issue: 17.12.13
Invitation Letter version number: 1.0

Qualitative Patient Information Sheet

Department Of Psychology
Clinical Psychology Unit

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

Clinical Psychology Unit
Department of Psychology
University of Sheffield
Western Bank
Sheffield S10 2TN UK
Telephone: 0114 2226635
Fax: 0114 2226610

Participant Information Sheet Version 2.0

Project title: Young People **with Inflammatory Bowel Disease (IBD): their relationship with their disease, identity and illness perceptions**

Invitation to participate

You are being invited to take part in a research study. Before you decide whether or not to take part, it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully. Please contact the researcher if there is anything that is not clear or if you would like more information. Thank you for reading this information sheet.

What is the project's purpose?

We would like to better understand young people's experiences of living with IBD and experience of moving from child to adult medical care. We also wish to investigate the illness perceptions of young people living with IBD. Illness perceptions are the beliefs a person holds about the cause, identity, consequences, timeline and cure/controllability of the illness they live with. We aim to determine whether these perceptions change over time, for example during teenage years into adulthood and through the transition from child to adult medical care.

4. Why have I been chosen?

You have been invited to take part because you have IBD and are aged between 16-21 years.

5. Do I have to take part?

No. Taking part in this research is entirely voluntary and you can refuse to participate at any time. If you do decide to take part, you will be given this information sheet to keep, and you will be asked to sign a consent form. You can withdraw your consent at any time without it affecting your current or future treatment or access to services.

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

Taking part in this study will involve a meeting with the researcher (Dr Alenka Brooks) who will interview you for up to 60mins. One section will be tape recorded and transcribed for analysis. Your consent for the audio taping will be obtained separately. You may still take part in the study even if you decide you would prefer this not to happen.

You will also be given a series of questionnaires to complete (by Dr Alenka Brooks or the research associate). These questionnaires should take no more than 60 minutes in total to complete. You will then be contacted in around 12 month's time to complete the questionnaires once again. The repeat questionnaires a year later may be done electronically, at your next clinic appointment or at your home. The questionnaires have been used extensively in people of all ages with IBD or similar conditions.

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

We do not anticipate that taking part in this research will cause you any distress or discomfort. Your well being is very important to the researcher. In the unlikely event that you do feel upset by some aspect of the research please tell the researcher immediately. She will ask you whether you would like to continue and will ensure that you feel fine before you leave.

8. What are the possible benefits of taking part?

Whilst we do not anticipate any immediate benefits of participating in the project, we hope that this work will allow us to improve our understanding of the experiences of young people living with IBD. It is hoped that this understanding can inform how professionals work with patients like you in the future, and help inform the design of care for young people living with IBD and moving into adult services with the hope of improving long-term outcomes.

9. What if something goes wrong?

If you feel at all uncomfortable or upset during the completion of the questionnaires, please tell the researcher straight away. You are of course entitled to make a complaint if you feel that you have not been treated well by any of the researchers involved in this project. In the first instance, you should contact Dr Georgina Rowse (Project supervisor) at the University of Sheffield should you wish to raise a complaint. However, should you feel your complaint has not been handled to your satisfaction you can also contact the University's registrar on the following contact details: Philip Harvey (registrar@sheffield.ac.uk), Firth Court, Western Bank, Sheffield, S10 2TN. Tel: 0114 222 21101.

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

All the information that we collect from you during the course of the research will be kept strictly confidential and will not be accessible by anyone outside of the research team. You will not be able to be identified in any reports or publications. All of your questionnaire responses will be completely anonymous (i.e. no names will be recorded). The consent forms with your name on will be kept separately from the rest of the information in a secure, locked filing cabinet. The information generated in the course of the research will be kept securely in paper or electronic form for a period 5 years after the completion of a research project and then destroyed in line with the university's guidance.

11. What type of information will be sought from me?

In the recorded in-depth interview you will be asked questions about a variety of aspects of living with IBD. This might include your thoughts on receiving a diagnosis, how the illness has impacted on being a young person, on family, friends, your feelings about the illness and ways of coping and your experiences of risk taking. Or the interviewer may focus on your thoughts regarding your move from child to adult care (transition) in which case the topics we discuss may include your thoughts on relationships with staff and the transfer of responsibility for your IBD management from guardian or parent to you.

You will also be asked to complete well established questionnaires about your illness perceptions, quality of life, disease activity (symptoms and how severe they are), psychological well-being (mood and worries) and risk taking behaviour. You will be asked for some demographic details, such as your age, ethnicity and educational level. We will only ask you to complete questionnaires 12 months later, not the interview.

We will also review your medical notes held at the hospital you are being treated at for information such as details regarding your condition, which part of the body it affects, how long you have had IBD and previous treatments you have had.

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

This study is being conducted in fulfilment of a higher degree (MD, Doctor of Medicine). It is hoped that the results of this project will be published in international peer reviewed journals. It must be emphasised again that you will not be identified in any subsequent reports or publications. If you would like to receive a summary of the results, please let Dr Alenka Brooks know by email (alenka.brooks@sth.nhs.uk).

13. Who is organising and funding the research?

This project is organised a the Clinical Psychology Unit at the University of Sheffield, the Department of Gastroenterology at both Sheffield Teaching Hospitals NHS Foundation Trust and Sheffield Children’s Hospital . Dr Alenka Brooks will be conducting the research with a psychology research assistant to be appointed to this project. Dr Georgina Rowse is the lead project supervisor.

14. Who has ethically reviewed the project?

This project has been approved by the North East – Sunderland NHS Research Ethics Committee.

15. Contact for further information

You can contact the research team via e-mail or telephone or letter at any time by the following details:

Dr Alenka Brooks	**Dr Georgina Rowse**	**Prof Alan Lobo**	**Dr Priya Narula**
Specialist Registrar Gastroenterology	*Senior Lecturer in Clinical Psychology*	*Professor of Gastroenterology*	*Consultant Paediatric Gastroenterologist*
Department of Gastroenterology, P39	Clinical Psychology Unit Department of Psychology	Department of Gastroenterology, P39	Sheffield Children’s Hospital

Royal Hallamshire Hospital Sheffield S10 2JF Tel: 0114 271 1900 (bleep) E-Mail: alenka.brooks@sth.nhs.uk	Western Bank University of Sheffield S10 2TN Tel: 0114 222 6650 E-Mail: g.rowse@sheffield.ac.uk	Royal Hallamshire Hospital Sheffield S10 2JF Tel: 0114 2712353 E-Mail: alan.lobo@sth.nhs.uk	Western Bank Sheffield S10 2TH Tel: 0114 2767173 E-mail: priya.narula@sch.nhs.uk

If you have any questions at all about this project, please do not hesitate to ask the research team at the above address, at any stage. I would like to thank you for taking part in this project and spending time to answer the questionnaires

Qualitative & Quantitative GP Information Sheet

Department Of Psychology
Clinical Psychology Unit

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

Clinical Psychology Unit
Department of Psychology
University of Sheffield
Western Bank
Sheffield S10 2TN UK
Telephone: 0114 2226635
Fax: 0114 2226610

[GP Name]

[GP Address]

[Date]

Dear [GP Name]

[Patient Name: D.o.B]

We are writing to inform you of the above named patients participation in a research project being jointly conducted by the University of Sheffield, Sheffield Children's Hospital NHS Foundation Trust and Sheffield Teaching Hospitals NHS Foundation Trust.

The research is funded by the charity Crohn's and Colitis UK and is titled ***Young People with Inflammatory Bowel Disease (IBD): their relationship with their disease, identity and illness perceptions*** and has been approved by the North East – Sunderland NHS Research Ethics Committee. Participation involves the completion of a number of questionnaires. A number of participants may also be involved in interviews to talk about their experience of living with Inflammatory Bowel Disease. We enclose a copy of the information sheet for your information and for the patient’s file. We do not anticipate any direct consequences of having taken part in this research project.

If you require any further detail regarding the project or your patient’s participation in the research please do not hesitate to get in contact with us.

Yours sincerely

AJ Brooks

Dr Alenka Brooks

Specialist Registrar Gastroenterology

Dr Alenka Brooks	**Dr Georgina Rowse**	**Prof Alan Lobo**	**Dr Priya Narula**
Department of Gastroenterology, P39 Royal Hallamshire Hospital Sheffield S10 2JF	*Senior Lecturer in Clinical Psychology* Clinical Psychology Unit Department of Psychology Western Bank University of Sheffield S10 2TN	*Professor of Gastroenterology* Department of Gastroenterology, P39 Royal Hallamshire Hospital Sheffield S10 2JF	*Consultant Paediatric Gastroenterologist* Sheffield Children’s Hospital Western Bank Sheffield S10 2TH

Qualitative Consent Form

The University Of Sheffield.

Department Of Psychology
Clinical Psychology Unit

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

Clinical Psychology Unit
Department of Psychology
University of Sheffield
Western Bank
Sheffield S10 2TN UK
Telephone: 0114 2226635
Fax: 0114 2226610

Sheffield Teaching Hospitals NHS
NHS Foundation Trust
In hospital and in the community
proud to make a difference

Consent Form Qualitative Study Version 1.0. 17th December 2013

Study Number: STH18172

Patient Identification Number:

CONSENT FORM

Title of Project: Young People with Inflammatory Bowel Disease: their relationship with their disease, identity and illness perceptions

1. I confirm that I have read and understand the information sheet dated 25.01.14 (version 2.0) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily. ☐

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

3. I understand that relevant sections of my medical notes and data collected during the study, may be looked at by individuals from regulatory authorities or from the NHS Trust, ☐

where it is relevant to my taking part in this research. I give permission for these individuals to have access to my records.

4. I agree for discussions with the researcher to be audio-tape recorded, with possible use of verbatim quotations in the write up and publication of the project. ☐

5. I agree to my GP being informed of my participation in the study. ☐

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

____________________	____________________	____________________
Name of Participant	Date	Signature
____________________	____________________	____________________
Name of Person obtaining consent	Date	Signature

Interview Schedule: living with IBD study

Interview Schedule

Young people's experiences of living with IBD

Introduction

As you know from the information sheet, I am hoping to talk with you today about your experiences of living with inflammatory bowel disease (IBD). I am hoping we can have a chat/conversation about a variety of topics such as your experience of getting a diagnosis of IBD, if and how IBD has had an impact on your life, about your ways of coping and other people's perception of your illness.

For all of these questions, there are no right or wrong answers; I am just interested in what your experiences have been. If you would rather not answer any of the questions, please do say and we can move on to something else. You should also feel free to stop the interview at any time, or take a break if needed. Remember that anything we discuss in this interview will remain confidential as described in the information sheet and the consent form.

Questions

To make a start, can you tell me a little bit about your first experiences of IBD

- What did you or your family first notice (symptoms/experiences)
- Would you mind telling me a bit about your experience of being diagnosed with IBD?
- How did you feel about being diagnosed with IBD? (*possible prompts*: what it meant, any expectations, worries?)
- Have you told anyone about having IBD?
- Could you tell me about the reaction of people around you /what other people thought to you being diagnosed with IBD? (*possible prompts*: friends, partners, family)
- How would you describe your experience of getting to know and understand IBD, your treatment, your doctor, the health professionals and the system they work in?

(Optional prompt) Would you like to take a break now?

Could you tell me more about how living with IBD is, as a young person/from the perspective of a young person?

- How you feel about yourself? (how you think about yourself, describe yourself)
- Relationships? (*possible prompts*: forming and maintaining relationships with friends, partners, family; short-term/long-term relationships, love, sex)
- Your socialising (going out with friends, drinking/drugs, travelling, leisure & sport activities)
- Education and employment? (*possible prompts*: school, exams, subjects chosen, college & university, choice of career)

(Optional prompt) Would you like to take a break now?

You have told me about […summarise diagnosis and living with IBD experiences…] could you now tell me a little about your ways of coping with living with IBD?

- How has it been coping with living with IBD?
- What ways, if any, have you found to cope with living with IBD?
- Do you have particular strategies or tips that you feel helps you cope?
- How, if at all, have your family and friends supported you through living with IBD?
- Do you feel you can talk to people about your experience of IBD (physical symptoms, hopes and worries with friend, partner, family)?
- Have you used any face to face or social medial support networks directly related to IBD or other related conditions during your time living with IBD? What have you thought about these?
- Is there anything else important about these issues that you would like to tell me?

You have told me about […summarise coping with IBD…] could you now tell me about other people's reaction to you and your IBD?

- Could you tell me about how you feel your family & family members see you and how they think about your IBD?
- How do you feel your IBD has been for other members of your family? (*possible prompts*: siblings, parents, grand parents)
- Could you tell me about your experiences of talking about your IBD with other people outside your family? (*possible prompts*: friends, girlfriends/boyfriends/partners, school, college, university, employers)
- Is there anything else important about these issues that you would like to tell me

We have spent a bit of time thinking about how things have been and how things are now, I wonder if you could tell me any thoughts you have about how living with IBD will be for you in the future?

- Hopes/worries?
- Leaving home/living independently
- Relationships
- Your family, having a family of your own
- Education/career

Okay, that's everything that I had hoped to cover.

- **Was there anything that you thought I might ask you about that I didn't?**
- **Is there anything that you think it would be useful or important for me to know that we haven't talked about yet?**
- **Do you have any questions for me?**

Conclusion

Thank you very much for your time. This interview will now be transcribed, and I will spend some time looking at what we have discussed today, before using the discussion to help me write up some of the issues that are relevant in both my project and for a research paper. [Unless otherwise stated…] You can be assured that everything we have done today will remain confidential and anonymous, just as it says in the information sheet. Neither your name nor any names mentioned today will be transcribed in the interview.

- Would you like me to send you a copy of the transcript of the interview?
- Would you like a copy of a summary of the results from this project?

If you have any further questions about the project, please do contact me using the details on the information sheet. If you feel the need to discuss further any of the issues that we have discussed today, please do contact either of the people on the information sheet.

Would you mind if we contacted you about taking part in any future research at all?

Interview Schedule: Transition Study

Interview Schedule

Young people's experiences of transition from child to adult services

Introduction

As you know from the information sheet, I am hoping to talk with you today about your experiences of living with inflammatory bowel disease (IBD). I am hoping we can have a chat/conversation about a variety of topics such as your experience of moving from being looked after by a children's hospital to an adult hospital for your IBD (transition). I hope we will have a conversation about a variety of topics such as your thoughts on your treatment, relationships with staff, ways of coping with transition and IBD, and the transfer of responsibility for your IBD management from your guardian or parent to you.

For all of these questions, there are no right or wrong answers; I am just interested in what your experiences have been. If you would rather not answer any of the questions, please do say and we can move on to something else. You should also feel free to stop the interview at any time, or take a break if needed. Remember that anything we discuss in this interview will remain confidential as described in the information sheet and the consent form.

Questions

To make a start, I wonder if you could tell me a little bit about having IBD, when you first noticed symptoms and what happened from then on for you.

- What was noticed first? How old were you?
- How did you feel about this?
- How this was dealt with by GP?
- What experience of tests/diagnosis etc was like?
- What did you think of this? (*possible prompts*: hopes, worries)
- How you have found treatment since then?

Thank you, so you have recently moved from being looked after by a children's hospital for your IBD to an adult hospital, I wonder if you could tell me a little bit about how that has been for you?

- How did you feel about the transfer?
- What have you noticed that is the same or different across the hospitals/teams?

- How have you felt about the timing?
- How have you felt about decisions that have been made with regards to transition?
- How, if at all, has moving hospitals made a difference to you or your life?
- Have your experiences made a difference to how you feel about yourself, or you're IBD?

(Optional prompt) Would you like to take a break now?

Could you tell me about the relationships with staff at both hospitals?

- How do you feel about the relationships you have had with staff at the Children's hospital? (*possible prompts*: doctors, nurses, etc)
- How, do your relationships with staff in the adult hospital feel the same or different to those at the Children's hospital? What do you think about this?
- In what ways could your relationships with staff at either hospital be better?

(Optional prompt) Would you like to take a break now?

Could you tell me more about how decisions have been made about your IBD before, during and after transition?

- Can you tell me about who makes decisions about your IBD now? How do you feel about this?
- Has who makes the decisions about your IBD changed over the course of transition?
- How have you felt about getting more involved with managing your IBD? (*possible prompts*: self medicating, booking appointments, speaking to specialist nurse)
- How do you see the future with regards to managing your IBD yourself with the help your doctors and nurses? What do you think about this?

(Optional prompt) Would you like to take a break now?

You have told me about […summarise transition experiences…] could you now tell me about your ways of coping with transition?

- What ways, if any, have you found to cope with your experiences of transition?
- Has anybody supported you through transition? (*possible prompts*: friends, family)
- Have you had any support from face to face or social medial support networks directly related to IBD or other related conditions during your transition with IBD? How have you found this?
- Is there anything else important about these issues that you would like to tell me?

Okay, that's everything that I had hoped to cover.

- **Was there anything that you thought I might ask you about that I didn't?**
- **Is there anything that you think it would be useful or important for me to know that we haven't talked about yet?**
- **Do you have any questions for me?**

Conclusion

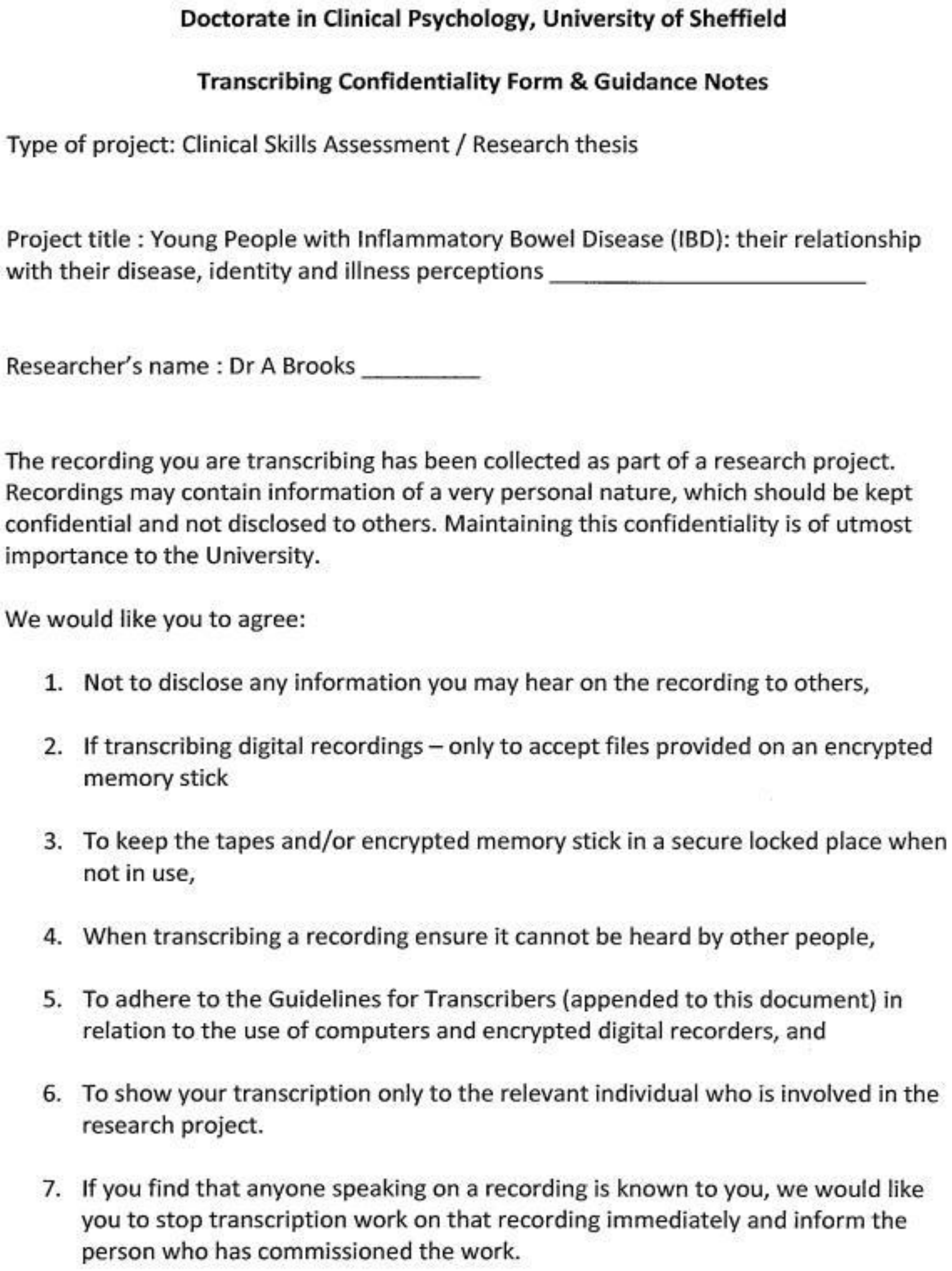
Thank you very much for your time. This interview will now be transcribed, and I will spend some time looking at what we have discussed today, before using the discussion to help me write up some of the issues that are relevant in both my project and for a research paper. [Unless otherwise stated…] You can be assured that everything we have done today will remain confidential and anonymous, just as it says in the information sheet. Neither your name nor any names mentioned today will be transcribed in the interview.

- Would you like me to send you a copy of the transcript of the interview?
- Would you like a copy of a summary of the results from this project?

If you have any further questions about the project, please do contact me using the details on the information sheet. If you feel the need to discuss further any of the issues that we have discussed today, please do contact either of the people on the information sheet.

Would you mind if we contacted you about taking part in any future research at all?

Transcriber confidentiality



Doctorate in Clinical Psychology, University of Sheffield

Transcribing Confidentiality Form & Guidance Notes

Type of project: Clinical Skills Assessment / Research thesis

Project title : Young People with Inflammatory Bowel Disease (IBD): their relationship with their disease, identity and illness perceptions ________________________

Researcher's name : Dr A Brooks _________

The recording you are transcribing has been collected as part of a research project. Recordings may contain information of a very personal nature, which should be kept confidential and not disclosed to others. Maintaining this confidentiality is of utmost importance to the University.

We would like you to agree:

1. Not to disclose any information you may hear on the recording to others,
2. If transcribing digital recordings – only to accept files provided on an encrypted memory stick
3. To keep the tapes and/or encrypted memory stick in a secure locked place when not in use,
4. When transcribing a recording ensure it cannot be heard by other people,
5. To adhere to the Guidelines for Transcribers (appended to this document) in relation to the use of computers and encrypted digital recorders, and
6. To show your transcription only to the relevant individual who is involved in the research project.
7. If you find that anyone speaking on a recording is known to you, we would like you to stop transcription work on that recording immediately and inform the person who has commissioned the work.

Declaration

I have read the above information, as well as the Guidelines for Transcribers, and I understand that:

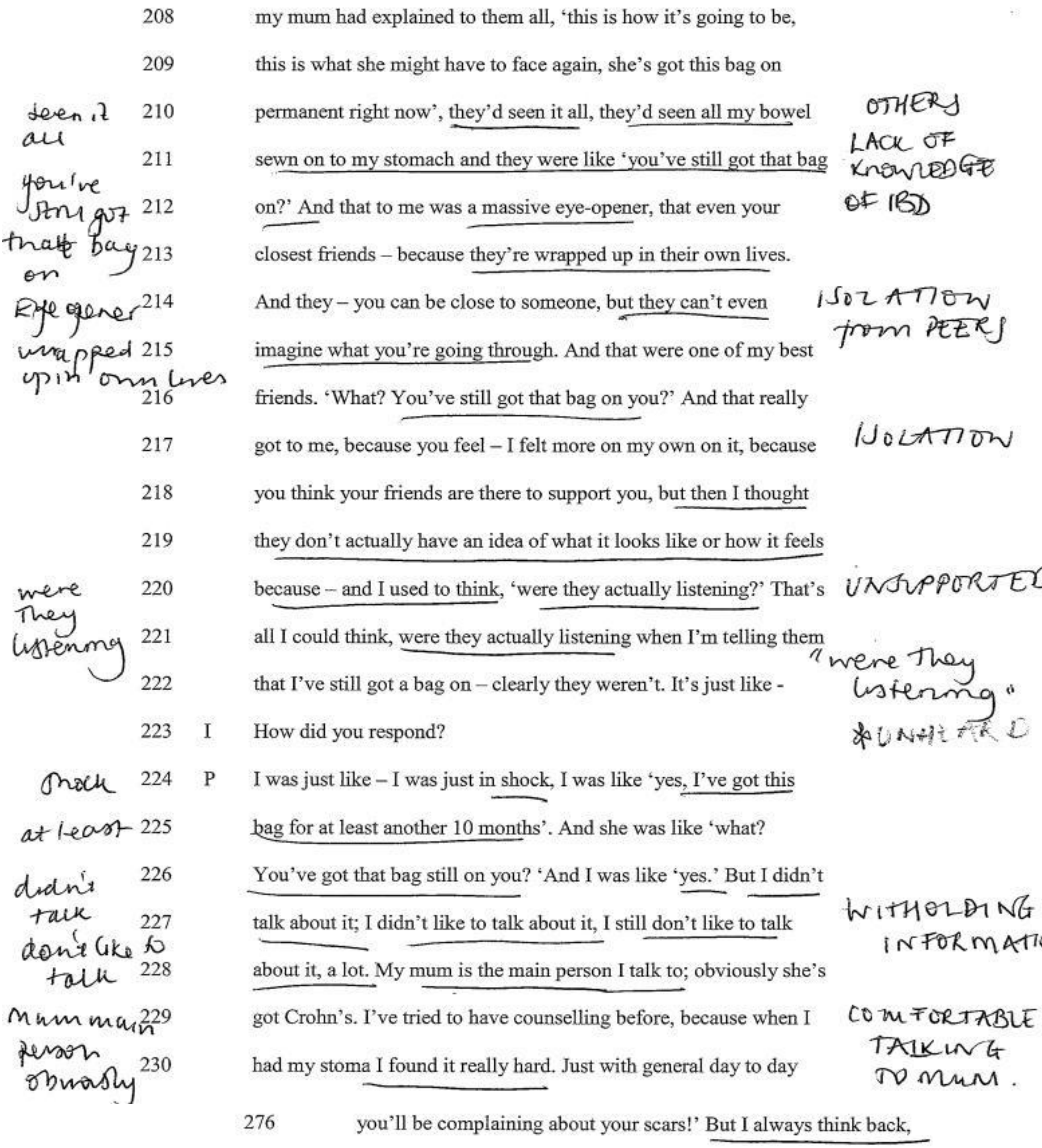
1. I will discuss the content of the recording only with the individual involved in the research project
2. If transcribing digital recordings – I will only accept files provided on an encrypted memory stick
3. I will keep the tapes and/or encrypted memory stick in a secure place when not in use
4. When transcribing a recording I will ensure it cannot be heard by others
5. I will treat the transcription of the recording as confidential information
6. I will adhere to the requirements detailed in the Guidelines for transcribers in relation to transcribing recordings onto a computer and transcribing digital audio files
7. If the person being interviewed on the recordings is known to me I will undertake no further transcription work on the recording

I agree to act according to the above constraints

Your name Sharon Keighley
Signature
Date 16/07/14.

Occasionally, the conversations on recordings can be distressing to hear. If you should find it upsetting, please stop the transcription and raise this with the researcher as soon as possible.

Worked Example of IPA for a reseearch participant



seen it all
you've still got that bag on
Eye opener
wrapped up in own lives
were they listening
shock
at least
didn't talk
don't like to talk
Mum main person obviously

my mum had explained to them all, 'this is how it's going to be, this is what she might have to face again, she's got this bag on permanent right now', they'd seen it all, they'd seen all my bowel sewn on to my stomach and they were like 'you've still got that bag on?' And that to me was a massive eye-opener, that even your closest friends – because they're wrapped up in their own lives. And they – you can be close to someone, but they can't even imagine what you're going through. And that were one of my best friends. 'What? You've still got that bag on you?' And that really got to me, because you feel – I felt more on my own on it, because you think your friends are there to support you, but then I thought they don't actually have an idea of what it looks like or how it feels because – and I used to think, 'were they actually listening?' That's all I could think, were they actually listening when I'm telling them that I've still got a bag on – clearly they weren't. It's just like -

I How did you respond?

P I was just like – I was just in shock, I was like 'yes, I've got this bag for at least another 10 months'. And she was like 'what? You've got that bag still on you? 'And I was like 'yes.' But I didn't talk about it; I didn't like to talk about it, I still don't like to talk about it, a lot. My mum is the main person I talk to; obviously she's got Crohn's. I've tried to have counselling before, because when I had my stoma I found it really hard. Just with general day to day

you'll be complaining about your scars!' But I always think back,

OTHERS LACK OF KNOWLEDGE OF IBD
ISOLATION from PEERS
ISOLATION
UNSUPPORTE
"were they listening"
*UNHEARD
WITHOLDING INFORMATI
COMFORTABLE TALKING TO MUM.

APPENDIX 4

Quantitative Patient Information Sheet

The
University
Of
Sheffield.

Department Of Psychology
Clinical Psychology Unit

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

Clinical Psychology Unit
Department of Psychology
University of Sheffield
Western Bank
Sheffield S10 2TN UK
Telephone: 0114 2226635
Fax: 0114 2226610

Sheffield Teaching Hospitals NHS
NHS Foundation Trust
In hospital and in the community
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Participant Information Sheet Version 2.0

Project title: **Young People with Inflammatory Bowel Disease (IBD): their relationship with their disease, identity and illness perceptions**

Invitation to participate

You are being invited to take part in a research study. Before you decide whether or not to take part, it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully. Please contact the researcher if there is anything that is not clear or if you would like more information. Thank you for reading this information sheet.

What is the project's purpose?

We would like to better understand the illness perceptions of young people living with IBD. Illness perceptions are the beliefs a person holds about the cause, identity, consequences, timeline and cure/controllability of the illness they live with. We aim to determine whether these perceptions change over time, for example during teenage years into adulthood and through the transition from child to adult medical care.

3. Why have I been chosen?

You have been invited to take part because you have IBD and are aged between 16-21 years.

4. Do I have to take part?

No. Taking part in this research is entirely voluntary and you can refuse to participate at any time. If you do decide to take part, you will be given this information sheet to keep, and you will be asked to sign a consent form. You can withdraw your consent at any time without it affecting your current or future treatment or access to services.

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

Taking part in this study will involve a meeting with one of the researchers (Dr Alenka Brooks or the research associate). You will also be given a series of questionnaires to complete. These questionnaires should take no more than 60 minutes in total to complete. You will then be contacted in around 12 month's time to complete the questionnaires once again. The repeat questionnaires a year later may be done electronically, at your next clinic appointment or at your home. The questionnaires have been used extensively in people of all ages with IBD or similar conditions.

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

We do not anticipate that taking part in this research will cause you any distress or discomfort. Your well being is very important to the researcher. In the unlikely event that you do feel upset by some aspect of the research please tell the researcher immediately. She will ask you whether you would like to continue and will ensure that you feel fine before you leave.

7. What are the possible benefits of taking part?

Whilst we do not anticipate any immediate benefits of participating in the project, we hope that this work will allow us to improve our understanding of the experiences of young people living with IBD. It is hoped that this understanding can inform how professionals work with patients like you in the *future, and help inform the design of care for young people living with IBD and moving into adult services with the hope of improving long-term outcomes.*

8. What if something goes wrong?

If you feel at all uncomfortable or upset during the completion of the questionnaires, please tell the researcher straight away. You are of course entitled to make a complaint if you feel that you have not been treated well by any of the researchers involved in this project. In the first instance, you should contact Dr Georgina Rowse (Project supervisor) at the University of Sheffield should you wish to raise a complaint. However, should you feel your complaint has not been handled to your satisfaction you can also contact the University's registrar on the following contact details: Philip Harvey (registrar@sheffield.ac.uk), Firth Court, Western Bank, Sheffield, S10 2TN. Tel: 0114 222 21101.

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

All the information that we collect from you during the course of the research will be kept strictly confidential and will not be accessible by anyone outside of the research team. You will not be able to be identified in any reports or publications. All of your questionnaire responses will be completely anonymous (i.e. no names will be recorded). The consent forms with your name on will be kept separately from the rest of the information in a secure, locked filing cabinet. The information generated in the course of the research will be kept securely in paper or electronic form for a period 5 years after the completion of a research project and then destroyed in line with the university's guidance.

10. What type of information will be sought from me?

You will be asked to complete well established questionnaires about your illness perceptions, quality of life, disease activity (symptoms and how severe they are), psychological well-being (mood and worries), taking your medications and risk taking behaviour. You will also be asked for some demographic details, such as your age, ethnicity and educational level. We will ask you to complete the same questionnaires 12 months later.

We will also review your medical notes held at the hospital you are being treated at for information such as details regarding your condition, which part of the body it affects, how long you have had IBD and previous treatments you have had.

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

This study is being conducted in fulfilment of a higher degree (MD, Doctor of Medicine). It is hoped that the results of this project will be published in international peer reviewed journals. It must be emphasised again that you will not be identified in any subsequent reports or publications. If you would like to receive a summary of the results, please let Dr Alenka Brooks know by email (alenka.brooks@sth.nhs.uk).

12. Who is organising and funding the research?

This project is organised by the Clinical Psychology Unit at the University of Sheffield, the Department of Gastroenterology at both Sheffield Teaching Hospitals NHS Foundation Trust and Sheffield Children's Hospital. Dr Alenka Brooks will be conducting the research with a clinical psychologist research associate Dr Anna Ryder. Dr Georgina Rowse is the lead project supervisor.

13. Who has ethically reviewed the project?

This project has been approved by the North East - Sunderland NHS Research Ethics Committee.

14. Contact for further information

You can contact the research team via e-mail or telephone or letter at any time by the following details:

Dr Alenka Brooks	**Dr Georgina Rowse**	**Prof Alan Lobo**	**Dr Priya Narula**
Specialist Registrar Gastroenterology	*Senior Lecturer in Clinical Psychology*	*Professor of Gastroenterology*	*Consultant Paediatric Gastroenterologist*
Department of Gastroenterology, P39 Royal Hallamshire Hospital Sheffield S10 2JF	Clinical Psychology Unit Department of Psychology Western Bank University of Sheffield S10 2TN	Department of Gastroenterology, P39 Royal Hallamshire Hospital Sheffield S10 2JF	Sheffield Children's Hospital Western Bank Sheffield S10 2TH
Tel: 0114 271 1900 (bleep)	Tel: 0114 222 6650	Tel: 0114 2712353	Tel: 0114 2767173
E-Mail: alenka.brooks@sth.nhs.uk	E-Mail: g.rowse@sheffield.ac.uk	E-Mail: alan.lobo@sth.nhs.uk	E-mail: priya.narula@sch.nhs.uk

If you have any questions at all about this project, please do not hesitate to ask the research team at the above address, at any stage. I would like to thank you for taking part in this project and spending time to answer the questionnaires.

Quantitative Consent Form

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Consent Form Quantitative Study Version 1.0. 17th December 2013

Study Number: STH18172

Patient Identification Number:

CONSENT FORM

Title of Project: Young People with Inflammatory Bowel Disease: their relationship with their disease, identity and illness perceptions

7. I confirm that I have read and understand the information sheet dated 25.01.14 (version 2.0) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily. ☐

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

9. I understand that relevant sections of my medical notes and data collected during the study, may be looked at by individuals from regulatory authorities or from the NHS Trust, where it is relevant to my taking part in this research. I give permission for these individuals to have access to my records. ☐

10. I agree to my GP being informed of my participation in the study. ☐

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

Name of Participant	Date	Signature
Name of Person obtaining consent	Date	Signature

Data Collection Sheet (1)

The University Of Sheffield.

Department Of Psychology
Clinical Psychology Unit

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

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Data Collection Sheet 1 Version 1.0. 17th December 2013

To be completed with the patient

Study Title: Young People with Inflammatory Bowel Disease: their relationship with their disease, identity and illness perceptions

Study Number: STH18172

Patient Identification Number:

Participant to complete

Age:

DOB:

Postcode:

Gender:

Relationship status:

Please tick the category which best describes your current circumstances

Single ☐

In relationship ☐

Divorced ☐

Residential information:

Please tick the category which best describes your current circumstances

Living with guardian or parents ☐

Living alone ☐

Living with friends ☐

Living with partner ☐

Educational level:

Tick the highest level of education you have

GCSEs/O Levels ☐

NVQ/BTEC/GNVQ/Diploma ☐

AS/A Levels ☐

Degree ☐

Higher Degree ☐

Any other (please specify) ____________________

Current Employment:

Please tick the category which best describes your current circumstances

student ☐

unemployed ☐

employed ☐

self-employed ☐

Ethnicity:

White ☐

Mixed/multiple ethnic groups ☐

Asian/Asian British ☐

Black/African/Caribbean/Black British ☐

Other ethnic group ☐

To be completed with investigator

Diagnosis:

Age at diagnosis:

Duration of disease (months):

Previous surgery (details):

Current stoma: Yes/No

Past stoma: Yes/No

Current medication:

Current Immunosuppressive medication: Yes/No

How many spells?

Last year ___________

Last 2 years ___________

Last 5 years ___________

Height:

Weight

Data Collection Sheet (2)

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Data Collection Sheet 2 Version 1.0. 17th December 2013
To be completed with information from clinical notes

Study Title: Young People with Inflammatory Bowel Disease (IBD): their relationship with their disease, identity and illness perceptions

Study Number: STH18172

Patient Identification Number:

Recruitment Site: SCH RHH

<u>Patient Details</u>

Confirm the following:

Diagnosis:

Age at diagnosis:

Duration of disease (months):

Number of IBD related hospital admissions in past year:

Number of IBD flare ups in past year:

Previous surgery (details):

Current stoma: Yes/No Past stoma: Yes/No

Current medication:

Current Immunosuppressive medication: Yes/No

How many spells?

Last year ___________

Last 2 years ___________

Last 5 years ___________

Height:

Weight:

Number of DNAs to outpatients in last year:

Disease Classification

Montreal classification of Crohn's disease (CD)

Age at diagnosis

A1	<16 years
A2	17-40 years
A3	>40 years

Location

L1	Ileal
L2	Colon
L3	Ileocolonic
L4	isolated upper GI

Behaviour

B1	non-stricturing, non-penetrating
B2	stricturing
B3	penetrating
p	perianal disease modifier

Montreal classification of extent of Ulcerative Colitis (UC)

Ulcerative proctitis (E1):	involvement limited to the rectum
Left sided colitis (E2):	involvement limited to the portion of the colorectum distal to the splenic flexture
Extensive UC (E3):	involvement extends proximal to the splenic flexture

APPENDIX 5

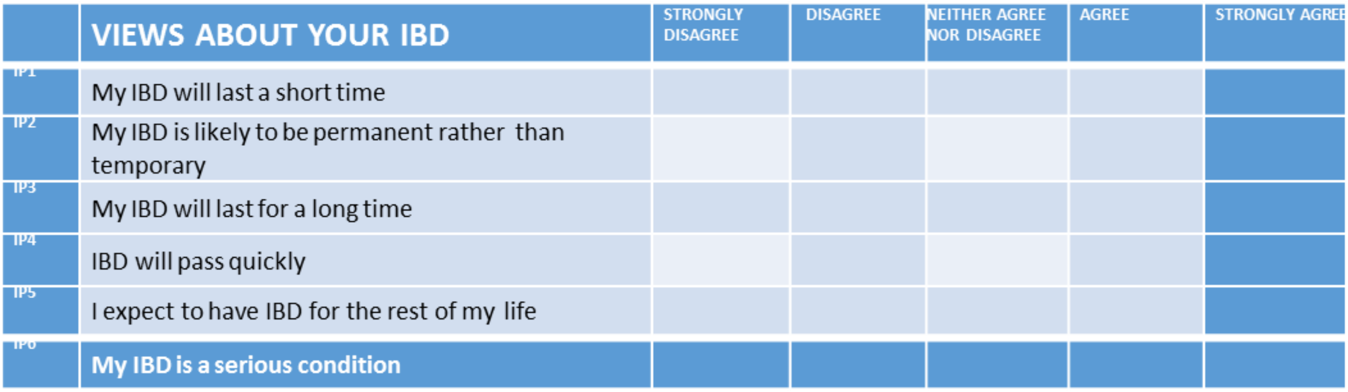
The Illness Perceptions Questionnaire-Revised

I have experienced this symptom *since my IBD* This symptom is *related to my IBD*

Pain	Yes	No	____________________	Yes	No
Sore Throat	Yes	No	____________________	Yes	No
Nausea	Yes	No	____________________	Yes	No
Breathlessness	Yes	No	____________________	Yes	No
Weight Loss	Yes	No	____________________	Yes	No
Fatigue	Yes	No	____________________	Yes	No
Stiff Joints	Yes	No	____________________	Yes	No
Sore Eyes	Yes	No	____________________	Yes	No
Wheeziness	Yes	No	____________________	Yes	No
Headaches	Yes	No	____________________	Yes	No
Upset Stomach	Yes	No	____________________	Yes	No
Sleep Difficulties	Yes	No	____________________	Yes	No
Dizziness	Yes	No	____________________	Yes	No
Loss of Strength	Yes	No	____________________	Yes	No

We are interested in your own personal views of how you now see your IBD.

Please indicate how much you agree or disagree with the following statements about your IBD by ticking the appropriate box.

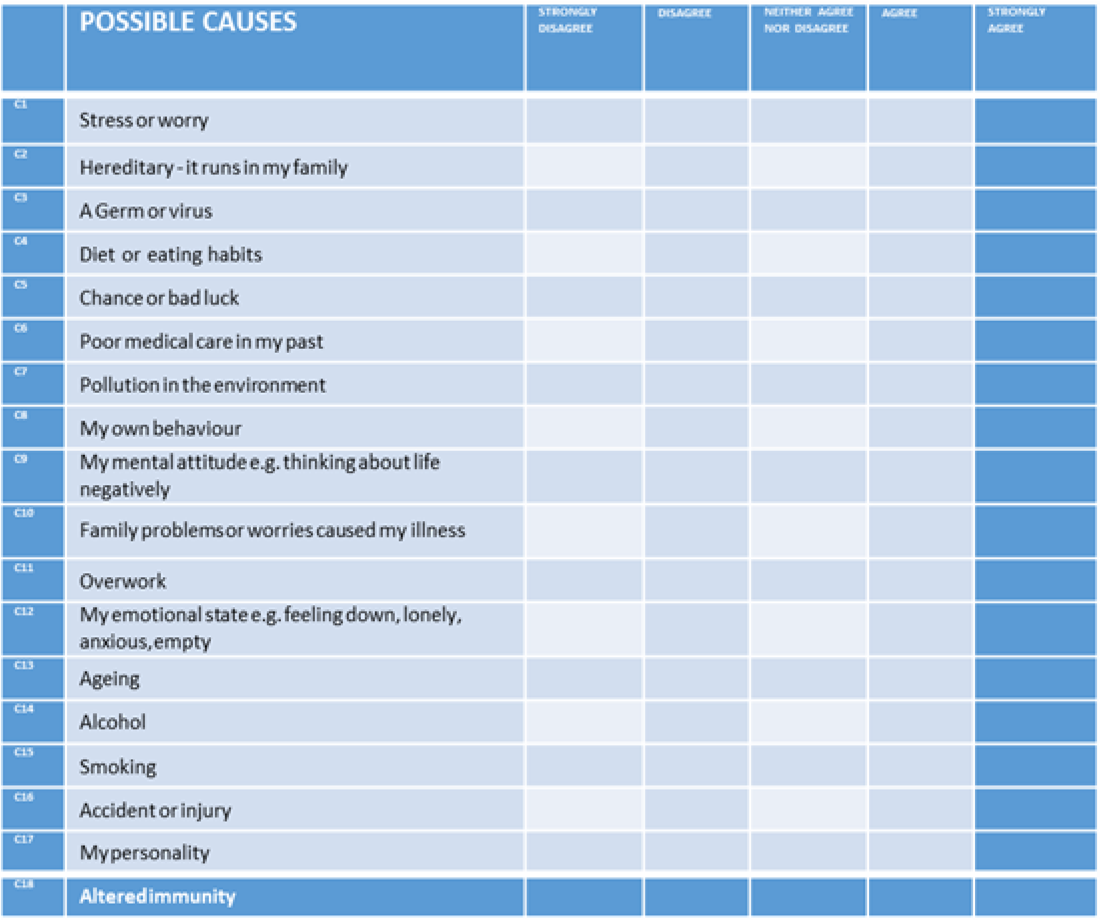


	VIEWS ABOUT YOUR IBD	STRONGLY DISAGREE	DISAGREE	NEITHER AGREE NOR DISAGREE	AGREE	STRONGLY AGREE
IP1	My IBD will last a short time					
IP2	My IBD is likely to be permanent rather than temporary					
IP3	My IBD will last for a long time					
IP4	IBD will pass quickly					
IP5	I expect to have IBD for the rest of my life					
IP6	**My IBD is a serious condition**					

	VIEWS ABOUT YOUR IBD	STRONGLY DISAGREE	DISAGREE	NEITHER AGREE NOR DISAGREE	AGREE	STRONGLY AGREE
IP7	My IBD has major consequences on my life					
IP8	My IBD does not have much effect on my life					
IP9	My IBD strongly affects the way others see me					
IP10	My IBD has serious financial consequences					
IP11	My IBD causes difficulties for those who are close to me					
IP12	There is a lot which I can do to control my symptoms					
IP13	What I do can determine whether my IBD gets better or worse					
IP14	The course of my IBD depends on me					
IP15	Nothing I do will affect my IBD					
IP16	I have the power to influence my IBD					
IP17	My actions will have no affect on the outcome of my IBD					
IP18	My IBD will improve in time					
IP19	There is very little that can be done to improve my IBD					
IP20	My treatment will be effective in curing my IBD					
IP21	The negative effects of my IBD can be prevented (avoided) by my treatment					
IP22	My treatment can control my IBD					
IP23	There is nothing which can help my IBD					
IP24	The symptoms of my IBD are puzzling to me					
IP25	My IBD is a mystery to me					
IP26	I don't understand my IBD					
IP27	My IBD doesn't make any sense to me					
IP28	I have a clear picture or understanding of my IBD					
IP29	The symptoms of my IBD change a great deal from day to day					
IP30	My symptoms come and go in cycles					
IP31	My IBD is very unpredictable					
IP32	I go through cycles in which my IBD gets better and worse.					
IP33	I get depressed when I think about my IBD					
IP34	When I think about my IBD I get upset					
IP35	My IBD makes me feel angry					
IP36	My IBD does not worry me					
IP37	Having IBD makes me feel anxious					
IP38	**My IBD makes me feel afraid**					

CAUSES OF MY INFLAMMATORY BOWEL DISEASE (IBD)

We are interested in what <u>you</u> consider may have been the cause of your IBD. As people are very different, there is no correct answer for this question. We are most interested in your own views about the factors that caused your IBD rather than what others including doctors or family may have suggested to you. Below is a list of possible causes for your IBD. Please indicate how much you agree or disagree that they were causes for you by ticking the appropriate box



	POSSIBLE CAUSES	STRONGLY DISAGREE	DISAGREE	NEITHER AGREE NOR DISAGREE	AGREE	STRONGLY AGREE
C1	Stress or worry					
C2	Hereditary - it runs in my family					
C3	A Germ or virus					
C4	Diet or eating habits					
C5	Chance or bad luck					
C6	Poor medical care in my past					
C7	Pollution in the environment					
C8	My own behaviour					
C9	My mental attitude e.g. thinking about life negatively					
C10	Family problems or worries caused my illness					
C11	Overwork					
C12	My emotional state e.g. feeling down, lonely, anxious, empty					
C13	Ageing					
C14	Alcohol					
C15	Smoking					
C16	Accident or injury					
C17	My personality					
C18	Altered immunity					

In the table below, please list in rank-order the three most important factors that you now believe caused <u>YOUR IBD.</u> You may use any of the items from the box above, or you may have additional ideas of your own.

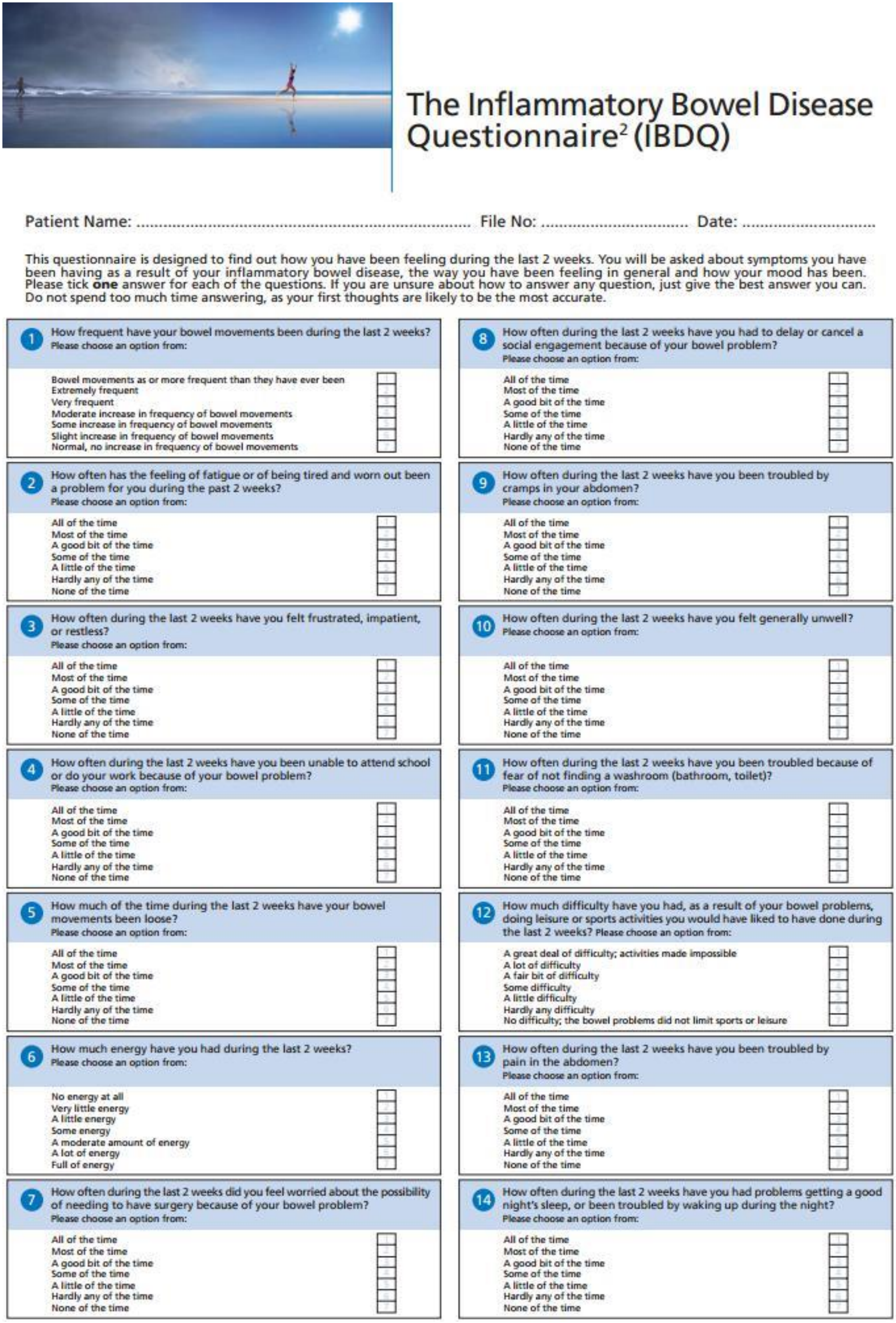
The most important causes for me:-

1. ____

2. ____

3. ____

The IBD Quality of Life Questionnaire



The Inflammatory Bowel Disease Questionnaire[2] (IBDQ)

Patient Name: .... File No: .... Date: ....

This questionnaire is designed to find out how you have been feeling during the last 2 weeks. You will be asked about symptoms you have been having as a result of your inflammatory bowel disease, the way you have been feeling in general and how your mood has been. Please tick **one** answer for each of the questions. If you are unsure about how to answer any question, just give the best answer you can. Do not spend too much time answering, as your first thoughts are likely to be the most accurate.

1 How frequent have your bowel movements been during the last 2 weeks?
Please choose an option from:

Bowel movements as or more frequent than they have ever been ☐ 1
Extremely frequent ☐ 2
Very frequent ☐ 3
Moderate increase in frequency of bowel movements ☐ 4
Some increase in frequency of bowel movements ☐ 5
Slight increase in frequency of bowel movements ☐ 6
Normal, no increase in frequency of bowel movements ☐ 7

2 How often has the feeling of fatigue or of being tired and worn out been a problem for you during the past 2 weeks?
Please choose an option from:

All of the time ☐ 1
Most of the time ☐ 2
A good bit of the time ☐ 3
Some of the time ☐ 4
A little of the time ☐ 5
Hardly any of the time ☐ 6
None of the time ☐ 7

3 How often during the last 2 weeks have you felt frustrated, impatient, or restless?
Please choose an option from:

All of the time ☐ 1
Most of the time ☐ 2
A good bit of the time ☐ 3
Some of the time ☐ 4
A little of the time ☐ 5
Hardly any of the time ☐ 6
None of the time ☐ 7

4 How often during the last 2 weeks have you been unable to attend school or do your work because of your bowel problem?
Please choose an option from:

All of the time ☐ 1
Most of the time ☐ 2
A good bit of the time ☐ 3
Some of the time ☐ 4
A little of the time ☐ 5
Hardly any of the time ☐ 6
None of the time ☐ 7

5 How much of the time during the last 2 weeks have your bowel movements been loose?
Please choose an option from:

All of the time ☐ 1
Most of the time ☐ 2
A good bit of the time ☐ 3
Some of the time ☐ 4
A little of the time ☐ 5
Hardly any of the time ☐ 6
None of the time ☐ 7

6 How much energy have you had during the last 2 weeks?
Please choose an option from:

No energy at all ☐ 1
Very little energy ☐ 2
A little energy ☐ 3
Some energy ☐ 4
A moderate amount of energy ☐ 5
A lot of energy ☐ 6
Full of energy ☐ 7

7 How often during the last 2 weeks did you feel worried about the possibility of needing to have surgery because of your bowel problem?
Please choose an option from:

All of the time ☐ 1
Most of the time ☐ 2
A good bit of the time ☐ 3
Some of the time ☐ 4
A little of the time ☐ 5
Hardly any of the time ☐ 6
None of the time ☐ 7

8 How often during the last 2 weeks have you had to delay or cancel a social engagement because of your bowel problem?
Please choose an option from:

All of the time ☐ 1
Most of the time ☐ 2
A good bit of the time ☐ 3
Some of the time ☐ 4
A little of the time ☐ 5
Hardly any of the time ☐ 6
None of the time ☐ 7

9 How often during the last 2 weeks have you been troubled by cramps in your abdomen?
Please choose an option from:

All of the time ☐ 1
Most of the time ☐ 2
A good bit of the time ☐ 3
Some of the time ☐ 4
A little of the time ☐ 5
Hardly any of the time ☐ 6
None of the time ☐ 7

10 How often during the last 2 weeks have you felt generally unwell?
Please choose an option from:

All of the time ☐ 1
Most of the time ☐ 2
A good bit of the time ☐ 3
Some of the time ☐ 4
A little of the time ☐ 5
Hardly any of the time ☐ 6
None of the time ☐ 7

11 How often during the last 2 weeks have you been troubled because of fear of not finding a washroom (bathroom, toilet)?
Please choose an option from:

All of the time ☐ 1
Most of the time ☐ 2
A good bit of the time ☐ 3
Some of the time ☐ 4
A little of the time ☐ 5
Hardly any of the time ☐ 6
None of the time ☐ 7

12 How much difficulty have you had, as a result of your bowel problems, doing leisure or sports activities you would have liked to have done during the last 2 weeks? Please choose an option from:

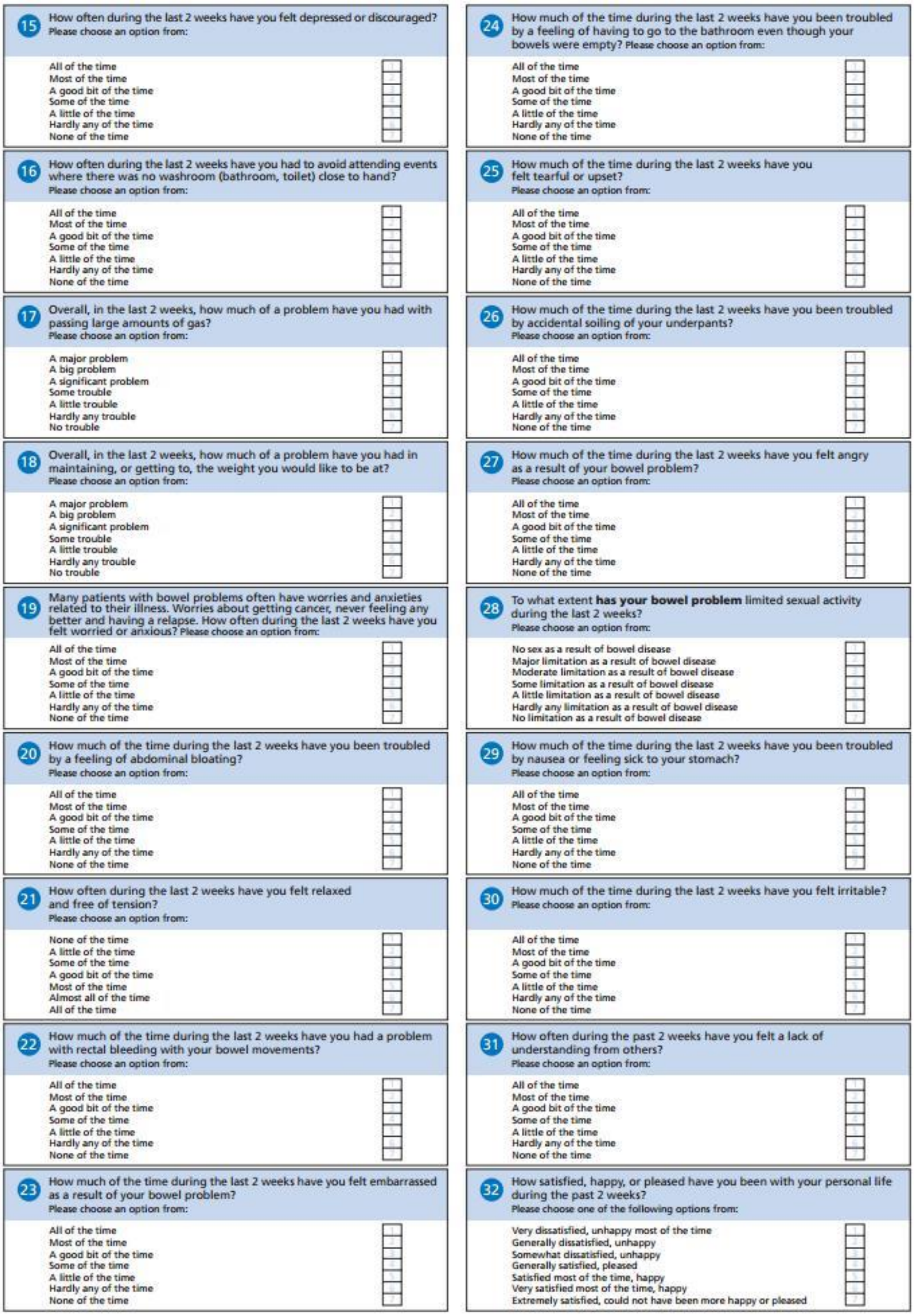
A great deal of difficulty; activities made impossible ☐ 1
A lot of difficulty ☐ 2
A fair bit of difficulty ☐ 3
Some difficulty ☐ 4
A little difficulty ☐ 5
Hardly any difficulty ☐ 6
No difficulty; the bowel problems did not limit sports or leisure ☐ 7

13 How often during the last 2 weeks have you been troubled by pain in the abdomen?
Please choose an option from:

All of the time ☐ 1
Most of the time ☐ 2
A good bit of the time ☐ 3
Some of the time ☐ 4
A little of the time ☐ 5
Hardly any of the time ☐ 6
None of the time ☐ 7

14 How often during the last 2 weeks have you had problems getting a good night's sleep, or been troubled by waking up during the night?
Please choose an option from:

All of the time ☐ 1
Most of the time ☐ 2
A good bit of the time ☐ 3
Some of the time ☐ 4
A little of the time ☐ 5
Hardly any of the time ☐ 6
None of the time ☐ 7



15 How often during the last 2 weeks have you felt depressed or discouraged?
Please choose an option from:

All of the time ☐ 1
Most of the time ☐ 2
A good bit of the time ☐ 3
Some of the time ☐ 4
A little of the time ☐ 5
Hardly any of the time ☐ 6
None of the time ☐ 7

16 How often during the last 2 weeks have you had to avoid attending events where there was no washroom (bathroom, toilet) close to hand?
Please choose an option from:

All of the time ☐ 1
Most of the time ☐ 2
A good bit of the time ☐ 3
Some of the time ☐ 4
A little of the time ☐ 5
Hardly any of the time ☐ 6
None of the time ☐ 7

17 Overall, in the last 2 weeks, how much of a problem have you had with passing large amounts of gas?
Please choose an option from:

A major problem ☐ 1
A big problem ☐ 2
A significant problem ☐ 3
Some trouble ☐ 4
A little trouble ☐ 5
Hardly any trouble ☐ 6
No trouble ☐ 7

18 Overall, in the last 2 weeks, how much of a problem have you had in maintaining, or getting to, the weight you would like to be at?
Please choose an option from:

A major problem ☐ 1
A big problem ☐ 2
A significant problem ☐ 3
Some trouble ☐ 4
A little trouble ☐ 5
Hardly any trouble ☐ 6
No trouble ☐ 7

19 Many patients with bowel problems often have worries and anxieties related to their illness. Worries about getting cancer, never feeling any better and having a relapse. How often during the last 2 weeks have you felt worried or anxious? Please choose an option from:

All of the time ☐ 1
Most of the time ☐ 2
A good bit of the time ☐ 3
Some of the time ☐ 4
A little of the time ☐ 5
Hardly any of the time ☐ 6
None of the time ☐ 7

20 How much of the time during the last 2 weeks have you been troubled by a feeling of abdominal bloating?
Please choose an option from:

All of the time ☐ 1
Most of the time ☐ 2
A good bit of the time ☐ 3
Some of the time ☐ 4
A little of the time ☐ 5
Hardly any of the time ☐ 6
None of the time ☐ 7

21 How often during the last 2 weeks have you felt relaxed and free of tension?
Please choose an option from:

None of the time ☐ 1
A little of the time ☐ 2
Some of the time ☐ 3
A good bit of the time ☐ 4
Most of the time ☐ 5
Almost all of the time ☐ 6
All of the time ☐ 7

22 How much of the time during the last 2 weeks have you had a problem with rectal bleeding with your bowel movements?
Please choose an option from:

All of the time ☐ 1
Most of the time ☐ 2
A good bit of the time ☐ 3
Some of the time ☐ 4
A little of the time ☐ 5
Hardly any of the time ☐ 6
None of the time ☐ 7

23 How much of the time during the last 2 weeks have you felt embarrassed as a result of your bowel problem?
Please choose an option from:

All of the time ☐ 1
Most of the time ☐ 2
A good bit of the time ☐ 3
Some of the time ☐ 4
A little of the time ☐ 5
Hardly any of the time ☐ 6
None of the time ☐ 7

24 How much of the time during the last 2 weeks have you been troubled by a feeling of having to go to the bathroom even though your bowels were empty? Please choose an option from:

All of the time ☐ 1
Most of the time ☐ 2
A good bit of the time ☐ 3
Some of the time ☐ 4
A little of the time ☐ 5
Hardly any of the time ☐ 6
None of the time ☐ 7

25 How much of the time during the last 2 weeks have you felt tearful or upset?
Please choose an option from:

All of the time ☐ 1
Most of the time ☐ 2
A good bit of the time ☐ 3
Some of the time ☐ 4
A little of the time ☐ 5
Hardly any of the time ☐ 6
None of the time ☐ 7

26 How much of the time during the last 2 weeks have you been troubled by accidental soiling of your underpants?
Please choose an option from:

All of the time ☐ 1
Most of the time ☐ 2
A good bit of the time ☐ 3
Some of the time ☐ 4
A little of the time ☐ 5
Hardly any of the time ☐ 6
None of the time ☐ 7

27 How much of the time during the last 2 weeks have you felt angry as a result of your bowel problem?
Please choose an option from:

All of the time ☐ 1
Most of the time ☐ 2
A good bit of the time ☐ 3
Some of the time ☐ 4
A little of the time ☐ 5
Hardly any of the time ☐ 6
None of the time ☐ 7

28 To what extent **has your bowel problem** limited sexual activity during the last 2 weeks?
Please choose an option from:

No sex as a result of bowel disease ☐ 1
Major limitation as a result of bowel disease ☐ 2
Moderate limitation as a result of bowel disease ☐ 3
Some limitation as a result of bowel disease ☐ 4
A little limitation as a result of bowel disease ☐ 5
Hardly any limitation as a result of bowel disease ☐ 6
No limitation as a result of bowel disease ☐ 7

29 How much of the time during the last 2 weeks have you been troubled by nausea or feeling sick to your stomach?
Please choose an option from:

All of the time ☐ 1
Most of the time ☐ 2
A good bit of the time ☐ 3
Some of the time ☐ 4
A little of the time ☐ 5
Hardly any of the time ☐ 6
None of the time ☐ 7

30 How much of the time during the last 2 weeks have you felt irritable?
Please choose an option from:

All of the time ☐ 1
Most of the time ☐ 2
A good bit of the time ☐ 3
Some of the time ☐ 4
A little of the time ☐ 5
Hardly any of the time ☐ 6
None of the time ☐ 7

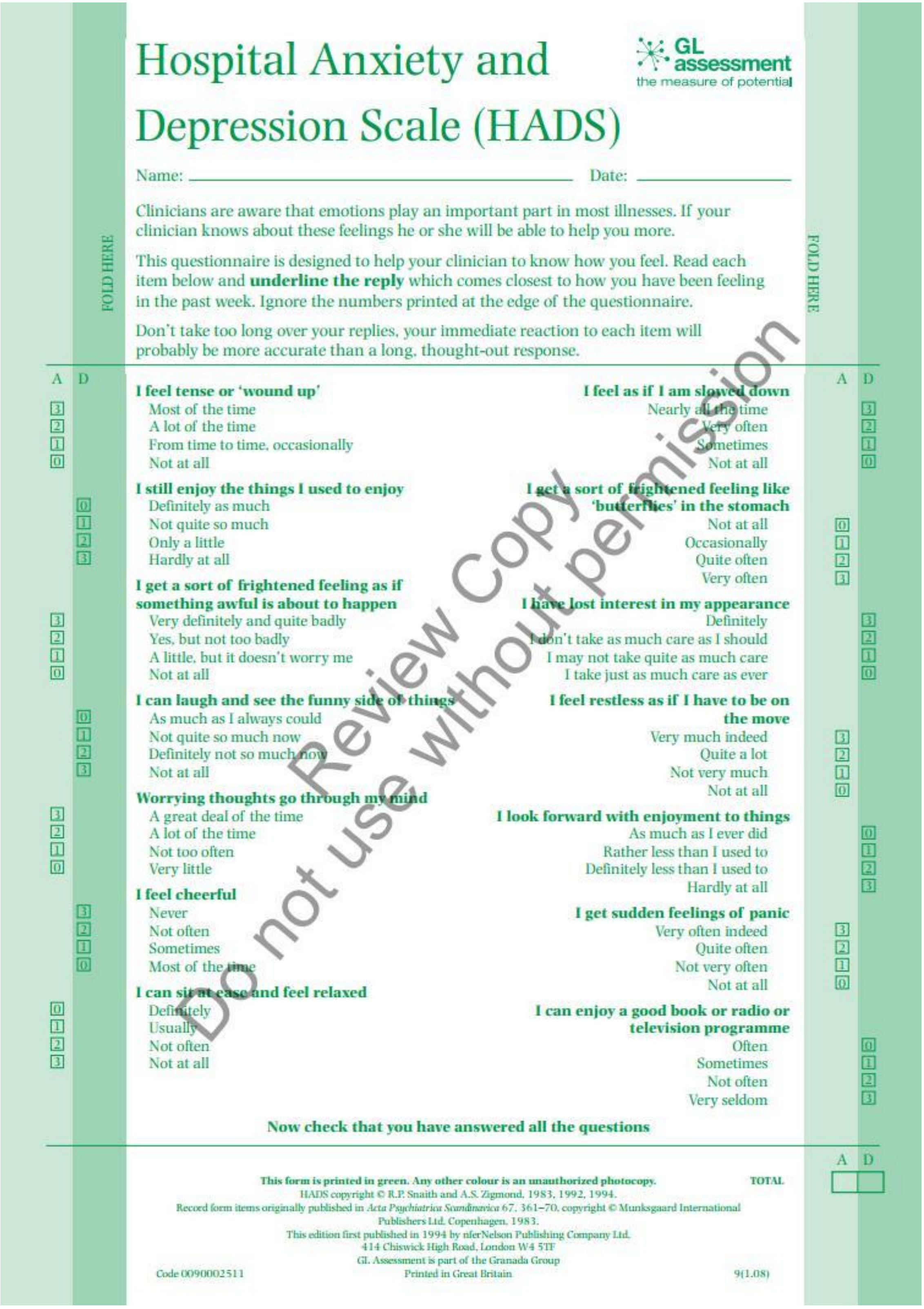
31 How often during the past 2 weeks have you felt a lack of understanding from others?
Please choose an option from:

All of the time ☐ 1
Most of the time ☐ 2
A good bit of the time ☐ 3
Some of the time ☐ 4
A little of the time ☐ 5
Hardly any of the time ☐ 6
None of the time ☐ 7

32 How satisfied, happy, or pleased have you been with your personal life during the past 2 weeks?
Please choose one of the following options from:

Very dissatisfied, unhappy most of the time ☐ 1
Generally dissatisfied, unhappy ☐ 2
Somewhat dissatisfied, unhappy ☐ 3
Generally satisfied, pleased ☐ 4
Satisfied most of the time, happy ☐ 5
Very satisfied most of the time, happy ☐ 6
Extremely satisfied, could not have been more happy or pleased ☐ 7

The Hospital Anxiety and Depression Scale



Hospital Anxiety and Depression Scale (HADS)

GL assessment
the measure of potential

Name: ______________________ Date: ____________

Clinicians are aware that emotions play an important part in most illnesses. If your clinician knows about these feelings he or she will be able to help you more.

This questionnaire is designed to help your clinician to know how you feel. Read each item below and **underline the reply** which comes closest to how you have been feeling in the past week. Ignore the numbers printed at the edge of the questionnaire.

Don't take too long over your replies, your immediate reaction to each item will probably be more accurate than a long, thought-out response.

FOLD HERE

FOLD HERE

A	D	
		I feel tense or 'wound up'
3		Most of the time
2		A lot of the time
1		From time to time, occasionally
0		Not at all
		I still enjoy the things I used to enjoy
	0	Definitely as much
	1	Not quite so much
	2	Only a little
	3	Hardly at all
		I get a sort of frightened feeling as if something awful is about to happen
3		Very definitely and quite badly
2		Yes, but not too badly
1		A little, but it doesn't worry me
0		Not at all
		I can laugh and see the funny side of things
	0	As much as I always could
	1	Not quite so much now
	2	Definitely not so much now
	3	Not at all
		Worrying thoughts go through my mind
3		A great deal of the time
2		A lot of the time
1		Not too often
0		Very little
		I feel cheerful
	3	Never
	2	Not often
	1	Sometimes
	0	Most of the time
		I can sit at ease and feel relaxed
0		Definitely
1		Usually
2		Not often
3		Not at all

	A	D
I feel as if I am slowed down		
Nearly all the time		3
Very often		2
Sometimes		1
Not at all		0
I get a sort of frightened feeling like 'butterflies' in the stomach		
Not at all	0	
Occasionally	1	
Quite often	2	
Very often	3	
I have lost interest in my appearance		
Definitely		3
I don't take as much care as I should		2
I may not take quite as much care		1
I take just as much care as ever		0
I feel restless as if I have to be on the move		
Very much indeed	3	
Quite a lot	2	
Not very much	1	
Not at all	0	
I look forward with enjoyment to things		
As much as I ever did		0
Rather less than I used to		1
Definitely less than I used to		2
Hardly at all		3
I get sudden feelings of panic		
Very often indeed	3	
Quite often	2	
Not very often	1	
Not at all	0	
I can enjoy a good book or radio or television programme		
Often		0
Sometimes		1
Not often		2
Very seldom		3

Now check that you have answered all the questions

	A	D
TOTAL		

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