A Comparison of Psychosocial Functioning between Early, Mid and Late Adolescence in Young People with Inflammatory Bowel Disease

and

Clinical Research Portfolio

Volume I

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Chapter 1

Systematic Review

Psychosocial Functioning and Health Related Quality of Life in Paediatric Inflammatory Bowel Disease: A Systematic Review

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Written according to guidelines for submission to the *Journal of Pediatric Gastroenterology and Nutrition* (See Appendix 1.1)

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Abstract

Objectives: This systematic review describes the literature focussing on psychosocial functioning and health related quality of life (HRQOL) in young people with inflammatory bowel disease (IBD). It aims to critique the methodological quality of the identified studies, discuss the implications of their findings and make recommendations for future research. The following question was posed: what impact does IBD have on psychosocial functioning and HRQOL in children and adolescents?

Methods: A systematic search strategy was used to identify relevant articles which were subject to strict inclusion and exclusion criteria. Identified papers were rated for methodological quality and data was extracted.

Results: A total of 12 articles with 'acceptable' or 'good' quality rating scores were included in the review. After describing the demographic and methodological aspects of the studies, five main outcomes: self-esteem, HRQOL, anxiety and depression, social competence and behavioural functioning were examined.

Conclusions: Due to the conflicting results and methodological limitations of the research in this field, only tentative conclusions could be drawn. Young people with IBD appear to have reduced HRQOL and an increased risk of developing psychiatric conditions compared to their healthy peers. The evidence for lowered self-esteem, self-reported symptoms of depression and anxiety, impaired social competence and behavioural problems was mixed. Methodological limitations are discussed and the implications of the review for future research and clinical practice outlined.

Introduction

What is IBD?

Inflammatory bowel disease (IBD), comprising Crohn's disease (CD), ulcerative colitis (UC) and indeterminate colitis (IC) is a chronic condition that is commonly diagnosed in childhood or adolescence. Around 15 to 25 percent of individuals with IBD are diagnosed before the age of 20 (1). The incidence of paediatric IBD is reported to be increasing in Europe and North America although reasons for this remain unknown (2).

IBD is characterised by an unpredictable illness course and includes symptoms of abdominal pain, diarrhoea, nausea, fatigue, delayed puberty and weight loss. These symptoms, in addition to treatment (including surgery, steroid injections or having a colostomy bag) can be embarrassing, socially limiting and can lead to changes in physical appearance. This may have a negative impact on body image, self-esteem and mood (3-5). The social constraints of the disease, in addition to the considerable amount of school often missed due to illness and hospital appointments, may impact on social functioning (3,4). Significantly, the family dynamics may be altered resulting in the child having fewer opportunities to develop autonomy as they grow older.

How does IBD effect psychosocial functioning/health related quality of life?

The burden of living with IBD, as identified in adults (6), may be even greater in the developing child. If developmental tasks and transitions are halted, greater psychosocial difficulties and reduced health related quality of life (HRQOL) might be expected. Difficulties in these areas have been shown to have an adverse impact on treatment adherence (7) and may predispose children to developing more severe psychological or psychiatric conditions later in life. In addition to this, recent prospective studies examining the

pathogenic role of psychological stress in adults with IBD have revealed that individuals with heightened anxiety and depression are at a higher risk of further disease activity (8).

Psychosocial functioning/HRQOL and its measurement

HRQOL, including physical, psychological and social functioning, can be defined as one means of assessing the burden of chronic illness. Studies tend to refer to either HRQOL or psychosocial functioning and typically examine the impact of IBD on areas such as behavioural, emotional and social functioning and self-esteem. In order to increase the sensitivity of the search for this review both terms were included and are used interchangeably.

Psychosocial functioning or HRQOL are typically measured using validated structured interviews (allowing for diagnosis of psychiatric disorders) and/or validated norm-referenced questionnaires. Most questionnaires generate standardised T scores derived from the normative sample with which the measure was developed, and distinguish children who required mental health input from those who did not. Thus T scores are 'cut-offs' that allow judgments to be made about the clinical significance of a young person's difficulties.

Generic measures of HRQOL (e.g. PedsQL) (9), which compare children with IBD to healthy peers and children with other conditions, have been used in the past. While these allow easy comparison across illness groups, they may not be specific enough to reflect impaired functioning in young people with IBD. Researchers in Canada and The Netherlands have collaboratively developed and validated the IMPACT, a paediatric IBD specific questionnaire measuring six domains: bowel symptoms, systemic symptoms, social/functional concerns, body image, emotional concerns and test and treatment concerns (10,11). In addition to these

broad HRQOL measures, questionnaires that focus on specific symptoms (e.g. depression) or areas of functioning (e.g. social functioning) are also popular.

Mackner and Crandall (12) highlight the benefits of including a comparison group when assessing psychosocial functioning/HRQOL. A control group (of healthy age-matched peers or those with another chronic illness) can identify problems that are specific to young people with IBD. While normative reference data is often used in the place of matched control groups, these data cannot account for cohort effects, geographical location and socio-economic factors that may be specific to the population being studied.

Objectives

This is a growing area of research where various aspects of psychosocial functioning have been examined using a range of different measures. While the most recent review (12) summarises the literature up to 2006, it was non-systematic. As several articles have been published in the intervening years, it was felt timely for a systematic review to be conducted to evaluate this somewhat confused research literature in greater depth. There is increasing recognition that this population may be experiencing difficulties that could be ameliorated and intervention trials are already under way to evaluate the efficacy of psychological treatments (13). A thorough examination of the evidence to date is therefore clinically relevant.

This review seeks to identify the relevant literature focussing on psychosocial functioning and HRQOL in young people with IBD, to critique the methodological quality of this literature, discuss the implications of the findings and make recommendations for future

research and clinical practice. The following review question is proposed in order to address this:

What impact does IBD have on psychosocial functioning and HRQOL in children and adolescents?

Methods

Search strategy:

In order to identify suitable studies the following electronic databases: Ovid MEDLINE, EMBASE, PsychINFO, British Nursing Index, HMIC, EBSCO (CINHAL) and Web of Science were searched using the following search terms including the Boolean operator "AND":

[affect or emotion or psychosocial or quality of life or depression or self esteem or self concept or stress or attitude or aggression or shy or social or coping or body image or anorexia or body dysmorphia or social interaction or well being or mental health or mood or mental disorder or behaviour or anxiety or anxious or anger or fear or frustration or peer or agoraphobia or eating disorder or bulimia or mood disorder or interpersonal relations or life style or lifestyle or autonomy or self efficacy or social perception or psychology or psychiatry]

AND

[adolescent or pediatric or paediatric or child or children or youth or young person or young people or teen]

AND

[crohn or colitis or inflammatory bowel disease].

Due to the wide-ranging definitions of HRQOL and psychosocial functioning these detailed search terms were chosen in order to increase the sensitivity of the search. A multi-database search was conducted using the text-words above in addition to searching each database individually using subject headings. The results of the subject heading search informed the final text-word search. The references of the most recent review (12) were examined to ensure no appropriate studies had been missed.

Inclusion/exclusion criteria:

All studies retrieved by the database search were examined using the following inclusion criteria. Those not meeting these criteria were excluded from the review.

- Published in a peer reviewed journal between the years of 1990 and 2009
- Study examined data from original research
- Study is written in English
- Study uses quantitative methods
- Participants aged 18 years or younger
- Participants have a medically confirmed diagnosis of CD, UC or IC
- Outcome measures include HRQOL or aspects of psychosocial functioning (e.g. social/behavioural functioning, self-esteem, body image, depression or anxiety)
- Established or standardised questionnaires are used

Data extraction and quality rating:

Studies meeting inclusion criteria were quality rated by the author using a checklist adapted from those outlined by SIGN (14) and CASP (15) (see Appendix 1.2). Studies were rated on 17 items in four main areas: selection of participants, assessment, confounding factors and

statistical analysis. For each item it was possible to score 2 if the item was well covered, 1 if adequately covered, or 0 if poorly covered giving a total possible score of 34. A quality rating percentage score of good (>75%), acceptable (>50%) or poor (<50%) was awarded to each study.

Fifty percent of studies were randomly selected and independently rated by another researcher using the same quality rating scale. There was 100% agreement between raters for the assignment of papers to quality rating categories. Following quality rating, methodological, demographic and clinical information was systematically extracted from each article.

Results

The database search identified 2141 articles. Of these, 1863 were either duplicates or were not deemed relevant to the current review and were excluded on the basis of title. Abstracts of the remaining 278 articles were examined using full inclusion criteria, resulting in the exclusion of a further 252 articles. This left 26 potentially appropriate articles, 14 of which were excluded after reviewing the full text (10,11,16-27) (see Figure 1). The 12 remaining articles were deemed suitable to be included in the review and are discussed below (4,5,28-37).

INSERT FIGURE 1 HERE

Demographic and methodological information

The identified studies had a total of 5330 participants between the ages of 4 and 18 years (mean: 14.1 years). 790 participants had IBD and 4540 were controls (4474 healthy, 20

headache, 20 diabetes, 26 functional gastrointestinal complaints). 10 studies (n=706) provided information on disease type (66% CD, 31% UC and 3% IC) and 10 studies (n=740) reported gender (54% male and 46% female) (see Table 1).

INSERT TABLE 1 HERE

Eleven of the studies were cross-sectional observational studies and one used a prospective longitudinal design (36). Four studies (33%) did not have a control group (5,28,36,37), five (42%) used either matched controls recruited at the time of the study (4,29,35), another illness group (32), or illness groups and healthy controls (31). Three studies (25%) used previously collected reference group data (30,33,34).

Time since diagnosis varied widely between studies from zero months (5,36), more than one to two months (28), more than three months (35), more than six months (30,33,34) to more than one year (4). From the available information (four studies did not report time since diagnosis) the average duration of disease was 2.74 years. Only six studies reported disease severity in categories that could be compared between studies (4,5,33,34,36,37). In these studies (n=539) 36% had mild, 45% intermediate/moderate and 19% severe disease activity.

A wide range of standardised assessments were administered via questionnaires and clinician-led interviews. The majority of studies included both self- and parent-report questionnaires (four used self-report measures only). Four studies conducted standardised diagnostic interviews with either the child (31) or the child and parent (5,28,37).

Quality rating revealed that three articles (5,28,30) scored in the 'acceptable' range (>50%) while the remaining nine papers scored in the 'good' range (>75%) (see Appendix 1.3). Methodological shortcomings will be discussed in relation to the results as they arise below.

Psychosocial functioning

The five main outcomes (self-esteem; HRQOL; anxiety and depression; social competence; and behavioural problems/functioning) identified will be considered separately in order that comparisons can be made between studies. It should be noted that a mean of four outcome assessments (range 1-11) were used in each study and therefore the same studies will be discussed in relation to different outcomes. For this reason Table 1 provides a summary of each study in its entirety for reference. In interpreting psychosocial functioning/HRQOL scores, larger or increasing scores indicate better functioning unless otherwise stated.

Self-esteem

Self-esteem was measured using standardised, validated self-report questionnaires in five studies (4,30-33). Only one of these studies, using a measure of self-esteem, 'I think I am' (ITIA), developed in Sweden (38), found that young people with IBD had significantly lowered self-esteem compared to healthy controls (F_r=8.46, p>0.04) (31). T scores were not provided making it difficult to determine if the reduction in self-esteem was clinically significant. Additionally, this study used 20 outcome measures on a small sample (n=20) without adjusting significance levels for multiple comparisons. Another study using ITIA as the only outcome measure (33) found no significant difference in self-esteem between young people with IBD and a previously assessed healthy reference group.

Two studies using the Piers-Harris Children's Self-Concept Scale (PHCSCS) (39), a more commonly used measure yielding T scores, also found no significant difference in self-esteem between young people with IBD and healthy controls (4,32). Indeed Gold *et al.* (32) found that young people with IBD actually had significantly better self-concept than the normative group. It should be noted that participants in both of these studies had mild disease activity. In line with these findings De Boer *et al.* (30), using the Dutch version of the Self Perception Profile for Adolescents (SPPA; Harter) (40), did not find young people with IBD had lowered self-esteem. They did, however, find that self-esteem was a good predictor of all domains of HRQOL, but were unable to make any assumptions about the direction of causality.

HRQOL

Five articles assessed HRQOL (29,30,34-36). The two studies that administered generic multi-dimensional HRQOL instruments (29,30) had somewhat conflicting results. Using the Child Health Questionnaire (CHQ) (41,42) Cunningham *et al.* (29) found that while parents reported their children with IBD to be more impaired than healthy controls in the overall areas of physical health ($F=50.17$, $p<0.001$) and psychological health ($F=5.789$, $p<0.05$); young people themselves did not report more difficulties except in the general health subscale. In contrast, De Boer *et al.* (30) found that adolescent boys with IBD self-reported significantly worse overall HRQOL than the reference group ($p<0.01$). Some methodological limitations, however, should be borne in mind when interpreting these results. Although the HRQOL measure (Dutch Children's AZL/TNO Quality of Life Questionnaire, DUCATQOL) (43) administered was reported to be internally consistent and reproducible, no validation studies have yet been published. Furthermore, the age range of the reference data did not

match that of participants resulting in unsatisfactory analysis (females with IBD could not be compared to controls in two out of four domains of the DUCATQOL).

Two studies using an IBD specific HRQOL measure, the IMPACT (10,11), in addition to generic HRQOL questionnaires, found that HRQOL was significantly lower in young people with IBD (34,35). Loonen *et al.* (34) analysed their data by two age strata in accordance with the normative data for the generic HRQOL measure (TNO-AZL Children's Quality of Life questionnaire, TACQOL) (44). They found that although adolescents (12-18 years, n=65) had significantly lower HRQOL than healthy peers on four domains (body complaints, motor functioning, autonomy and negative emotions) ($p<0.05$), younger children (8-11 years, n=18) had comparable or better HRQOL than controls. It should be noted that the small sample of younger children had mainly inactive or mild disease. Marcus *et al.* (35) found that young people reported significantly lower HRQOL than matched healthy controls on both the IBD specific IMPACT ($p<0.001$) and on a well established generic measure of HRQOL (PedsQL 4.0) (9) ($p<0.001$). The remaining study to use the IMPACT was a large multi-site prospective cohort study that administered the questionnaire to 218 young people with IBD (36). Mean HRQOL scores significantly improved from baseline during the first year post diagnosis ($p<0.05$) (36).

Mood (anxiety and depression)

Seven studies investigated anxiety and depression using either structured diagnostic interviews or self-report questionnaires. It should be noted that increasing scores on anxiety and depression measures indicate increasing levels of distress.

Structured diagnostic interviews

Four studies (5,28,31,37) used standardised clinical interviews with either children or their parents. These studies found that young people with IBD had increased levels of psychiatric disturbance or symptoms of depression and anxiety meeting DSM-III-R criteria (45). Prevalence varied from 25% (37) to 73% (5). Engstrom (31) compared 20 young people with IBD to headache, diabetes and healthy controls using the Child Assessment Schedule (CAS) (46) and found that significantly more young people with IBD fulfilled criteria for psychiatric disorder (mainly depression or anxiety) than the three control groups (χ^2=11.34, p<0.01).

The results of the other three studies using structured diagnostic interviews should perhaps be approached with caution. Burke *et al.* (28) and Szajnberg *et al.* (5) recruited newly or recently diagnosed young people with IBD and administered the Kiddie Schedule for Affective Disorders and Schizophrenia (K-SADS) (47). Although this is a well validated semi-structured interview, both studies had small sample sizes of 36 (28) and 15 (5) and no control groups. Burke *et al.* (28) found that 42% of children with a mean disease duration of 3.5 months reported symptoms of depression, while Szajnberg *et al*. (5) reported that 73% of their sample had psychiatric diagnoses at the time of their IBD diagnosis.

Although Szigethy *et al.* (37) omitted a control group, they had a much larger sample of 102 young people with IBD. They used the Schedule for Affective Disorders and Schizophrenia for School Aged Children – Present and Lifetime Version (SADS-PL) (48) interview with 19 children scoring above the clinical cut-off ($\geq$12) on a self-report questionnaire (the Children's Depression Inventory, CDI) (49). They reported that this confirmed a clinically significant diagnosis of depression in 16 out of the 19 interviewed and uncovered previously undiagnosed co-morbid anxiety disorders in 11 of these individuals.

Self-report questionnaires

Four studies administered the CDI, a self-report measure of depression, to young people giving mixed results (4,31,32,35). Whilst Engstrom (31) found young people with IBD reported significantly more depressive symptoms than healthy controls (F_r=10.00, p<0.02), the other three studies did not find evidence of increased symptoms of depression in comparison with healthy controls (4,35) or another illness group (32). Two of these studies (4,31) also assessed anxiety using a self-report measure; the Revised Children's Manifest Anxiety Scale (RCMAS) (50); they both failed to find increased symptoms of anxiety in the IBD group compared to controls.

Social competence

Three studies examined social competence as an outcome (4,31,32). Engstrom (31) and Gold *et al.* (32) used a parent-report questionnaire, the Child Behaviour Checklist (CBCL) (51), while Mackner and Crandall (4) administered the self-report version, the Youth Self Report form (YSR) (52). Both measures have a social competence scale in which an increasing score indicates better social functioning. While two studies (4,32) found social competence to be in the normal range and comparable to controls, Engstrom (31) found that mothers rated their children with IBD as significantly less socially competent than healthy children (F_r=7.86, p<0.04). Given the small sample size and large number of other measurements used in this study, however, it would be prudent to interpret these results with caution (e.g. by adopting a more conservative significance level).

Behavioural problems/functioning

Four studies examined behavioural functioning using either the CBCL (30-32) or YSR (4). These measures yield a total behavioural problems score as well as internalising behaviour

(withdrawn, somatic complaints and anxious/depressed) and externalising behaviour (rule-breaking and aggressive behaviour) scores. For these domains, an increasing score indicates greater levels of behavioural problems.

Engstrom (31) found that young people with IBD had significantly more total behavioural (χ^2 F_r=9.34, p<0.03) and internalising behaviour (χ^2 F_r=9.83, p<0.02) problems than healthy controls. De Boer *et al.* (30), comparing young people with IBD to a healthy reference group, found significant differences on the total behavioural problems (p<0.05) and internalising behaviour subscales (p<0.01) for boys, while for girls the only significant difference was found for internalising behaviour (p<0.05). In contrast, Gold *et al.* (32) and Mackner and Crandall (4) found mean scores in the normal range and no significant differences between young people with IBD and controls. It was noted, however, that a subset of 20% of participants with IBD reported clinically impaired levels of behavioural/emotional functioning (4).

Discussion

The reviewed studies present a somewhat mixed picture of psychosocial functioning/HRQOL in children and adolescents with IBD. While the evidence for decreased HRQOL and increased incidence of psychiatric disorders seems fairly consistent across studies, the evidence for lowered self-esteem, symptoms of depression and anxiety (measured by self-report measures), impaired social competence and behavioural functioning is less clear due to conflicting results. In order to make sense of these findings, confounding factors that may have influenced outcomes will be considered and placed in the context of other research.

Self-report vs. parent report

The majority of studies assessing self-esteem using self-report measures found that young people with IBD reported comparable self-esteem to healthy peers. These findings are surprising given the number and extent of bodily changes associated with IBD e.g. steroidal weight gain, surgical scars and colostomy bags. In comparison with adults, children and adolescents with IBD often have the added burden of delayed puberty and slowed growth. In a study using a disease specific HRQOL instrument, the IMPACT, body image was found to be impaired in adolescents with IBD (34). Research on the incidence of body image disturbances in children with IBD, although studied in other chronically ill children (e.g. those with diabetes), is conspicuously absent from the research literature.

In making sense of the unimpaired levels of self-esteem, in addition to the inconsistent evidence for anxiety and depression, the discrepancy between findings of studies using self-report and parent-report measures needs to be considered. Research findings indicate that young people with IBD may have difficulty reporting psychological symptoms (31) and tend to report fewer symptoms compared with their parents (22,23,29). A study by Canning (53) found a similar discrepancy in reporting with a sample of children with other chronic illnesses (including cancer, cystic fibrosis and diabetes) and their parents. In the healthy comparison group, however, children reported symptoms more frequently than their parents (53).

It has been suggested that the under-reporting or minimising of symptoms seen in young people with IBD could be due to denial which may be adaptive in buffering them from experiencing the full impact of the disease. Indeed two studies have found that young people with IBD tend to use more avoidant coping styles than healthy peers (27,31). Conversely, it

is possible that young people with IBD are reporting symptoms accurately and it is their parents, who are themselves depressed, anxious or over-involved with their children, that are pathologising normal behaviour and *over*-reporting symptoms compared to parents of non-chronically ill children.

Disease severity

Disease severity may also contribute to the variation in results. Increased disease severity was found to correlate with increased depression (37), lowered self-esteem (33) and decreased HRQOL (29,35,36). It seems intuitive that young people experiencing more severe symptoms would report lower HRQOL than those in remission. Most of the studies reviewed had large proportions of participants categorised with either 'mild' or 'moderate' disease severity. Therefore information about the difficulties experienced by individuals with more severe symptoms may be missing. The underrepresentation of this group may also make correlations between severity and psychosocial functioning more difficult to see. A number of studies found no association between disease severity and psychopathology (4,17,18,28).

There is, however, some evidence that psychosocial factors are more predictive of emotional and behavioural functioning than disease factors (24,28). Indeed, low socio-economic status has been found to correlate with increased depression (32) and decreased self-esteem (33), while parental separation correlated with reduced self-esteem (33). This is consistent with research in the general population where these factors are considered to increase risk for psychological difficulties (54). It is of interest to note that children with IBD have a consistently higher proportion of co-habiting or married parents than those in healthy control groups (31). Perhaps parents stay together to care for their sick child, or alternatively young

people from more stable family backgrounds are more likely to have their IBD diagnosed and treated.

Age

Age may also be predictive of HRQOL. Loonen *et al.* (34) found that while adolescents with IBD had impaired HRQOL, younger children had comparable or better HRQOL than healthy peers. A longitudinal study examining HRQOL over the first year of diagnosis (36) reported that for each increasing year of age, there was an associated five point decrease in self-reported HRQOL. Similarly, Szigethy *et al.* (37) noted that diagnosis later in childhood was associated with increased depressive symptoms. It is possible that IBD has a greater detrimental impact on the adolescent's ability to complete developmental tasks (such as developing independence and autonomy) and subsequently causes greater psychological distress. In light of these findings, examining children and adolescents as one group may lead to difficulties being masked. Additionally, the validity of making comparisons between developmentally delayed adolescents with IBD and controls matched on chronological age should be questioned.

Time since diagnosis

Individuals with a wide range of disease durations were included in the reviewed studies, from recent onset to more than one year post diagnosis. While Burke *et al.* (28) did not find HRQOL scores were predicted by time since diagnosis, they were examining recent-onset cases (<1-2 months). A longitudinal study found improvements in HRQOL over the first six months following diagnosis which persisted over the course of the first year (36). Difficulties in psychosocial functioning/HRQOL seen prior to six months post-diagnosis are perhaps more likely to be normal adjustment reactions to being acutely unwell and receiving a

diagnosis of a chronic illness. Therefore the stage at which HRQOL is assessed may determine what is actually being measured and affect the results.

Strengths and weaknesses of the evidence

The reviewed studies have a number of methodological limitations which make interpreting this body of evidence quite challenging. The frequent lack of comparison groups and reliance on normative data makes it difficult to determine whether differences are due to cohort effects or impact of the disease. While there may not be large numbers of young people with IBD experiencing clinically significant symptoms, there may be subsets that are impaired and would benefit from extra support from their Gastroenterology team. Standardised, validated measures that provide T scores would allow the clinical significance of results to be determined.

The small sample sizes, which are common and often unavoidable in paediatric research, make it more difficult to determine the validity of significant results. None of the included studies based sample size on a power calculation and only one calculated effect sizes for their results. The majority of studies included participants from a wide age-range with varying disease severity and disease durations. This review indicates that these factors may have an influence on HRQOL and as such should be considered carefully in the study design and analysis. Inclusion and exclusion criteria were often not reported in sufficient detail. All studies, bar one, used a cross-sectional design which means causality cannot be determined.

It should be noted, however, that more recently published studies appear to be addressing some of the limitations outlined above. Otley *et al.*'s (36) ongoing longitudinal study will provide valuable information about HRQOL over time. Since the validation of an IBD

specific HRQOL measure (the IMPACT) a growing number of studies are reporting robust results that allow easy comparison. There has also been an increase in the use of objective, standardised disease severity rating questionnaires (such as the Pediatric Crohn's Disease Activity Index; PCDAI) (55) allowing for more accurate recording and better comparison between studies.

Strengths and weaknesses of the review

This review used an extensive search strategy to identify all relevant studies to the review question. The strict inclusion and exclusion criteria ensured that only articles with a high level of methodological quality were included. Despite these strengths there are several weaknesses that should be considered when interpreting the conclusions of this review. Due to time constraints it was not possible to conduct hand searches of major journals in the field nor to independently quality rate all included studies. For the same reason, unpublished studies and articles not available in English were not included in the review. This may have resulted in a publication bias in the included studies. Due to the diverse measures used on a wide range of outcomes it was not possible to conduct statistical analysis in this review.

Conclusions

Due to the conflicting findings, methodological variation and limitations of the research in this field only tentative conclusions can be drawn. Young people with IBD appear to be at a higher risk of reduced HRQOL and of developing psychiatric conditions such as anxiety or depression compared to their healthy peers. There may be a higher incidence of low self-esteem, self-reported symptoms of depression and anxiety, impaired social competence and internalising behaviour problems.

More research, however, is required. This needs to take into account the discrepancy in child and parent reporting by using multiple informants; addressing the issue of disease severity by either ensuring groups are more homogenous or using statistical techniques to adjust for variation; and addressing the issue of age by examining children and adolescents separately. In order to avoid pathologising normal adjustment reactions and labelling young people with psychiatric diagnoses, only those who have had sufficient time to adjust to their IBD diagnosis should be recruited. Ensuring studies have larger sample sizes informed by a power calculation where appropriate, using standardised well-validated measures, and reporting results more consistently would increase the quality of this area of research. Research into body image would be timely as this appears to be an under-researched area.

Developing a clearer understanding of the impact of IBD on HRQOL and psychosocial functioning would be beneficial for clinical staff working with this illness group as it would allow early interventions to be targeted to those most at risk. This may prevent more serious mental health problems, difficulties with adherence, and possibly increased disease activity in the future.

Reference List

(* indicates study included in the review)

1. Kim SC, Ferry GD. Inflammatory bowel diseases in pediatric and adolescent patients: clinical, therapeutic, and psychosocial considerations. *Gastroenterology* 2004;126:1550-1560.

2. Armitage E, Drummond HE, Wilson DC, et al. Increasing incidence of both juvenile-onset Crohn's disease and ulcerative colitis in Scotland. *Eur J Gastroenterol Hepatol* 2001;13.

3. Engstrom I. Inflammatory bowel disease in children and adolescents: mental health and family functioning. *J Pediatr Gastroenterol Nutr* 1999;28:S28-S33.

4. Mackner LM, Crandall WV. Long-term psychosocial outcomes reported by children and adolescents with inflammatory bowel disease. *Am J Gastroenterol* 2005;100:1386-1392. *

5. Szajnberg N, Krall V, Davis P, et al. Psychopathology and relationship measures in children with inflammatory bowel disease and their parents. *Child Psychiatry Hum Dev* 1993;215-232. *

6. Drossman DA, Patrick DL, Mitchell CM, et al. Health-related quality of life in inflammatory bowel disease: functional status and patient worries and concerns. *Dig Dis Sci* 1989;34:1379-1386.

7. Hommel KA, Denson LA, Crandall WV, et al. Behavioral functioning and treatment adherence in pediatric inflammatory bowel disease: review and recommendations for practice. *Gastroenterol Hepatol* 2008;4:785-791.

8. Mittermaier C, Dejaco C, Waldhoer T, et al. Impact of depressive mood on relapse in patients with inflammatory bowel disease: a prospective 18-month follow-up study. *Psychosom Med* 2004;66:79-84.

9. Varni JW, Seid M, Kurtin PS. Reliability and validity of the pediatric quality of life inventory version 4.0 generic core scales in healthy and patient populations. *Med Care* 2001;39:800-812.

10. Griffiths AM, Nicholas D, Smith C, et al. Development of a quality-of-life index for pediatric inflammatory bowel disease: dealing with differences related to age and IBD type. *J Pediatr Gastroenterol Nutr* 1999;28:S46-S52.

11. Otley A, Smith C, Nicholas D, et al. The IMPACT questionnaire: a valid measure of health-related quality of life in pediatric inflammatory bowel disease. *J Pediatr Gastroenterol Nutr* 2002;35:557-563.

12. Mackner LM, Crandall WV. Psychological factors affecting pediatric inflammatory bowel disease. *Curr Opin Pediatr* 2007;19:548-552.

13. Szigethy E, Carpenter J, Baum E, et al. Case study: Longitudinal treatment of adolescents with depression and inflammatory bowel disease. *J Am Acad Child Adolesc Psychiatry* 2006;45:396-400.

14. Sign 50: *A Guideline Developer's Handbook, methodology checklists*. Scottish Intercollegiate Guidelines Network; 2004.

15. CASP. Critical Apraisal Skills Programme. Public Health Resource Unit. Oxford. 2004. Available at: http://www.phru.nhs.uk/pages/phd/resources.htm. Accessed 28 December, 2009.

16. Burke P, Kocoshis SA, Chandra R, et al. Determinants of depression in recent onset pediatric inflammatory bowel-disease. *J Am Acad Child Adolesc Psychiatry* 1990;29:608-610.

17. Cotton S, Kudel I, Humenay Roberts Y, et al. Spiritual well-being and mental health outcomes in adolescents with or without inflammatory bowel disease. *J Adolesc Health* 2009;44:485-492.

18. Engstrom I, Lindquist BL. Inflammatory bowel-disease in children and adolescents - a somatic and psychiatric investigation. *Acta Paediatr Scand* 1991;80:640-647.

19. Engstrom I. Family interaction and locus of control in children and adolescents with inflammatory bowel disease. *J Am Acad Child Adolesc Psychiatry* 1991;913-920.

20. Janicke DM, Gray WN, Kahhan NA, et al. Brief report: the association between peer victimization, prosocial support, and treatment adherence in children and adolescents with inflammatory bowel disease. *J Pediatr Psychol* 2009;34:769-773.

21. Loonen HJ, Grootenhuis MA, Last BF, et al. Measuring quality of life in children with inflammatory bowel disease: the Impact-II (NL). *Qual Life Res* 2002;11:47-56.

22. Loonen HJ, Derkx BHF, Koopman HM, et al. Are parents able to rate the symptoms and quality of life of their offspring with IBD? *Inflamm Bowel Dis* 2002;8:270-276.

23. Mackner LM, Crandall WV. Brief report: Psychosocial adjustment in adolescents with inflammatory bowel disease. *J Pediatr Psychol* 2006;31:281-285.

24. MacPhee M, Hoffenberg EJ, Feranchak A. Quality-of-life factors in adolescent inflammatory bowel disease. *Inflamm Bowel Dis* 1998;4:6-11.

25. Moody G, Eaden JA, Mayberry JF. Social implications of childhood Crohn's disease. *J Pediatr Gastroenterol Nutr* 1999;28:S43-S45.

26. Perrin JM, Kuhithau K, Churhtai A, et al. Measuring quality of life in pediatric patients with inflammatory bowel disease: psychometric and clinical characteristics. *J Pediatr Gastroenterol Nutr* 2008;46:164-171.

27. Van Der Zaag-Loonen HJ, Grootenhuis MA, Last BF, et al. Coping strategies and quality of life of adolescents with inflammatory bowel disease. *Qual Life Res* 2004;13:1011-1019.

28. Burke PM, Neigut D, Kocoshis S, et al. Correlates of depression in new-onset pediatric inflammatory bowel-disease. *Child Psychiatry Hum Dev* 1994;24:275-283. *

29. Cunningham C, Drotar D, Palermo TM, et al. Health-related quality of life in children and adolescents with inflammatory bowel disease. *Children's Healthcare* 2007;36:29-43. *

30. De Boer M, Grootenhuis M, Derkx B, et al. Health-related quality of life and psychosocial functioning of adolescents with inflammatory bowel disease. *Inflamm Bowel Dis* 2005;11:400-406. *

31. Engstrom I. Mental health and psychological functioning in children and adolescents with inflammatory bowel-disease - a comparison with children having other chronic illnesses and with healthy children. *J Child Psychol Psychiatry* 1992;33:563-582. *

32. Gold N, Issenman R, Roberts J, et al. Well-adjusted children: an alternate view of children with inflammatory bowel disease and functional gastrointestinal complaints. *Inflamm Bowel Dis* 2000;6:1-7. *

33. Lindfred H, Saalman R, Nilsson S, et al. Inflammatory bowel disease and self-esteem in adolescence. *Acta Paediatr* 2008;97:201-205. *

34. Loonen HJ, Grootenhuis MA, Last BF, et al. Quality of life in paediatric inflammatory bowel disease measured by a generic and a disease-specific questionnaire. *Acta Paediatr* 2002;91:348-354. *

35. Marcus SB, Strople JA, Neighbors K, et al. Fatigue and health-related quality of life in pediatric inflammatory bowel disease. *Clin Gastroenterol Hepatol* 2009;7:554-561. *

36. Otley AR, Griffiths AM, Hale S, et al. Health-related quality of life in the first year after a diagnosis of pediatric inflammatory bowel disease. *Inflamm Bowel Dis* 2006;12:684-691. *

37. Szigethy E, Levy-Warren A, Whitton S, et al. Depressive symptoms and inflammatory bowel disease in children and adolescents: a cross-sectional study. *J Pediatr Gastroenterol Nutr* 2004;39:395-403. *

38. Ouvinen-Birgerstam P. *Jag tycker jag ar. Manual* (in Swedish). Stockholm: Psykologiforlaget; 1985.

39. Piers EV, Harris DB. Age and other correlates of self-concept in children. *J Educ Psychol* 1964;55:91-95.

40. Treffers DA, Goedhart AW, Veerman JW, et al. *Competentiebelevingsschaal voor Adolescenten*. Swets & Zeitlinger BV; 2002.

41. Landgraf JM, Abetz L, Ware JE. *The CHQ User's Manual*. 1st ed. Boston: The Health Institute: New England Medical Centre; 1996.

42. Landgraf JM, Abetz LN. The physical and psychosocial well-being of children representing three cultural groups: inital self-reports using the Child Health Questionnaire (CHQ-CF87). *Psychology and Health, Quality of Life: Recent Advances in Theory and Methods* 1997;12:1-16.

43. Kolsteren MM, Koopman HM, Schalekamp G. Health-related quality of life in children with celiac disease. *J Pediatri* 2001;138:593-595.

44. Vogels T, Verrips GHW, Koopman HM. *TACQOL manual: parent form and child form*. Leiden: Leiden Centre for Child Health and Pediatrics LUMC-TNO; 2000.

45. *Diagnostic and Statistical Manual of Mental Disorders*, Third Edition, Revised: DSM-III-R. Washington, DC: American Psychiatric Association; 1987.

46. Hodges K, Kline J, Fitch P, et al. The Child Assessment Schedule: a diagnostic interview for research and clinical use. *Catalog of Selected Documents in Psychology* 1981;11:56.

47. Orvaschel H, Puig-Antich J, Chambers W, et al. Retrospective assessment of pre-pubertal major depression with K-SADS-E. *J Am Acad Child Psychiatry* 1982;21:392-397.

48. Kaufman J, Birmaher B, Brent D, et al. *Schedule for affective disorders and schizophrenia for school age children: present and lifetime version (K-SADS-PL).* Pittsburgh: Department of Psychiatry: University of Pittsburgh School of Medicine; 1996.

49. Kovacs M. *Children's Depression Inventory (CDI).* New York: Multi-Health Systems; 1992.

50. Reynolds CR, Richmond BO. *Revised Children's Manifest Anxiety Scale Manual*. Los Angeles, CA: Western Psychological Services; 2000.

51. Achenbach TM. *Manual for the Child Behaviour Checklist (CBCL).* Burlington, VT: University Associates of Psychiatry; 1988.

52. Achenbach TM. *Manual for the Youth Self-Report*. Burlington: University of Vermont, Department of Psychiatry; 1991.

53. Canning EH. Mental disorders in chronically ill children: case identification and parent-child discrepancy. *Psychosom Med* 1994;56:104-108.

54. Carr A. *The Handbook of Child and Adolescent Clinical Psychology: A Contextual Approach,* 2nd ed. London: Routledge; 1999.

55. Hyams JS, Ferry GD, Mandel FS. Development and validation of a pediatric Crohn's disease activity index. *J Pediatr Gastroenterol Nutr* 1991;12:439-447.

Figure 1: Flow chart of study selection process

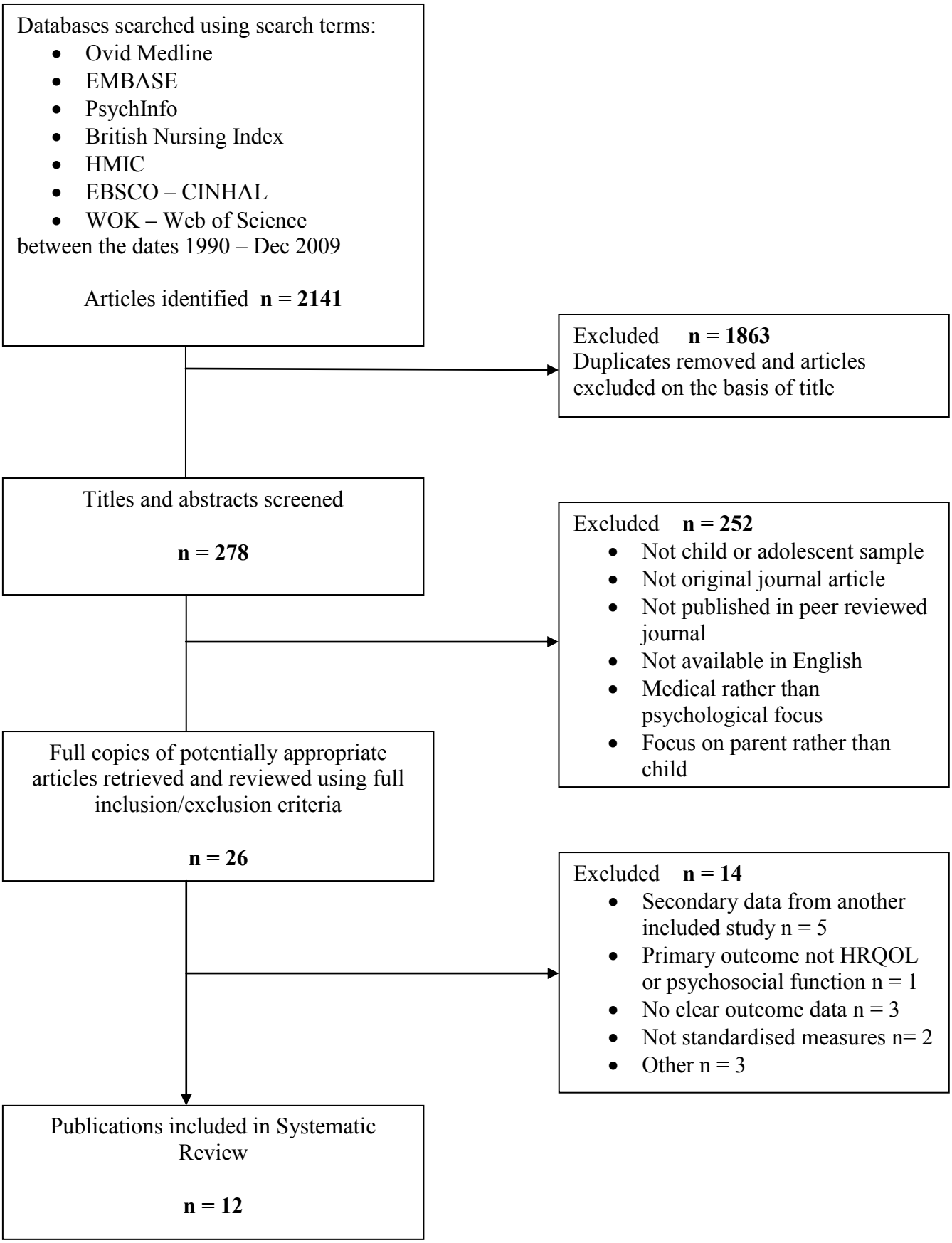

Table 1: Table summarising studies included in systematic review

Study	Country	Participants (IBD: n) (Controls: n)	Age range	Diagnosis (CD, UC or IC)	Time since diagnosis	Outcomes assessed	Assessments	Self-report or parent-report	Significant results
Burke et al., 1994	USA	IBD: 36 No control group	No info Mean age: 11.98yrs	CD or UC	>1-2months Mean duration: 3.5months	Depression Anxiety (maternal depression life events family relationships)	Kiddie-SADS interview FRI A-SADS-L interview FILE	Parent & self-report	14% met diagnostic criteria for major depression, 28% for atypical depression 10 children had a history of anxiety. The depressed group was less severely ill than the non depressed group (p=0.006)
Cunningham et al., 2007	USA	IBD: 49 Healthy controls: 49	10-18 yrs Mean age: 14.96yrs	'IBD' no further info	No info Mean duration: no info	HRQOL	Child Health Questionnaire (CHQ)	Parent & child versions	*Parent report*: IBD group significantly impaired HRQOL compared to controls (Physical Health score p<0.000, Psychosocial score p<0.05). *Child report:* No significant differences in HRQOL compared to controls (except in general health).

De Boer et al., 2005	Netherlands	IBD: 40 Healthy children: 1359 (reference data DUCATQOL)	12-18 yrs Mean age: 15.2yrs	CD, UC or IC	≥6 months Mean duration: 3.8yrs	HRQOL Self-esteem Anxiety (trait) Behaviour problems	DUCATQOL Dutch version SPPA Dutch version STAI CBCL	Self-report x3, parent completed CBCL	Boys with IBD had significantly worse HRQOL ($p<0.01$) & more behavioural problems ($p<0.05$) & internalising behaviour ($p<0.01$) compared to healthy peers. Girls had more internalising behaviour ($p<0.05$) only. No significant differences in state anxiety or self-esteem compared to controls.
Engstrom, 1992	Sweden	IBD: 20 Headache control: 20 Diabetes control: 20 Healthy control: 20	7-18 yrs Mean age: 16.5yrs	UC or CD	No info Mean duration 4.2yrs (range 1.0-8.2yrs)	Psychological adjustment Social competence Well-being Emotional adjustment Psychiatric disorders Self-esteem Depression Anxiety Cognitive abilities	CBCL Frisk Well-being scale Rotter sentence completion test ITIA CDI RCMAS Raven's matrices CAS	Parent-report, self-report & child interview	On most variables children with IBD had highest levels of psychiatric disturbance i.e. IBD > healthy children for behaviour problems ($p<0.03$); social competence ($p<0.04$); emotional adjustment ($p=0.001$); psychiatric disorders ($p=0.01$); self-esteem ($p<0.01$) & depression ($p<0.02$).

Gold et al., 2000	Canada	IBD: 36 Functional Gastrointestinal Complaints (FGI) controls: 26	8-18 yrs Mean age: 13.31yrs	UC or CD Excluded if had a colectomy	No info Mean duration: 2yrs	Depression Self-concept Social adjustment	CBCL CDI Piers Harris Children's Self concept Questionnaire developed by researchers	Self-report & parent-report	IBD group were less depressed & had fewer behaviour problems than controls ($p=0.03$). No scores were in the clinical range. Children with IBD have a higher than average self-concept.
Lindfred et al., 2008	Sweden	IBD: 71 Previously collected healthy reference group: 1037 Normative data from ITIA: 2662	10-16 yrs Mean age: 14.6yrs	CD, UC or IC	>6 months Mean duration: 2.9yrs	Self-esteem	I think I am (ITIA)	Self-report	No significant difference in self-esteem between IBD group & comparison or normative group.
Loonen et al., 2002	Netherlands	IBD: 83 Dutch school children controls: 1810	8-18 yrs Mean age: 14.3yrs	CD, UC or IC	>6 months Mean duration: no info	HRQOL	TACQOL IMPACT III (NL)	Self-report	Adolescents with IBD had significantly lowered HRQOL on 4 domains ($p<0.05$). Younger children had comparable or better HRQOL than healthy peers.

Mackner & Crandall, 2005	USA	IBD: 50 Healthy controls: 42	11-17yrs Mean age: 14.69yrs	CD, UC or IC	>1 year Mean duration: 3.53yrs	Psychosocial functioning: Behavioural/ emotional functioning Social competence Self-esteem Coping strategies Social support	YSR CDI RCMAS PHSCS Coping Strategies Inventory Social Support Questionnaire	Self-report	No significant differences on any measures.
Marcus et al., 2009	USA	IBD: 70 Healthy controls: 157	10-17yrs Mean age: 14.1yrs	CD, UC or IC	>3months Mean duration: 34 months	HRQOL Fatigue	PEDS-QL Multi-dimensional Fatigue Scale PEDS-QL 4.0 IMPACT III CDI-SF	Self-report & parent-report	IBD group had significantly lower generic HRQOL than healthy controls ($p<0.0001$). No significant difference in depressive symptoms between IBD & controls.
Otley et al., 2006	USA & Canada	IBD: 218 No controls	>9yrs Mean age: 12.7yrs	CD, UC or IC	0 months – followed up to 1 year	HRQOL	IMPACT III	Self-report	Significant improvement in HRQOL scores 1yr post-diagnosis ($p<0.05$).

Szajnberg et al., 1993	USA	IBD: 15 No controls	No info (appears to be 4.92-15yrs) Mean age: 11.6yrs	CD or UC	0 months	Psychopathology child & parent Maternal attachment Attachment related disorders in children (separation anxiety, dysthymia/ depression) OCD disorder children	K-SADS-P interview AAI CBCL MCMI Locke Wallace Mental Scale FILE IOF COBI Irvine Sentence Completion Test WISC-R TAT	Mostly parent-report or interview with parents. Some interview /assessment of child but no self-report measures	73% had DSM-III diagnoses (predominantly separation anxiety & major depression), a significant number showed internalising behaviour ($p<0.01$).
Szigethy et al., 2004	USA	IBD: 102 No controls	11-17yrs Mean age: 14.7 yrs	CD or UC	No info Mean duration: 2.4yrs (range 0-9.7yrs)	Depression (& its relationship with disease factors)	CDI SADS-PL if scored >12 on CDI	Self-report, clinical interview with child & parent	High rates of clinically significant depressive symptoms in older children & adolescents with IBD. 25% had depressive symptoms ($\geq$12 CDI) & 16/19 psychiatrically interviewed had clinically significant depressive disorder.

Key to terms used in Table 1

AAI: Adult Attachment Interview
A-SADS-L: Adult Schedule for Affective Disorders
and Schizophrenia, Lifetime Version
CAS: Children's Assessment Schedule
CBCL: Child Behaviour Checklist
CDI: Child Depression Inventory (SF: short form)
DUCATQOL: The Dutch Children's AZL/TNO Quality of FILE: Family Inventory for Life Events
FRI Family Relationship Index Scale
ITIA: I think I am
IOF: Impact of Events Scale
IMPACT III: IBD specific HRQOL instrument
K-SADS-P: Kiddie Schedule for Affective Disorders and Schizophrenia
MCMI: Millon Clinical Multi-Axial Inventory
PHSCS: Pier's Harris Children's Self-Concept Scale
RCMAS: Revised Children's Manifest Anxiety Scale
SADS-PL: Schedule for Affective Disorders and Schizophrenia for School Aged Children – Present & Lifetime Version
SPPA: Self Perception Profile for Adolescents (Dutch version)
STAI: State-Trait Anxiety Inventory for Children (Dutch version)
TACQOL: TNO-AZL Children's Quality of Life
TAT: Thematic Apperception Test
WISC-R: Weschler Intelligence Scale Revised
YSR: Youth Self-Report Scale
Life Questionnaire
COBI: Clinician's Objective Burden Index

Chapter 2

Major Research Project

A Comparison of Psychosocial Functioning between Early, Mid and Late Adolescence in Young People with Inflammatory Bowel Disease

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Written according to guidelines for submission to
*Inflammatory Bowel Disease*s (See Appendix 2.1)

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Abstract

Background: The onset of Inflammatory Bowel Disease (IBD) is highest during adolescence. The symptoms may make the essential developmental transitions associated with this stage more challenging and cause difficulties in psychosocial functioning. While previous research has compared adolescents with IBD to healthy controls, it may be more informative to take a developmental approach, examining psychosocial functioning within the early, mid and late stages of adolescence.

Aims: The primary aim of this exploratory study was to investigate whether stage of adolescence has an effect on social functioning, body image and self-esteem in adolescents with IBD. The secondary aims were to determine whether stage of adolescence has an effect on mood, and whether demographic and disease factors have an effect on outcome measures.

Methods: 63 adolescents aged between 11 and 17 years with IBD were recruited from a gastroenterology outpatient clinic. Each adolescent completed measures of social functioning, body image, self-esteem and mood. Demographic and disease information was also gathered. Outcome measures were compared between the three groups (early, mid and late adolescence) using parametric and non-parametric statistical tests.

Results: There were no significant differences in any of the outcomes between the three groups. The only significant finding from regression analysis was that gender significantly predicted self-esteem. Nearly half the sample reported impaired social functioning and a quarter had significant levels of anxiety.

Conclusions: Stage of adolescence was not found to have an effect on psychosocial functioning or mood in this population. The small sample size, assigning developmental groups according to age and the mild disease severity of participants limit the conclusions that can be drawn from this study.

Introduction

Inflammatory Bowel Disease (IBD) is caused by chronic inflammation of the gastrointestinal tract and comprises three disorders: Crohn's disease (CD), ulcerative colitis (UC) and indeterminate colitis (IC). These conditions can cause recurring symptoms including frequent diarrhoea, abdominal pain, fatigue, perianal disease, poor appetite, nausea, delayed puberty, weight loss and growth delay. The onset of IBD within childhood years is reported to be highest in adolescence (1).

Adolescence and IBD

During adolescence, there are a number of biological, psychological and social changes that may make coping with a chronic disease more challenging (2). From a psychosocial perspective the tasks of adolescence are to establish an identity, develop peer and romantic relationships and establish greater independence and autonomy (3). Adolescence can be considered as consisting of three developmental stages: early (ages 11-13), middle (14-15) and late (16-18), although some degree of overlap is inevitable (4).

Early adolescence can be characterised by the tremendous assimilation of new experiences, including the physical changes of puberty and social changes such as moving to high school. These introduce new demands requiring more sophisticated social and cognitive skills. Conflict between young people and their parents tends to increase at the start of puberty, while greater importance is placed on friendships and being part of the crowd.

In mid adolescence there is a peak in preoccupation with others', especially peers', view of self (5). Self-esteem has been shown to dip in early to mid adolescence (6). At this stage

young people are often concerned with establishing their independence and autonomy, tending to spend more time with their friends, or alone, than with their parents.

In late adolescence rising levels of self-esteem (7) are accompanied by decreasing levels of family conflict. Some young people may have developed formal operational cognitive skills (8) and be able to solve abstract problems. One of the key tasks of this stage is forming emotionally intimate partnerships, and beginning to develop a clear self-identity. At this stage adolescents may be more future oriented, thinking in terms of further education, jobs and life goals.

The symptoms of IBD can make it more difficult for adolescents to complete the essential developmental transitions outlined above. During a 'flare-up' when the disease is active, they may need to spend a great deal of time in the bathroom and fear becoming a target for 'bathroom humour'. The perceived need to be near a bathroom at all times may also limit social activities. Adolescents are likely to miss considerable time off school due to illness and hospital appointments, affecting both academic work and peer relationships.

Studies of psychosocial functioning

Studies examining social functioning in adolescents with IBD have had mixed outcomes. Studies using self-report norm-referenced measures of social competence found mean scores in the average range (9,10), whilst others using comparison groups and parent-report measures found lower social competence scores in young people with IBD than in healthy comparison groups (11,12).

Some adolescents with IBD will undergo surgery or have a colostomy bag which can lead to reluctance to engage in peer or intimate relationships, as well as having an impact on body image. Delayed puberty and slowed growth, in addition to side effects from steroids such as weight gain or facial changes, may also impact on body image and self-esteem. There has been little research to date on the impact of IBD on body image, although population based studies suggest that adolescents with a chronic illness report higher body dissatisfaction than healthy adolescents (13). Loonen *et al.* (14) found adolescents with IBD had significantly impaired scores on the body complaints domain of a health-related quality of life (HRQOL) measure. Conversely, a more recent study using a norm-based scale to assess feelings about physical appearance found mean scores in the average range and no difference between young people with IBD and healthy controls (10). It should be noted, however, that to the author's knowledge no specific measures of body image have been administered to adolescents with IBD.

Studies examining self-esteem in this population using norm-based questionnaires report mean scores in the average range (9,10,15*)* and comparable levels of self-esteem to healthy adolescent controls (16). Other studies using comparison groups, however, found that children and adolescents with IBD had significantly lower self-esteem than healthy controls (11,10).

While relatively little research has examined the areas mentioned above, studies investigating the prevalence of mood disorders in this population are more numerous. A recent review concluded that young people with IBD were more likely to meet criteria for anxiety or depression than healthy peers, but that rates of mood disorder were similar to those associated with other chronic illnesses (17). Research examining depression in the general population

suggests adolescents who have completed puberty have significantly higher rates of depression than their pre-pubertal peers (18).

HRQOL and IBD

Recently, several studies have used HRQOL, encompassing physical, social and psychological functioning, as a primary outcome measure. There are a number of factors that may impact upon HRQOL/psychosocial functioning. Most studies have found girls to have lower HRQOL than boys (14), although others have found no gender differences (16,19). In the adult literature, females have been found to have lower HRQOL than males (e.g. 20).

While HRQOL is found to improve significantly in the first six months post-diagnosis and then continue to improve throughout the first year (19), information on longer term functioning is not available. Disease type may impact on psychosocial functioning. The adult literature suggests patients with CD have reduced HRQOL compared to those with UC (e.g. 21). Loonen *et al.* (14) reported that young people with CD had lower HRQOL scores than those with UC, although these differences were not significant. CD was found to have a greater impact on social functioning than UC in one study (22) although other researchers found no difference (16,10).

Increasing age has been shown to be associated with more impaired psychosocial functioning and lower HRQOL (19,16,14). A longitudinal study of young people with IBD found that for each year of age gained, HRQOL scores decreased by five points (19). Recent cross-sectional studies report significant associations between age and self-esteem (with self-esteem being lower in mid adolescence) (16), and increasing age and more impaired emotional functioning (23). It has been suggested that this could be the result of the adolescent's increasing ability

to predict the long-term implications of their illness, in addition to the effects of IBD on their attainment of key developmental tasks (14).

Rationale to the proposed research

While research has started to examine the psychosocial sequelae of IBD in adolescents, it has primarily focussed on making comparisons between adolescents with IBD and their healthy peers. Adolescence is a time of transition, with a huge degree of heterogeneity within the 11 to 18 age group, making regarding this population as homogenous questionable. It therefore seems useful to take a between stage approach to exploring the psychosocial consequences of IBD in adolescence.

Lowered self-esteem, body dissatisfaction and impaired social functioning can be risk factors for later depression and anxiety (24); therefore, gaining a detailed picture of this population would have important service implications, allowing input to be targeted to the most vulnerable group to minimise the likelihood of future problems developing.

The aim of this study was to investigate the impact of IBD on psychosocial functioning in early, mid and late adolescence by addressing the following research questions:

(1) Does stage of adolescence have an effect on social functioning, body image and self-esteem?
(2) Does stage of adolescence have an effect on mood (anxiety and depression) and does mood correlate with social functioning, body image and self-esteem?
(3) If numbers permit, do disease type (CD, UC or IC), disease severity, disease duration, gender and socio-economic status have an effect on social functioning, body image and self-esteem in adolescents with IBD?

From the available research, the following tentative hypotheses were proposed:

(1) Younger adolescents will report less impairment in the areas of social functioning, body image and self-esteem than older adolescents.

(2) Younger adolescents will report fewer symptoms of anxiety and depression than older adolescents.

(3) Adolescents with CD will report greater impairment in the areas of social functioning, body image and self-esteem than adolescents with UC or IC.

Methods

This exploratory study uses a cross-sectional between groups design to compare psychosocial functioning in early, mid and late adolescence.

Ethical considerations

Ethical approval was granted by the West of Scotland Research Ethics Committee (09/S1001/54) as well as the local NHS Research and Development department (GN09GA437) (see Appendices 2.2-2.5).

Participants

Adolescents attending the gastroenterology outpatient clinic at The Royal Children's Hospital in Glasgow were recruited. All young people with a diagnosis of IBD in the west of Scotland attend this clinic and 170 of these are adolescents. Adolescents diagnosed for more than six months with CD, UC or IC, aged between 11-18 years old and attending mainstream high school were eligible for the study. Participants who had serious comorbid medical conditions, major psychiatric diagnoses or who had a level of impaired cognitive functioning which

would prevent them from being able to give informed consent or complete the questionnaires were excluded.

Justification of sample size

While no studies examining psychosocial functioning between the stages of adolescence could be identified, studies comparing psychosocial functioning and HRQOL in adolescents with IBD to healthy controls reported medium effect sizes (12,14,15). These papers provided the best available indication of likely effect size.

An initial power calculation[1], taking significance criterion (alpha) to be 0.05 and effect size to be medium (f = 0.25 according to Cohen, 26) indicated that a sample of 159 was required to give power of 0.8. Information from the research site, however, indicated a maximum of 100-110 adolescents as a realistic target in the available time period. With a sample of 105 (35 per group), a medium effect size (f = 0.25) and a significance criterion of 0.05, this study would have power of 0.6 to detect significant differences between groups.

Procedures

Two concurrent recruitment procedures were used to maximise sample size. Adolescents fulfilling inclusion criteria were either sent information packs the week prior to their outpatient appointment, or were sent information packs, consent forms and questionnaires at any time during the data collection period (December 2009 to April 2010) (see Appendix 2.6 and 2.7). The former (clinic) group were approached at the outpatient clinic and invited to participate. The latter (postal) group were asked to sign consent forms and return them by post. Reminders were sent to non-responders after three weeks. In order to encourage

[1] Calculated using an online power calculator (27).

participation gift vouchers were awarded to participants and all information packs included a covering letter co-signed by the Consultant Paediatrician (see Appendix 2.8). Of 132 adolescents approached 63 agreed to take part (48% response rate). 28 (44%) were recruited at clinic and 35 (56%) via postal methods.

Several measures (outlined below in the order they were administered) were used to gather information on psychosocial functioning. Participants recruited at the clinic were asked to complete questionnaires in a clinic room after giving consent. This took under 20 minutes during which time the main researcher was present in order to provide assistance where required. Participants recruited through the postal method signed appropriate consent forms and returned these in a pre-paid envelope. They then completed questionnaires assisted by an 'instruction sheet' (see Appendix 2.9) and returned these in a separate envelope.

Measures

1. **Social competence scale of The Youth Self Report checklist (YSR) (27)**

   This is one of the most widely used standardised assessments for measuring social competence in adolescents. The self-report social competence scale measures participation in hobbies, games, sports, chores, friendships and activities. Higher scores indicate better social competence. The YSR has adequate psychometric properties (27) and yields T scores which are a useful indicator of clinical significance.

2. **Revised Body-Esteem Scale (RBES) (28)**

   This measures adolescents' attitudes and feelings about their body and appearance. There are three subscales: general feelings about appearance, weight satisfaction, and

evaluations attributed to others about one's body and appearance. Respondents indicate their degree of agreement with 23 statements (e.g. "I like what I look like in pictures") using a five-point scale (see Appendix 2.10). This has been shown to be valid and reliable in a wide age range (29). Higher scores indicate better levels of body-esteem.

3. **The Rosenberg Self-Esteem Scale (RSES) (30,31)**

   This is a widely used and well validated brief (10 item) measure of global self-esteem for use with adolescents. Participants indicate the extent to which they agree with statements (e.g. "On the whole, I am satisfied with myself") on a four point scale. Higher scores indicate better self-esteem.

4. **Hospital Anxiety and Depression Scale (HADS) (32)**

   This is a brief (14 item) self-report measure developed for use with adult medical out-patients. Construct and concurrent validity have now been demonstrated in physically ill adolescents (aged 12-17) (33). The questionnaire has two subscales; one for depression and one for anxiety. A possible limitation was the use of the HADS with 11 year olds; however, by including only 11 year olds that had entered high school, participants should have had adequate cognitive skills to complete this measure. For this age group, it has been suggested that scores $\geq$9 and $\geq$7 indicate clinically significant symptoms of anxiety and depression respectively (33).

- Demographic information including age, gender, socio-economic status (by post-code using the Scottish Index of Multiple Deprivation, SIMD) (34) and family composition was collected via a brief (four item) questionnaire given to adolescents (see Appendix 2.11).

- Current disease severity was measured using the Pediatric Crohn's Disease Activity Index (PCDAI) (35) and the Pediatric Ulcerative Colitis Activity Index (PUCAI) (36). The PCDAI and PUCAI have good reliability and validity and are collected routinely by the gastroenterology team.

- Additionally, information on total number of admissions to hospital, length of time in hospital, disease duration, current medication, referral to psychology and whether the adolescent had undergone resectional or non-resectional surgery was gathered from patient files.

Data Analysis

Data screening revealed that data was normally distributed for some outcomes (social functioning and self-esteem) and non-normally distributed for others (body image, depression and anxiety). As a result either parametric or their non-parametric equivalents were used where appropriate. A Kruskal-Wallis one-way analysis of variance was conducted to compare demographic variables between the three groups.

Primary analyses: Psychosocial functioning was compared between the three age groups (early, mid and late) using analysis of variance (ANOVA) for social functioning and self-esteem, and Kruskal-Wallis for body image, depression and anxiety.

Secondary analyses: A Spearman's rho was conducted to determine whether mood (anxiety and depression) correlated with social functioning, body image and self-esteem. A pre-planned multiple linear regression analysis was conducted to determine the effect of other variables on outcome. Social functioning was used as the outcome variable while age, gender,

socio-economic status (SES), disease type (CD or UC), disease duration, disease severity (coded as 'active' or 'in-remission' from PCDAI or PUCAI scores) and stage of adolescence were entered as predictors in a single entry procedure. This was repeated for self-esteem (the only other variable to meet the assumptions for regression). The poorest predictors were excluded so that the final model included gender, diagnosis, SES and stage of adolescence. On the basis of the results of the regression, interactions between gender and stage of adolescence were added to the model. The difference between the two models was compared using an F-test. All analyses were performed using SPSS version 18.

Results

Demographic features of sample

Data was gathered from 63 adolescents between 11 and 17 years of age (mean: 13.75 years, SD 1.7). There were 27 adolescents in the early, 25 in the mid, and 11 in the late group. There was a nearly equal ratio of males to females (32:31), 68% had CD, 21% UC and 11% IC. Participants had a mean disease duration of 3.3 years (SD 2.1) and the majority were either in remission (57%) or had mild disease activity (38%). 33% of the total sample had been referred for psychological input. No significant differences were found between groups on demographic variables apart from admissions to hospital ($p<0.05$) (see Table 1).

INSERT TABLE 1 HERE

Clinical significance

Clinical normative data were only available for the YSR and HADS. Mean YSR social competence T scores were in the 'normal range' for 55%, 'borderline range' for 10% and

'clinical range' for 35% of the whole sample (n=58[2]). The HADS provides clinical cut-offs for anxiety and depression. In this sample (n=63) 11% and 27% reported clinically significant symptoms of depression and anxiety respectively (see Table 2 and Appendix 2.12).

INSERT TABLE 2 HERE

Stage of adolescence and psychosocial functioning (including mood)

There were no significant differences between the early, mid and late groups on any outcome measures: social functioning ($F(2) = 1.12$, ns), self-esteem ($F(2) = 0.07$, ns), body image ($H(2) = 1.93$, ns), anxiety ($H(2) = 1.18$, ns) or depression ($H(2) = 0.26$, ns) (see Table 3). All effect sizes were small (see Table 4). Both depression and anxiety were found to be positively correlated with each other and significantly negatively correlated with body image and self-esteem ($p<0.01$) but only depression was significantly negatively correlated with social functioning ($p<0.01$). All outcomes significantly correlated with one another with the exception of body image and social functioning (see Table 5).

INSERT TABLES 3, 4 AND 5 HERE

Other factors that may influence psychosocial functioning

Multiple linear regression using gender, diagnosis[3], SES and stage of adolescence as predictor variables with social functioning and self-esteem as outcomes, revealed that only gender significantly predicted the outcome of self-esteem ($p<0.01$). Females were more likely

[2] Some participants did not fully complete the YSR. Missing data was dealt with by excluding cases listwise.

[3] Only CD and UC were used in the regression due to the small number of participants in the IC group.

to have low self-esteem than males. The addition of the interaction between gender and stage of adolescence to the regression model did not significantly predict social functioning or self-esteem (see Tables 6 and 7).

INSERT TABLES 6 AND 7 HERE

Discussion

Synopsis of findings

The results of this study suggest that levels of psychosocial functioning do not differ between early, mid and late adolescence in young people with IBD. There were no significant differences in any of the outcomes between the three age groups. Overall social competence was not found to be more impaired in the IBD sample than for the healthy population from which normative data were gathered, and mean depression and anxiety scores were below clinical cut-offs. There were quite sizeable subsets, however, of adolescents with clinically significant levels of impaired social functioning and anxiety. Nearly half the sample reported impaired social functioning and a quarter had significant levels of anxiety. Regression analysis found that gender significantly predicted self-esteem, with females showing more impairment than males. There was no effect of disease type, disease severity, duration of disease or SES on the outcomes of social functioning or self-esteem. Correlations between measures of mood and psychosocial functioning were all significant and in the expected direction apart from those between social functioning and anxiety, and social functioning and body image; both of these were non-significant but in the expected direction.

Possible explanations in the context of existing research

Stages of adolescence and psychosocial functioning

The main finding, that psychosocial functioning does not appear to be influenced by developmental stages, corresponds with studies where correlations between age and HRQOL in adolescents with IBD were not found (15,37). Other studies, however, provide evidence that age is correlated with HRQOL (14,19), self-esteem (16) and emotional functioning (23). It is possible that age *does* play a role but the small sample size of this study provided insufficient power to detect significant differences between groups. The small effect sizes, however, would suggest that even with a much larger sample significant differences between groups (particularly for self-esteem and body image) would not have been seen. Therefore, either developmental stage has no effect on psychosocial functioning and the primary hypothesis can be rejected, or there is an alternative explanation as to why differences were not seen between groups in this study.

Some variation with age would be expected across adolescence particularly for self-esteem (6) and depression (18). The similarity of scores between groups in the present study is therefore noteworthy. Perhaps the small size of the 'late adolescence' group and the failure to recruit any 18 year olds resulted in numbers that were insufficient to show these trends.

An alternative explanation may be that defining the age ranges of the three groups in accordance with established theories of adolescent development (4) is inappropriate for this population. Many adolescents with IBD complete puberty at a later age than those in the general population. Therefore it is possible that the adolescents making up the groups defined by chronological age were not as homogenous as had been hoped, potentially affecting group comparisons. Nevertheless, even when age was considered as a continuous variable it failed

to correlate with psychosocial outcomes suggesting this finding was not purely due to incorrect grouping.

Psychosocial functioning in IBD vs. healthy adolescents

The present study found mean scores for social functioning and mood comparable to those expected for healthy adolescents. This corresponds with a number of studies examining social functioning (9,10), anxiety (38,10) and depression (9,10,39). There are, however, a number of studies providing conflicting evidence: that social functioning is impaired (38) and levels of anxiety and depression are higher (38,40-42) in adolescents with IBD. It is noteworthy that the majority of these studies used either structured diagnostic interviews or parent-report measures, while most of the studies which did not find differences, including the present study, used self-report questionnaires. It has been suggested that young people with IBD tend to report fewer psychological symptoms compared to their parents' reports of them (14,17,43). This may be due to the use of more avoidant coping styles, such as denial (37,38). Alternatively, it is possible young people with IBD report symptoms accurately and it is their parents who tend to over-report difficulties.

There has been very little research into the effect of IBD on body image and, to the author's knowledge, this is the first study to examine it as a main outcome. Adolescents did not have lowered mean scores for the three subscales of the RBES in any of the three age groups. It was hypothesised that side effects of steroid medication and the physical changes associated with surgery would affect body image; however, in this sample only 18% were taking acute medication at the time of participation, and only 14% had undergone surgery.

Other confounding factors

The unimpaired levels of overall psychosocial functioning found in this study could also be explained by the majority of participants either being in remission or having mild disease severity. This participant bias was unavoidable for two reasons: firstly adolescents feeling physically better are more likely to participate, and secondly, following instruction by the Ethics Committee and clinical guidance from the gastroenterology team, adolescents who were acutely unwell during the recruitment phase were not approached. While some studies have reported an association between increased disease severity and lowered psychosocial functioning/HRQOL (16,19,39,41,43), others have failed to find evidence of this (10,23,40,44). In the present study, no correlation was found between disease severity and psychosocial functioning or mood. Given the small number of participants with severe disease, however, this is perhaps unsurprising.

The finding that 33% of participants had been referred for psychological input was interesting. This figure may be an underestimation as it only includes adolescents referred to the psychology team within the hospital. Adolescents who had received psychological input could be expected to have improved psychosocial functioning. The Royal Children's Hospital has a gastroenterology multi-disciplinary team with the dedicated input of two Clinical Psychologists. It is possible that this psychologically informed way of working has reduced overall psychosocial distress in adolescents attending the clinic.

This study found adolescent girls were significantly more impaired than boys in the area of self-esteem but not social functioning[4]. This corresponds with a number of studies reporting

[4] It was not possible to make comparisons for body image, anxiety and depression due to data violating parametric assumptions. See analyses/results section.

gender differences in psychosocial functioning/HRQOL in young people with IBD (37,45), although others have failed to uncover gender differences (16,19). It makes sense that adolescents with IBD would mirror the general population where girls are more at risk of lowered self-esteem than boys (46).

In line with some previous research the present study did not find an association between psychosocial functioning and disease type (9), disease severity (17,23) or SES (16*).* While other studies have found disease type (44), disease severity (41,46) and SES (9) to impact upon psychosocial functioning, it is possible this sample was too small for differences to be detected.

Limitations of the present study and methods used to minimise or compensate for these

There are some limitations that should be considered when interpreting the results of this study. The greatest limitation is the small sample size which is responsible for the low power to detect significant differences. This is, however, common and often unavoidable in paediatric research. The low response rate was disappointing and may have resulted in participant bias (with more physically and psychologically well adolescents taking part). An unequal age distribution resulted in a smaller 'late adolescence' group. This is, however, representative of the clinic population where many adolescents start to transfer to local adult services from the age of 16. The predominance of participants that were in remission or with mild disease activity has been discussed.

Organisational constraints such as time and cost influenced the selection of measures. In order to ensure questionnaire completion time remained under 20 minutes, as recommended by the Ethics Committee, brief measures were selected. Two of the measures originally

proposed for anxiety and depression were deemed too costly and were replaced by a questionnaire that was available free of charge. Some of the measures used in this study (RBES and RSES) did not yield age-related T scores or provide clinical cut-offs, making it difficult to determine the clinical significance of the results. Due to time constraints it was not possible to recruit healthy controls. It would have been beneficial to compare the non-significant patterns seen in the IBD sample with a healthy aged-matched comparison group to determine whether these were specific to IBD or a normal feature of adolescent development.

In some respects the HADS was a highly appropriate measure of mood as it was developed specifically for patients with physical health difficulties. It is, however, primarily an adult measure despite being validated for adolescents (33) and may have been unsuitable for younger participants. A paediatric version of the HADS has recently been published (47) and would be more appropriate for future research.

The PCDAI and PUCAI, which allow collection of standardised disease severity scores, should be completed within one week of seeing the patient. This was not possible for some participants recruited via the postal method who had not attended the clinic for several months. Their scores were estimated by the Paediatric Gastroenterologist from their most recent appointment and blood results. An additional unforeseen problem was the lack of information on pubertal status in patient files. It had been hoped to gather this information to examine within group homogeneity and determine the developmental validity of the three groups but this was not possible.

Clinical and research implications of this study

This study is the first to examine psychosocial functioning from a developmental perspective and investigate body image in adolescents with IBD. The clinic from which young people were recruited provides specialist care to the entire west of Scotland. Therefore the sample consisted of individuals from a wide range of urban and rural locations of varying socio-economic levels.

By using specific measures of psychosocial functioning this study aimed to gather more detailed information than would be possible from a broad HRQOL measure. Although the study did not identify one age group that was more at risk of psychosocial difficulties, it did reveal that a sizeable subset of adolescents with IBD have impaired social functioning and increased levels of anxiety.

Clearly more research is required to further understand this complex area. Longitudinal studies would provide valuable information on adjustment to diagnosis and psychosocial functioning over time. Due to the low effect sizes, studies with large samples would be required. Including greater numbers of older adolescents would allow more accurate comparisons between developmental stages. Given the frequent disparity between pubertal timing and growth in adolescents with IBD compared to their healthy age-matched peers, it would be advantageous to use information on pubertal status and physical development in addition to chronological age to define developmental groups. Recruiting adolescents with more severe disease activity, who have undergone surgery and are on aggressive treatment regimes might result in greater effect sizes. Gathering information from several different informants (e.g. self-, parent- and proxy-reports) and using a healthy comparison group would also be beneficial. Selecting measures that are sensitive to young people's distress

would make it possible to determine whether adolescents with IBD are resilient or whether they are indeed experiencing difficulties in psychosocial functioning as a result of their disease. This enhanced understanding would facilitate identification (perhaps through routine screening) of those most at risk of experiencing difficulties so that early psychological intervention could be offered in order to prevent future, more serious problems with mood and adherence.

References

1. Sawczenko A, Sandhu BK, Logan RFA, et al. Prospective survey of childhood inflammatory bowel disease in the British Isles. *Lancet.* 2001;357:1093-1094.

2. Suris JC, Michaud PA, Viner R. The adolescent with a chronic condition. Part 1: developmental issues. *Arch. Dis. Child*. 2004;89:938-942.

3. Erickson EH. The Problem of Ego Identity. *J. Amer. Psychoanal. Assn*. 1956;4:56-121.

4. Berk LE. *Development through the lifespan.* Boston: Allyn and Bacon; 2007: p.362.

5. Elkind D, Bowen R. Imaginary audience behaviour in children and adolescents. *Dev Psychol*. 1979;15:38-44.

6. Seidman E. The impact of school transitions in early adolescence on the self-system and perceived social context of poor urban youth. *Child Dev*. 1994;65:507-522.

7. Harter S. Causes, correlates and functional role of global self-worth: a life span perspective. In: Kolligan J, Sternberg R, eds. Perceptions of competence and incompetence across the life span. *New Haven, CT: Yale University Press; 1990*.

8. Piaget J. The origins of intelligence in children. 1952. In: Berk LE. *Development through the lifespan.* Boston: Allyn and Bacon; 2007.

9. Gold N, Issenman R, Roberts J, et al. Well adjusted children: an alternate view of children with inflammatory bowel disease and functional gastrointestinal complaints. *Inflamm Bowel Dis.* 2000;6:1-7.

10. Mackner LM, Crandall WV. Long-term psychosocial outcomes reported by children and adolescents with inflammatory bowel disease. *Am J Gastroenterol*. 2005;100:1386-1392.

11. Engstrom I. Inflammatory bowel disease in children and adolescents: mental health and family functioning. *J Pediatr Gastroenterol Nutr*. 1999;28:S28-33.

12. Mackner LM, Crandall WV. Brief report: psychosocial adjustment in adolescents with inflammatory bowel disease. *J Pediatr Psychol*. 2006;31:281-285.

13. Neumark-Sztainer D, Story M, Resnick M, et al. Body dissatisfaction and unhealthy weight-control practices among adolescents with and without chronic illness: a population based study. *Arch Pediatr Adolesc Med*. 1995;149:1330-5.

14. Loonen HJ, Grootenhuis MA, Last BF, et al. Quality of life in paediatric inflammatory bowel disease measured by a generic and a disease specific questionnaire. *Acta Paediatr.* 2002;91:348-354.

15. De Boer M, Grootenhuis M, Derkx B, et al. Health-related quality of life and psychosocial functioning in adolescents with inflammatory bowel disease. *Inflamm Bowel Dis*. 2005;11:400-406.

16. Lindfred H, Saalman R, Nilsson S, et al. Inflammatory bowel disease and self-esteem in adolescence. *Acta Paediatr*. 2008;97:201-205.

17. Mackner LM, Crandall WV, Szigethy EM. Psychosocial functioning in pediatric inflammatory bowel disease. *Inflamm Bowel Dis*. 2006;12:239-244.

18. Angold A, Costello EJ. Puberty and depression. *Child Adolesc Psychiatr Clin N Am*. 2006;15:919-937.

19. Otley AR, Griffiths AM, Hale S, et al. Health-related quality of life in the first year after a diagnosis of pediatric inflammatory bowel disease. *Inflamm Bowel Dis*. 2006;12:684-691.

20. Rubin GP, Hungin APS, Chinn DJ, et al. Quality of life in patients with established inflammatory bowel disease: a UK general practice survey. *Aliment Pharmacol Ther*. 2004;19:529-35.

21. Nordin K, Pahlman L, Larsson K, et al. Health-related quality of life and psychological distress in a population-based sample of Swedish patients with inflammatory bowel disease. *Scand J Gastroenterol*. 2002;37:450-7.

22. Ferry GD. Quality of life in inflammatory bowel disease: background and definitions. *J Pediatr Gastroenterol Nutr.* 1999;28:S15-S18.

23. Cotton S, Kudel I, Humenay Roberts Y, et al. Spiritual well-being and mental health outcomes in adolescents with or without inflammatory bowel disease. *J Adolesc Health*. 2009;44:485-492**.**

24. Carr A. *The handbook of child and adolescent clinical psychology: a contextual approach.* 2nd ed. London: Routledge; 1999.

25. Cohen J. *Statistical power analysis for the behavioural sciences*. 2nd ed. Hillsdale, NJ: Erlbaum; 1998.

26. Faul F, Erdfelder E, Lang AG, et al. G*Power 3: a flexible statistical power analysis program for the social, behavioural, and biomedical sciences. *Behav Res Methods.* 2007;39:175-191.

27. Achenbach TM. *Manual of the Child Behaviour Checklist (CBCL).* Burlington, VT: University Associates of Psychiatry; 1991.

28. Mendelson BK, White DR. Manual for the body-esteem scale for children. C*oncordia University Research Bulletin.* 1993;12:1–10.

29. Mendelson BK, Mendelson MJ, White DR. Body-esteem scale for adolescents and adults. *J Pers Assess*. 2001;76:90-106.

30. Rosenberg M. *Society and the adolescent self-image*. Princeton, NJ: Princeton University Press; 1965.

31. Rosenberg Self-Esteem Scale. In: Johnston M, Wright SJ, Weinman J. *Measures in health psychology: a user's portfolio*. Windsor: NFER-NELSON; 1995.

32. Zigmond AS, Snaith RP. The hospital anxiety and depression scale. *Acta Psychiatr Scand*. 1983;67:361-370.

33. White D, Leach C, Sims R, et al. Validation of the hospital anxiety and depression scale for use with adolescents. *Br J Psychiatry.* 1999;175:452-454.

34. Scottish Government. Scottish Index of Multiple Deprivation 2009 [online]. Available at: http://www.scotland.gov.uk/Topics/Statistics/SIMD. Accessed 30 June, 2010.

35. Hyams JS, Ferry GD, Mandel FS, et al. Development and validation of a pediatric crohn's disease activity index. *J Pediatr Gastroenterol Nutr*. 1991;12:439-447.

36. Turner D, Otley AR, Mack D, et al. Development, validation, and evaluation of a pediatric ulcerative colitis activity index: a prospective multicenter study. *Gastroenterology*. 2007;133:423-432.

37. Van der Zaag-Loonen HJ, Grootenhuis MA, Last BF, et al. Coping strategies and quality of life of adolescents with inflammatory bowel disease. *Qual Life Res*. 2004;13:1011-1019.

38. Engstrom I. Mental health and psychological functioning in children and adolescents with inflammatory bowel-disease - a comparison with children having other chronic illnesses and with healthy children. *J Child Psychol Psychiatry.* 1992;33:563-582.

39. Marcus SB, Strople JA, Neighbors K, et al. Fatigue and health-related quality of life in pediatric inflammatory bowel disease. *Clin Gastroenterol Hepatol*. 2009;7:554-561.

40. Burke PM, Neigut D, Kocoshis S, et al. Correlates of depression in new onset pediatric inflammatory bowel disease. *Child Psychiatry Hum Dev*. 1994:275-283.

41. Szigethy E, Levy-Warren A, Whitton S, et al. Depressive symptoms and inflammatory bowel disease in children and adolescents: a cross-sectional study. *J Pediatr Gastroenterol Nutr*. 2004;39:395-403.

42. Szajnberg N, Krall V, Davis P, et al. Psychopathology and relationship measures in children with inflammatory bowel disease and their parents. *Child Psychiatry Hum Dev.* 1993:215-232.

43. Cunningham C, Drotar D, Palermo TM, et al. Health-related quality of life in children and adolescents with inflammatory bowel disease. *Children's Healthcare*. 2007;36:29-43.

44. Engstrom I, Lindquist BL. Inflammatory bowel-disease in children and adolescents - a somatic and psychiatric investigation. *Acta Paediatr Scand.* 1991;80:640-647.

45. Vaisto T, Aronen ET, Simola P, et al. Psychosocial symptoms and competence among adolescents with inflammatory bowel disease and their peers. *Inflamm Bowel Dis*. 2010;16:27-35.

46. Robins RW, Trzesniewski KH, Tracy JL, et al. Global self-esteem across the life span. *Psychol Aging*. 2002; 17:423-424.

47. O'Connor S, Carney T, House E, et al. Revision of the hospital anxiety and depression scale (HADS) to produce the paediatric index of emotional distress (PI-ED). *Patient Reported Outcomes Newsletter.* 2010;43:2-4.

Table 1: Demographic and disease information for the overall sample and the three age groups.

Characteristic	Overall Sample (n=63)	Early (11-13yrs) (n= 27)	Mid (14-15yrs) (n= 25)	Late (16-18yrs) (n= 11)	Sig.
Age in years: mean (SD)	13.75 (1.7)	12.07 (0.8)	14.44 (0.5)	16.18 (0.4)	
Gender: n (%)					
Male	32 (51)	13 (48)	13 (52)	6 (55)	0.93
Female	31 (49)	14 (52)	12 (48)	5 (45)	
SES: mean deciles (SD)	5.00 (2.7)	4.70 (2.5)	5.04 (3.0)	5.64 (2.6)	0.66
Family composition: n (%)					
Mother & father	48 (76)	20 (74)	19 (76)	9 (82)	0.93
Mother	12 (19)	6 (22)	5 (20)	1 (9)	
Mother& stepfather	3 (5)	1 (4)	1 (4)	1 (9)	
Number of siblings: n *(%)*					
0	8 (12.7)	2 (7)	5 (20)	1 (9)	0.21
1	29 (46)	15 (56)	12 (48)	2 (18)	
2	17 (27)	8 (30)	3 (12)	6 (55)	
3	7 (11.1)	2 (7)	3 (12)	2 (18)	
4	2 (3.2)	0	2 (8)		
Type of disease: n (%)					
CD	43 (68)	18 (67)	16 (64)	9 (82)	0.62
UC	13 (21)	5 (19)	7 (28)	1 (9)	
IC	7 (11)	4 (15)	2 (8)	1 (9)	
Disease duration in months: Mean (SD)	39.75 (24.8)	35.22 (25.8)	41.44 (25.8)	47.00 (18.4)	0.18
Disease severity (PCDAI/PUCAI) n (%)					
Remission	36 (59) [1]	18 (69) [2]	13 (54) [3]	5 (45)	0.48
Mild	24 (39)	8 (31)	10 (42)	6 (55)	
Moderate	1 (2)	0	1 (4)	0	
Number of admissions to hospital: mean (SD)	2.52 (1.5)	2.22 (1.2)	2.28 (1.4)	3.82 (2.0)	0.03*
Length of time in hospital (days): mean (SD)	9.08 (10.0)	7.30 (9.1)	8.92 (9.8)	13.82 (11.8)	0.14
Surgery n (%)					
No surgery	54 (86)	25 (93)	20 (80)	9 (82)	0.43
Non-resectional	2 (3)	0	2 (8)	0	
Resectional	7 (11)	2 (7)	3 (12)	2 (18)	
Acute medication (steroids or enteral feeds) n (%)					
No	52 (83)	23 (85)	19 (76)	10 (91)	0.50
Yes	11(17)	4 (15)	6 (24)	1 (9)	
Referral psychology n (%)					
No	42 (67)	18 (67)	18 (72)	6 (55)	0.60
Yes	21 (33)	9 (33)	7 (28)	5 (45)	

*Significant $p<0.05$ using a Kruskal-Wallis test

[1] n=61: 2 missing as no colons, [2] n=26: 1 missing as no colon, [3] n=24: 1 missing as no colon

Table 2: Clinical cut-offs for social functioning, anxiety and depression for the whole sample and three age groups.

Measure	Whole Sample (n=63)	Early (n=27)	Mid (n=25)	Late (n=11)
Range YSR activities: n (%)				
Normal	40 (63.5)	21 (77.8)	13 (52)	6 (54.5)
Borderline	12 (19.0)	2 (7.4)	8 (32)	2 (18.2)
Clinical	11 (17.5)	4 (14.8)	4 (16)	3 (27.3)
Range YSR Social: n (%)				
Normal	51 (83.6)	24 (92.3)	19 (79.2)	8 (72.7)
Borderline	7 (11.5)	1 (3.9)	3 (12.5)	3 (27.3)
Clinical	3 (4.9)[a]	1 (3.9)[b]	2 (8.3)[c]	0
Range T score: n (%)				
Normal	32 (55.2)	16 (64)	11 (45.8)	5 (55.6)
Borderline	6 (10.3)	4 (16)	2 (8.3)	0
Clinical	20 (34.5)[d]	5 (20)[e]	11 (45.8)[f]	4 (44.4)[g]
Depression > clinical cut-off: n (%)	7 (11.1)	2 (7.4)	2 (8)	3 (27.3)
Anxiety >clinical cut-off: n (%)	17 (27)	6 (22.2)	6 (24)	5 (45.5)

Some participants did not fully complete the YSR Social scale. Therefore some data is missing:
[a]n=61 (2 missing), [b]n=26 (1 missing), [c]n=24 (1 missing),
[d]n=58 (5 missing), [e]n= 25 (2 missing), [f]n=24 (1 missing), [g]n=9 (2 missing)

Table 3: Psychosocial functioning compared between early, mid and late adolescence.

	Age group			p value
	EARLY	MID	LATE	
Social Functioning * Total competence score YSR Mean (SD)	20.1 (4.1)	18.3 (4.5)	19.00 (4.7)	0.33
Self-esteem * Total score RSES Mean (SD)	21.4 (4.9)	20.3 (6.2)	21.8 (6.7)	0.93
Body Image △ Total score RBES Median (interquartile-range)	62 (42-71)	60 (46.5-69.0)	59 (22-74)	0.99
Depression △ HADS–D total score Median (interquartile-range)	1 (0-5)	2 (0.5-4.5)	4 (1-8)	0.38
Anxiety △ HADS–A total score Median (interquartile-range)	6 (2-8)	7 (4-8.5)	8 (3-13)	0.55

** Where data are normally distributed means and standard deviations are reported and ANOVA were used*

△ Where data are not normally distributed medians and interquartile ranges are reported and Kruskall-Wallis tests were used

Table 4: Effect sizes (r) for psychosocial functioning outcomes.

Measure	Early and Mid Adolescence	Mid and Late Adolescence	Early and Late Adolescence
Social Functioning	0.21	0.07	0.12
Self-Esteem	0.06	0.02	0.03
Body Image	0.02	0.00	0.02
Anxiety	0.11	0.05	0.15
Depression	0.05	0.19	0.21

Note: Effect sizes according to Cohen: 0.10 = small effect, 0.30 = medium effect, 0.50 = large effect. All effect sizes are small.

Table 5: Correlations between mood (anxiety and depression) and psychosocial functioning (social functioning, self-esteem, body image)

Variable	Social Functioning	Body Image	Self-Esteem	Depression	Anxiety
Social Functioning (r_s)	-				
Sig.					
Body Image (r_s)	.199	-			
Sig.	.134				
Self-Esteem (r_s)	.426*	.696*	-		
Sig.	.001	.000			
Depression (r_s)	-.395*	-.687*	-.833*	-	
Sig.	.002	.000	.000		
Anxiety (r_s)	-.253	-.567*	-.780*	.749*	-
Sig.	.055	.000	.000	.000	

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

Table 6: Multiple regression with interaction between gender and stage of adolescence for social functioning.

Model	B	SE B	β	t	Sig.
Step 1					
(Constant)	21.19	1.51		13.08	0.00
Gender	-2.10	1.18	-0.25	-1.78	0.08
Early-mid adolescence	-1.76	1.28	-0.21	-1.37	0.18
Early-late adolescence	-2.36	1.77	-0.20	-1.34	0.19
SES	0.00	0.00	0.11	0.77	0.45
Disease type (UC/CD)	-1.54	1.40	-0.15	-1.10	0.28
Step 2					
(Constant)	20.87	1.76		11.86	0.00
Gender	-1.86	1.86	-0.22	-1.00	0.32
Early-mid adolescence	-2.01	1.90	-0.24	-1.06	0.30
Early-late adolescence	-0.89	2.56	-0.08	-0.35	0.73
SES	0.00	0.00	0.13	0.90	0.37
Disease type (UC/CD)	-1.37	1.42	-0.14	-0.96	0.34
Gender × Early-Mid	0.51	2.59	0.05	0.20	0.84
Gender × Early-Late	-2.97	3.56	-0.19	-0.83	0.41

Note: R^2= 0.14 for Step 1; R^2 =0 .16 for Step 2.

Table 7: Multiple regression with interaction between gender and stage of adolescence for self-esteem.

Model	B	SE B	β	t	Sig.
Step 1					
(Constant)	22.38	1.90		11.81	0.00
Gender	-4.39	1.53	-0.37	-2.87	0.01*
Early-mid adolescence	-1.28	1.70	-0.11	-0.75	0.46
Early-late adolescence	-0.95	2.20	-0.06	-0.43	0.67
SES	0.00	0.00	0.19	1.48	0.15
Disease type (UC/CD)	-1.85	1.84	-0.13	-1.01	0.32
Step 2					
(Constant)	21.04	2.16		9.76	0.00
Gender	-2.90	2.37	-0.24	-1.23	0.23
Early-mid adolescence	-1.02	2.44	-0.08	-0.42	0.68
Early-late adolescence	2.82	3.10	0.18	0.91	0.37
SES	0.00	0.00	0.24	1.81	0.08
Disease type (UC/CD)	-1.48	1.83	-0.11	-0.81	0.42
Gender × Early-Mid	-0.45	3.34	-0.03	-0.14	0.89
Gender × Early-Late	-7.50	4.33	-0.36	-1.73	0.09

*Note: R^2= 0.19 for Step 1; R^2 =0 .24 for Step 2. *p>0.01*

Chapter 3

Advanced Clinical Practice I

Reflective Critical Account

A reflection on the process of process notes

Sarah Ross

Address for correspondence:

Section of Psychological Medicine
Academic Centre
Gartnavel Royal Hospital
1055 Great Western Road
Glasgow, G12 0XH
Tel 0141 211 3927

Word count: 3567

Submitted in partial requirement for the degree of Doctorate in Clinical Psychology (DClinPsy)

Abstract

In this account I chose to reflect on an experience in my specialist placement of struggling to write verbatim process notes after seeing a client with whom I was working using a psychodynamic approach. This experience prompted me to reflect on my personal and professional development, and therefore felt beneficial to consider in more depth. Johns' model of reflection (1994) was chosen to structure the account as it seemed to best fit with the psychodynamic approach I was trying to get to grips with.

As guided by Johns' model (1994), the experience is described followed by a reflection of what happened and how I felt at the time. Then both internal and external influencing factors are considered before alternative strategies are discussed. Finally I discuss my feelings about the reflection, what I have learnt and how I make sense of the experience in light of past experience and future practice.

In reviewing the reflection I note the change in my emotions throughout the process of writing the account, as well as the similarities between this and the feelings experienced in the incident I have described (writing the process notes). The impact of gaining experience of the psychodynamic approach is discussed in relation to my current and future practice. While my opinion of the current climate regarding access to, and Trainee Clinical Psychologists' experience of, psychodynamic interventions is also discussed.

Chapter 4

Advanced Clinical Practice II

Reflective Critical Account

A reflection on the challenge of contributing to team functioning as a Trainee Clinical Psychologist: 'The Fine Line'

Sarah Ross

Address for correspondence:

Section of Psychological Medicine
Academic Centre
Gartnavel Royal Hospital
1055 Great Western Road
Glasgow, G12 0XH
Tel 0141 211 3927

Word count: 3524

Submitted in partial requirement for the degree of Doctorate in Clinical Psychology (DClinPsy)

Abstract

This account details my reflections around the process of setting up advanced experiences in a placement agreement for my final Advanced Professional Practice placement. My feelings at discovering I may not be able to gain essential experience of consultation, supervision and contributing to team functioning are discussed. The requirements to become competent in the wide ranging role of the Clinical Psychologist within a multi-disciplinary team are discussed in the context of the doctoral training programme's Intended Learning Outcomes, recent government policy and the British Psychological Society's National Occupational Standards.

Johns' model of reflection (1994) was chosen to guide the reflection. After describing the experience and reflecting on my feelings and actions at the time, I consider both internal and external influencing factors that may have contributed to these. Any alternative strategies and their possible consequences are considered before I finally reflect on what has been learnt through the process. The action taken in trying to challenge the team's perception of my abilities and impress the importance of gaining experience on placement is also discussed.

This was followed by a meta-reflection on the process of writing the account as well as considering it in the context of current policy and the implications of this policy for both Trainee Clinical Psychologists and qualified Clinical Psychologists. The challenge of walking the 'fine line', contributing to team management and offering consultation and supervision where appropriate while respecting team culture and expectations, is discussed.

APPENDICES

APPENDIX 1.1

Journal of Pediatric Gastroenterology and Nutrition

Online Submission and Review System

SCOPE

The *Journal of Pediatric Gastroenterology and Nutrition* publishes original articles, special reports, review articles, rapid communications, case reports, letters to the editor, and news and views on all aspects of pediatric gastroenterology, hepatology, and nutrition.

The journal follows the International Committee of Medical Journal Editors' *Uniform Requirements for Manuscripts Submitted to Biomedical Journals* (URM). Manuscripts must be prepared in accordance with the URM (N Engl J Med 1997; 336:309-15 and updated at http://www.icmje.org/). **Manuscripts not prepared according to the Instructions to Authors will be returned to the author(s) without review.**

MANUSCRIPT PREPARATION

Manuscripts that do not adhere to the following instructions will be returned to the corresponding author for technical revision before undergoing peer review. Concise, clearly written articles are more likely to be accepted for publication in the Journal of Pediatric Gastroenterology, JPGN. Authors whose first language is not English are encouraged to ask a native English-speaking colleague or a professional author's editor to edit their manuscript before submission.

Title page: Include on the title page (a) complete manuscript title; (b) authors' full names, highest academic degrees, and affiliations; (c) name and address for correspondence, including fax number, telephone number, and e-mail address; (d) address for reprints if different from that of corresponding author; (e) all sources of support, including pharmaceutical and industry support, that require acknowledgment; and (f) disclosure of funding received for this work from any of the following organizations: National Institutes of Health (NIH); Wellcome Trust; Howard Hughes Medical Institute (HHMI); and other(s).

Structured abstract and key words: Limit the abstract to 250 words. Do not cite references in the abstract. Limit the use of abbreviations and acronyms. Use the following subheads: Objectives, Methods, Results, and Conclusions. List three to five key words.

Text: Organize the manuscript into four main headings: Introduction, Materials and Methods, Results, and Discussion. Define abbreviations at first mention in text and in each table and figure. If a brand name is cited, supply the manufacturer's name and address (city and state/country).

Data Analysis: Description of data analyses should provide the specific methods used, their rationale, their assumptions, whether data met those assumptions, and how any missing data were handled.

Abbreviations: For a list of standard abbreviations, consult the Council of Biology Editors Style Guide (available from the Council of Science Editors, 9650 Rockville Pike, Bethesda, MD 20814) or other standard sources. Write out the full term for each abbreviation at its first use unless it is a standard unit of measure.

References: The authors are responsible for the accuracy of the references. Key the

references (double-spaced) at the end of the manuscript. Cite the references in text in the order of appearance. Cite unpublished data—such as papers submitted but not yet accepted for publication and personal communications, including e-mail communications—in parentheses in the text. If there are more than three authors, name only the first three authors and then use et al. Refer to the List of Journals Indexed in Index Medicus for abbreviations of journal names, or access the list at http://www.nlm.nih.gov/tsd/serials/lji.html. Sample references are given below:

Journal article
I. Guarino A, Spagnuolo MI, Giacomet V, et al. Effects of nutritional rehabilitation on intestinal function and on CD4 cell number in children with HIV. J Pediatr Gastroenterol Nutr 2002;34:366-71.

Book chapter
2. Todd VR. Visual information analysis: frame of reference for visual perception. In: Kramer P, Hinojosa J, eds. Frames of Reference for Pediatric Occupational Therapy. Philadelphia: Lippincott Williams & Wilkins; 1999:205-56.

Entire Book
3. Ming S-C, Goldman H. Pathology of the Gastrointestinal Tract. Philadelphia: Lippincott Williams & Wilkins; 1998.

Software
4. Epi Info [computer program]. Version 6. Atlanta: Centers for Disease Control and Prevention; 1994.

Online journals
5. Friedman SA. Preeclampsia: a review of the role of prostaglandins. Obstet Gynecol [serial online] January 1988;71: 22-37. Available from: BRS Information Technologies, McLean, VA. Accessed December 15, 1990.

Database
6. CANCERNET-PDQ [database online]. Bethesda, MD: National Cancer Institute; 1996. Updated March 29, 1996.

World Wide Web
7. Gostin LO. Drug use and HIV/AIDS [JAMA HIV/AIDS web site]. June 1, 1996. Available at: http://www.ama-assn.org/special/hiv/ethics. Accessed June 26, 1997.

Tables: Cite tables consecutively in the text, and number them in that order. Each table should be submitted as a separate document. Each table must have a title. Use footnotes to define abbreviations and for other explanatory detail in a legend below the Tables. Tables should be self-explanatory and must supplement, rather than duplicate, the material in the text.

Figure legends: Each figure must have a legend. Legends should be brief and should be typed on a separate manuscript page after the references. Use scale markers in the image for electron micrographs, and indicate the type of stain used.

Figures: Art should be created/scanned and saved and submitted as individual files in either

TIFF (tagged image file format), EPS (encapsulated PostScript), or PPT (PowerPoint) format. Line art must have a resolution of at least 1200 dots per inch (dpi), while electronic photographs (radiographs, CT scans, etc.) and scanned images must have a resolution of at least 300 dpi. If fonts are used in the artwork, they must be converted to paths or outlines or they must be embedded in the files. Color images must be created/scanned and saved and submitted as CMYK files. Please note that artwork generated from office suite programs such as CorelDRAW and MS Word and artwork downloaded from the Internet (JPEG or GIF files) cannot be used. Cite figures consecutively on the site, and number them in the order in which they are discussed. All electronic art that cannot be successfully uploaded must be submitted on a 3½-inch high-density disk, a CD-ROM, or an Iomega Zip disk, accompanied by high-resolution laser prints of each image.

APPENDIX 1.2 Quality rating and data extraction form

Study identification (author, title, year of publication, journal title, pages):		
Checklist completed by:		
SECTION 1: INTERNAL VALIDITY		
		Quality rating
1.1	The study addresses an appropriate and clearly focussed question.	2 Well covered 1 Adequately covered 0 Poorly addressed
SELECTION OF PARTICIPANTS		
1.2	Participants are recruited in a scientifically appropriate manner and are representative of the defined population.	2 Well covered 1 Adequately covered 0 Poorly addressed
1.3	The cases and controls are taken from comparable populations (in all respects other than factor under investigation).	2 Well covered 1 Adequately covered 0 Poorly addressed
1.4	Inclusion and exclusion criteria are stated and the same exclusion criteria are used for both cases and controls.	2 Well covered 1 Adequately covered 0 Poorly addressed
1.5	The study indicates how many of the people asked to take part did so, in each of the groups being studied.	2 Well covered 1 Adequately covered 0 Poorly addressed
1.6	Comparisons are made between participants and non-participants to establish their similarities or differences.	2 Well covered 1 Adequately covered 0 Poorly addressed
1.7	A control group is used	2 Healthy children or another illness pop. 1 Norms from a standardised measure 0 No control group
1.8	Sufficient numbers of cases are selected and this was based on a power calculation.	2 Well covered 1 Adequately covered 0 Poorly addressed
1.9	Actual sample size is stated	2 Well covered 1 Adequately covered 0 Poorly addressed

ASSESSMENT		
1.10	The outcomes are clearly defined.	2 Well covered 1 Adequately covered 0 Poorly addressed
1.11	The study incorporates blinding where feasible (e.g. outcome is assessed blind if possible)	2 Well covered 1 Adequately covered 0 Poorly addressed
1.12	Methods are used to enhance the quality of measurements (e.g. self-report or multiple informants vs. proxy report)	2 Self-report or self-report & proxy-report 1 Proxy-report (parent or clinician) 0 Mixed methods or not specified
1.13	Assessment measures are published, standardised and validated for the population being assessed (i.e. reliability and validity data is available).	2 Well covered 1 Adequately covered 0 Poorly addressed
CONFOUNDING		
1.14	The main potential confounders are identified and taken into account in the design and analysis.	2 Well covered 1 Adequately covered 0 Poorly addressed
STATISTICAL ANALYSIS		
1.15	The analysis conducted is appropriate to the design.	2 Well covered 1 Adequately covered 0 Poorly addressed
1.16	Results are clearly reported	2 Well covered 1 Adequately covered 0 Poorly addressed
1.17	Confidence intervals, effect sizes, p-values etc. are provided where appropriate.	2 Well covered 1 Adequately covered 0 Poorly addressed
Quality scores **Quality rating: Good = >75%** **Acceptable = >50%** **Poor = <50%**		**Total score: _____(T possible = 34)** **Percentage: _____** **Quality rating: _____**

APPENDIX 1.3 Quality rating of studies included in systematic review

Study	Quality score (Total possible=34)	Percentage	Quality rating
Burke et al., 1994	19	56%	Acceptable
Cunningham et al., 2007	28	82%	Good
De Boer et al., 2005	20	59%	Acceptable
Engstrom, 1992	27	79%	Good
Gold et al., 2000	29	85%	Good
Lindfred et al., 2008	26	76%	Good
Loonen et al., 2002	28	82%	Good
Mackner & Crandall, 2005	26	76%	Good
Marcus et al., 2009	29	85%	Good
Otley et al., 2006	26	76%	Good
Szajnberg et al., 1993	17	50%	Acceptable
Szigethy et al., 2004	28	82%	Good

APPENDIX 2.1 Instruction to authors *Inflammatory Bowel Diseases*

Inflammatory Bowel Diseases

PREPARATION OF MANUSCRIPT Manuscripts that do not adhere to the following instructions will be returned to the corresponding author for technical revision before undergoing peer review. (See specific guidelines for Letters to the Editor below.) For questions on preparing manuscripts for submission, please contact Julie Nash - nashj@hss.edu.

Title Page Include on the title page (a) complete manuscript title; (b) authors' full names, highest academic degrees, and affiliations; (c) name and address for correspondence, including fax number, telephone number, and e-mail address; (d) address for reprints if different from that of corresponding author; and (e) sources of support that require acknowledgment.

Structured Abstract and Key Words Limit the abstract to 250 words. It must be factual and comprehensive. Do not cite references in the abstract. Limit the use of abbreviations and acronyms, and avoid general statements (e.g., ``the significance of the results is discussed''). It should be sectioned into Background, Methods, Results, and Conclusions. List three to five key words.

Text For full-length research articles, organize the manuscript in the following sequence: Abstract and Key Words, Introduction, Materials and Methods, Ethical Considerations, Results, Discussion, Acknowledgment, References, Tables, and Figure Legends. Original Research Articles: Authors are encouraged to submit articles in basic or clinical science. Review Articles of exceptional merit will also be accepted. Contributors should communicate with the Editors before submitting a review. Abbreviations must be defined at first mention in text and in each table and figure. If a brand name is cited, manufacturer and address (city and state/country) should be supplied. Acknowledge all forms of support, including pharmaceutical industry support, in an Acknowledgment paragraph.

Abbreviations For a list of standard abbreviations, consult the Council of Biology Editors Style Guide (available from the Council of Science Editors, 9650 Rockville Pike, Bethesda, MD 20814) or other standard sources. Write out the full term for each abbreviation at its first use unless it is a standard unit of measure.

References The authors are responsible for the accuracy of the references. Key the references (double-spaced) at the end of the manuscript. Cite the references in text in the order of appearance. Cite unpublished data, such as papers submitted but not yet accepted for publication, personal communications, in parentheses in the text. If there are more than three authors, only name the first three authors and then use et al. For abbreviations of journal names, refer to List of Journals Indexed in Index Medicus. This can be accessed at http://www.nlm.nih.gov/tsd/serials/lji.html. Sample references are given below:
Journal Article 1. Gudlaugsdottir S, van Dekken H, Stijnen T, et al. Prolonged use of proton pump inhibitors, CagA status, and the outcome of Helicobacter pylori gastritis. J Clin Gastroenterol. 2002;34:536-540.

Book Chapter 2. Tobin RW, Kimmey MB. Painful diseases of the gastrointestinal tract. In: Loeser JD, ed. Bonica's Management of Pain. 3rd ed. Philadelphia, PA: Lippincott Williams & Wilkins; 2001:1269-1292.

Entire Book 3. Rohen JW, Yokochi C, Lütjen-Drecoll E. Color Atlas of Anatomy: A Photographic Study of the Human Body. 5th ed. Philadelphia, PA: Lippincott Williams & Wilkins; 2002.

Software 4. Epi Info [computer program]. Version 6. Atlanta: Centers for Disease Control and Prevention; 1994.

Online Journals 5. Friedman SA. Preeclampsia: a review of the role of prostaglandins. Obstet Gynecol [serial online]. January 1988;71:22-37. Available from: BRS Information Technologies, McLean, VA. Accessed December 15, 1990.
Database 6. CANCERNET-PDQ [database online]. Bethesda, MD: National Cancer Institute; 1996. Updated March 29, 1996.

World Wide Web 7. Gostin LO. Drug use and HIV/AIDS [JAMA HIV/AIDS Web site]. June 1, 1996. Available at: http://www.ama-assn.org/special/hiv/ethics. Accessed June 26, 1997.

Figures Art should be created/scanned and saved and submitted as either a TIFF (tagged image file format), or an EPS (encapsulated postscript) file. Line art must have a resolution of at least 1200 dpi (dots per inch), and electronic photographsMradiographs, CT scans, and so onMand scanned images must have a resolution of at least 300 dpi. If fonts are used in the artwork, they must be converted to paths or outlines or they must be embedded in the files. Color images must be created/scanned and saved and submitted as CMYK files. Please note that artwork generated from office suite programs such as Corel Draw and MS Word and artwork downloaded from the Internet (JPEG or GIF files) cannot be used. Cite figures consecutively on the site, and number them in the order in which they are discussed.

Figure Legends Legends must be submitted for all figures. They should be brief and specific, and they should appear after the text and before the references. Use scale markers in the image for electron micrographs, and indicate the type of stain used.

Color Figures The journal accepts for publication color figures that will enhance the article, and at the discretion of the Editors, figures may be printed in color for no additional charge. Otherwise, authors who submit color figures will receive an estimate of the cost for color reproduction. Figures are published online in color at no additional cost.

Tables Create tables using the table creating and editing feature of your word processing software (e.g., Word). Do not use Excel or comparable spreadsheet programs. Submit all tables as separate files. Cite tables consecutively in the text, and number them in that order. Key each on a separate sheet, and include the table title, appropriate column heads, and explanatory legends (including definitions of any abbreviations used). Do not imbed tables within the body of the manuscript. They should be self-explanatory and should supplement, rather than duplicate, the material in the text.

Style Follow American Medical Association Manual of Style (9th edition). Stedman's Medical Dictionary (27th edition) and Merriam Webster's Collegiate Dictionary (10th edition) should be used as standard references. Refer to drugs and therapeutic agents by their

accepted generic or chemical names, and do not abbreviate them. Use code numbers only when a generic name is not yet available. In that case, supply the chemical name and a figure giving the chemical structure of the drug. Capitalize the trade names of drugs and place them in parentheses after the generic names. To comply with trademark law, include the name and location (city and state in USA; city and country outside USA) of the manufacturer of any drugs, supplies, or equipment mentioned in the manuscript. Use the metric system to express units of measure and degrees Celsius to express temperatures, and use SI units rather than conventional units.

Publisher's Contact - Journal Production

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Email: ibdprod@wiley.com

Appendix 2.2 Letter of ethical approval

WoSRES
West of Scotland Research Ethics Service

NHS
Greater Glasgow and Clyde

West of Scotland REC 5
Ground Floor,
Tennent Institute,
Western Infirmary,
38 Church Street,
Glasgow G11 6NT

Telephone: 0141-211-6270
Facsimile: 0141-211-1847

09 November 2009

Miss Sarah C Ross
2/2 19 Lyndhurst Gardens
Glasgow
G20 6QX

Dear Miss Ross

Study Title:	**The impact of Inflammatory Bowel Disease on psychosocial functioning in early, mid and late adolescence.**
REC reference number:	**09/S1001/54**
Protocol number:	**5**

Thank you for your letter of 7th October 2009, responding to the Committee's request for further information on the above research and submitting revised documentation.

The further information has been considered on behalf of the Committee by the Chair.

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, subject to the conditions specified below.

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.

For NHS research sites only, management permission for research ("R&D approval") should be obtained from the relevant care organisation(s) 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 the only involvement of the NHS organisation is as a Participant Identification Centre, management permission for research is not required but the R&D office should be notified of the study. Guidance should be sought from the R&D office where necessary.*

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

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).

Approved documents

The final list of documents reviewed and approved by the Committee is as follows:

Document	*Version*	*Date*
Covering Letter		07 October 2009
Participant Information Sheet: Parent/Guardian	Version 3	07 September 2009
Participant Information Sheet: Young Person	Version 3	07 September 2009
Participant Consent Form: Young Person	Version 3	07 September 2009
Participant Consent Form: Parent/Guardian	Version 3	07 September 2009
Questionnaire: HADS		
Participant Consent Form: Parental Consent for 11-12 year old children	Version 3	07 September 2009

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees (July 2001) and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

After ethical review

Now that you have completed the application process please visit the National Research Ethics Service website > After Review

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.

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

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

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

We would also like to inform you that we consult regularly with stakeholders to improve our service. If you would like to join our Reference Group please email referencegroup@nres.npsa.nhs.uk.

09/S1001/54	Please quote this number on all correspondence

Yours sincerely

PP **Dr Greg Ofili**
Chair

Email: sharon.jenner@ggc.scot.nhs.uk

Enclosures: "After ethical review – guidance for researchers" *[SL-AR1 for CTIMPs, SL- AR2 for other studies]*

Copy to: *Melissa McBride, R & D Department*

Appendix 2.3 Letter of ethical approval for amendment

WoSRES
West of Scotland Research Ethics Service

NHS
Greater Glasgow and Clyde

West of Scotland REC 5
Ground Floor,
Tennent Institute,
Western Infirmary,
38 Church Street,
Glasgow G11 6NT

Tel: 0141-211-6270
Fax: 0141-211-1847

17 December 2009

Miss Sarah C Ross
2/2 19 Lyndhurst Gardens
Glasgow
G20 6QX

Dear Miss Ross

Study title: **The impact of Inflammatory Bowel Disease on psychosocial functioning in early, mid and late adolescence.**
REC reference: **09/S1001/54**
Amendment number: **Amendment 1**
Amendment date: **10 November 2009**

The above amendment was reviewed at the meeting of the Committee held on 16 December 2009.

Ethical opinion

The members of the Committee taking part in the review gave a favourable ethical opinion of the amendment on the basis described in the notice of amendment form and supporting documentation.

Approved documents

The documents reviewed and approved at the meeting were:

Document	Version	Date
Participant Information Sheet: Parent/Guardian B (for postal method) with incentive	Version 2	10 November 2009
Participant Information Sheet: Parent/Guardian A (for postal method)	Version 1	10 November 2009
Participant Information Sheet: Young person B (for clinic method) with incentive	Version 4	10 November 2009
Participant Information Sheet: Young person B (for postal method) with incentive	Version 2	10 November 2009

Participant Information Sheet: Young person A (for postal method)	Version 1	10 November 2009
Protocol	Version 6	10 November 2009
Notice of Substantial Amendment (non-CTIMPs)	Amendment 1	10 November 2009
Covering Letter		13 November 2009
Letter of support from the Consultant Paediatric Gastroenterologist	Version 1	11 November 2009
Instruction sheet for filling in postal questionnaires	Version 1	10 November 2009
Covering letter for postal questionnaires	Version 1	10 November 2009
Participant Information Sheet: Parent/Guardian B (for clinic method) with incentive	Version 4	10 November 2009

Membership of the Committee

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

R&D approval

All investigators and research collaborators in the NHS should notify the R&D office for the relevant NHS care organisation of this amendment and check whether it affects R&D approval of the research.

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees (July 2001) and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

09/S1001/54:	**Please quote this number on all correspondence**

Yours sincerely

Sharon Jenner

Sharon Jenner
Committee Co-ordinator

E-mail: sharon.jenner@ggc.scot.nhs.uk

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

Copy to: *Melissa McBride, NHS Greater Glasgow and Clyde*

Appendix 2.4 Letter of R&D approval

NHS
Greater Glasgow and Clyde

Coordinator/administrator: Kirsty Theron
Telephone Number: 0141 211 6372
Fax Number: 0141 211 2811
E-Mail: Kirsty.theron2@ggc.ascot.nhs.uk

R&D Management Office
Western Infirmary
Tennent Institute
1st Floor, 38 Church Street
Glasgow, G11 6NT

24 November 2009

Dr Richard Russell,
Department of Paediatric Gastroenterology,
Royal Hospital for Sick Children,
Dalnair Street,
Glasgow G3 8SJ

R&D Management Approval

Dear Dr Russell,

Project Title: The impact of Inflammatory Bowel Disease on psychosocial functioning in early, mid and late adolescence
Chief Investigator: Miss Sarah Ross
R&D Reference: GN09GA437
Protocol no (including version and date): Version 5 (13/07/09)

I am pleased to confirm that Greater Glasgow & Clyde Health Board is now able to grant **Management Approval** for the above study.
As a condition of this approval the following information is required during the lifespan of the project:

1. SAES/SUSARS – If the study is a **Clinical Trial** as defined by the Medicines for Human Use Clinical Trial Regulations, 2004 (CTIMP only)
2. Recruitment Numbers on a quarterly basis (not required for commercial trials)
3. Any change of Staff working on the project named on the ethics form
4. Change of CI
5. Amendments – Protocol/CRF etc
6. Notification of when the Trial / study has ended
7. Final Report
8. Copies of Publications & Abstracts

Please add this approval to your study file as this letter may be subject to audit and monitoring.

Yours sincerely

Michael Barber

Dr Michael Barber
Research Co-ordinator

Delivering better health
www.nhsggc.org.uk

Appendix 2.5 Email of R&D approval for amendment

From: Theron, Kirsty
Sent: 13 January 2010 11:58
To: 'SARAH CATHERINE ROSS'
Cc: Barber, Michael; Russell, Richard (NHSmail)
Subject: Substantial Amendment - R&D Ref GN09GA437 Protocol No 6 Substantial Amendment 1 10 November 2009 -cc: Sarah Ross

Dear Dr Richard Russell,

R&D Ref: GN09GA437 **Ethics Ref**: 09/S1001/54

Investigator: Dr Richard Russell

Project Title: The impact of Inflammatory Bowel Disease on psychosocial functioning in early, mid and late adolescence

Protocol Number: Version 6

Amendment: Substantial Amendment 1 10 November 2009

Sponsor:

I am pleased to inform you that R&D have reviewed the above study's Amendment 1 (10/11/09) and can confirm that Management Approval is still valid for this study.

I wish you every success with this research project.

Yours sincerely,

Dr Michael Barber (PhD)

Research and Development Central Office

NHS Greater Glasgow and Clyde

Western Infirmary

38 Church Street

Glasgow, G11 6NT

tel: 0141-211-**8548** or **5 8548** (internal)

mailto:michael.barber@ggc.scot.nhs.uk

APPENDIX 2.6
Information sheet for young people - clinic version
(1 of 4 versions: parent - clinic version; young person - postal version; parent - postal version)

UNIVERSITY of GLASGOW

NHS Greater Glasgow and Clyde

A Comparison of Psychosocial Functioning between Early, Mid and Late Adolescence in Young People with Inflammatory Bowel Disease.

Information Sheet – Young person

We would like to invite you to take part in a research project. Before you decide you need to understand why the research is being done and what you would be asked to do. Please take time to read the following information carefully. You can talk to others about this project if you wish. You can also ask us if there is anything that is not clear or if you would like more information.

Who is carrying out this project?
This project is being carried out by Sarah Ross, Trainee Clinical Psychologist, from the Department of Psychological Medicine, University of Glasgow together with the department of Gastroenterology at Yorkhill.

Why are we doing this project?
This project is going to look at how Inflammatory Bowel Disease (or IBD) like Crohn's Disease or Ulcerative Colitis affects young people throughout their teenage years. We want to find out:

- How IBD makes teenagers feel about their body and appearance.
- How IBD makes you feel generally, and what effect it has on getting along with others.
- Whether people of different ages cope in different ways after they are told they have IBD.
- We are also interested in whether the length of time young people have been ill makes a difference to how they feel about themselves.

Finding out whether young people at certain ages are more likely to have problems, means that we can give those people more help in the future.

Why have I been invited to take part in this project?
You have been invited to take part in this project as you have Inflammatory Bowel Disease (or IBD) like Crohn's Disease or Ulcerative Colitis and are a young person.

Do I have to take part?
No, it is up to you to decide. We will describe the project to you and go through this information sheet. You will be asked to sign a form to show you have agreed to take part. You are free to stop taking part at any time, without giving a reason. This would not affect the care you receive or your future treatment.

What does taking part involve?
The main researcher (Sarah) will talk to you and your parent while you are waiting for your clinic appointment at the hospital. She will give you another copy of this information sheet and go through this with you and your parent. You will have the chance to ask any questions. If you would like to take part in the project, Sarah (the person carrying out the research) will ask you to sign a form to show you understand what the project is about and that you want to take part. If you are under 12 years old, your parent will also be asked to sign a form.

After this, you will go to a free clinic room with Sarah and spend around 20 minutes completing 5 short questionnaires.

If you agree, Sarah will gather some more information about you from your medical file once you have gone.

What happens to the information?
All your information and personal details will be kept completely private, and known only to Sarah. We will keep the information safely and cannot show it to other people, without you agreeing to this.

What are the possible benefits of taking part?
It is hoped that by taking part in this project, you will be helping us understand how living with Inflammatory Bowel Disease (IBD) affects how young people feel about themselves and how they cope with their everyday lives. This will help us to plan our service so that we can help teenagers with IBD better in the future. As a thank you for taking part we will give you a £10 gift voucher.

Who has reviewed the project?
This project has been reviewed by the West of Scotland Research Ethics Committee.

If you have any further questions?
We will give you a copy of the information sheet and signed consent (agreement) form to keep. If you would like more information about the project and wish to speak to someone not closely linked to the project, please contact Vikki Garrick (0141 201 9247).

Contacts:
Sarah Ross (Main Researcher), Trainee Clinical Psychologist
Section of Psychological Medicine, Gartnavel Royal Hospital, 1055 Great Western Road, Glasgow, G12 0XH
01294 323560 or s.ross.2@research.gla.ac.uk

Vikki Garrick, Paediatric Inflammatory Bowel Disease Nurse Specialist
The Royal Hospital for Sick Children, Dalnair Street
Glasgow, G3 8SJ Tel: 0141 201 9247

If you have a complaint about any aspect of the project?
If you are unhappy about any part of the project and wish to make a complaint, please contact Sarah first. You can also make a complaint through normal NHS complaint pathways.

Thank-you for your time and help!

APPENDIX 2.7

Consent form for young people (if under 12 parents signed a similar consent form as well)

UNIVERSITY of GLASGOW

NHS Greater Glasgow and Clyde

Subject number:

A Comparison of Psychosocial Functioning between Early, Mid and Late Adolescence in Young People with Inflammatory Bowel Disease.

Consent Form

Please initial each BOX to indicate agreement **Please initial box**

I have read and understand the information sheet dated 07/09/2009 (version 3) that explains what this project is about and have had the chance to ask questions. ☐

I understand that taking part in this project is my choice and that I can decide not to take part at any time. ☐

I agree to the person carrying out the project looking at some parts of my medical notes. ☐

I agree to take part in the above project. ☐

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Name of Participant	Date	Signature

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Name of Researcher	Date	Signature

1 copy to the participant, 1 copy to the researcher, 1 original copy for the participant's notes

APPENDIX 2.8
Covering letter sent to all participants

UNIVERSITY of GLASGOW

NHS Greater Glasgow and Clyde

The Royal Children's Hospital,
Yorkhill, Dalnair Street
Glasgow, G3 8SJ

Date:

Dear Parent/Guardian

A Comparison of Psychosocial Functioning between Early, Mid and Late Adolescence in Young People with Inflammatory Bowel Disease.

We are writing to ask whether you would be willing for ..... to take part in a research project. We want to find out how Inflammatory Bowel Disease (IBD) affects young people throughout their adolescence. We want to look at how IBD may impact on relationships, how adolescents feel about their body and appearance, and about themselves more generally.

The study is to be conducted by Sarah Ross (Trainee Clinical Psychologist) in the Gastroenterology Outpatient clinic at the Children's Hospital (Yorkhill). If you agree to your child taking part in this study, your child will be asked to spend a maximum of 20 minutes filling in some questionnaires in a spare clinic room while waiting for their routine outpatient appointment.

We have enclosed two short information sheets to give you and your child an idea of what is involved in this study. There are also two consent forms for your information. If you have any questions please contact Sarah Ross (07833095377) or, for someone not closely connected with the study, Vikki Garrick (0141 201 9247).

Yours sincerely,

Sarah Ross
Trainee Clinical Psychologist

Dr Richard Russell
Consultant Paediatric Gastroenterologist

APPENDIX 2.9
Sent to those completing questionnaires at home (postal version)

Instruction sheet for filling in questionnaires

Thank you for agreeing to take part in the study. Please fill in the 5 questionnaires in the order below, making sure you don't miss any out. Remember you can phone Sarah (the main researcher) if you are not sure about any of the questions or how to answer them. You can also get help from your parents, but remember we are interested in what you think.

Please fill the questionnaires in this order – it takes around 20 minutes.

(1) Questionnaire 1 - "Demographic Questionnaire"
Please just answer these 4 questions.

(2) Questionnaire 2 – "Youth Self-Report for ages 11-18"
Don't worry about filling in the crossed out part at the top. Please start at Question 1 – remember to look at the questions on the right hand side of the page ("compared to others of your age, about how much time do you spend in each?"). There are 2 sides.

On the other page put a circle around the number you think describes you. For example: for Question 1, if you think compared to other healthy young people your age your social life is the same, you circle number 2.

(3) Questionnaire 3 - "Body Esteem Scale for Adolescents & Adults"
Please circle the number to show how often you agree with the statements. For example: for Question 1, if you sometimes like what you look like in pictures, you would circle number 2 as it is in the 'sometimes' column. There are 2 pages (23 questions).

(4) Questionnaires 4 – "Rosenberg Self-Esteem Scale"
Please circle SA, A, D or SD depending on how much you agree with the statements. For example for Question 1, if you strongly agree with the statement "On the whole, I am satisfied with myself", you would circle SA. If you disagree, you would circle D.

(5) Questionnaires 5 - "Hospital Anxiety & Depression Scale"

Please underline or circle the reply that describes how you have been feeling over the last week. For example: if you feel "tense or 'wound up'" from time to time, occasionally – underline or circle this on the form. If you never feel tense or 'wound up' you would circle 'not at all'. Just ignore the bit down the left hand side of the page. There are 3 pages.

Thank you for filling in all the questionnaires. So we can send you your £10 Amazon gift voucher please put your email address on the sheet provided and post it back with your consent form in envelope A.

We realise that some of the questions may have made you think about things like friendships and how you feel about yourself. If you have found this a bit upsetting and want to talk about it, please either talk to your parent or you can phone Sarah (the main researcher) on 01294323552. Thank you again.

Don't forget to put your consent form in envelope A and the questionnaires in envelope B and send them back to the hospital.

APPENDIX 2.10

Body-Esteem Scale for Adolescents and Adults
Beverley K. Mendelson, Donna R. White, and Morton J. Mendelson

Indicate how often you agree with the following statements ranging from "never" (0) to "always" (4). Circle the appropriate number beside each statement.

	Never	Seldom	Some-times	Often	Always
1. I like what I look like in pictures.	0	1	2	3	4
2. Other people consider me good looking.	0	1	2	3	4
3. I'm proud of my body.	0	1	2	3	4
4. I am preoccupied with trying to change my body weight.	0	1	2	3	4
5. I think my appearance would help me get a job.	0	1	2	3	4
6. I like what I see when I look in the mirror.	0	1	2	3	4
7. There are lots of things I'd change about my looks if I could.	0	1	2	3	4
8. I am satisfied with my weight.	0	1	2	3	4
9. I wish I looked better.	0	1	2	3	4
10. I really like what I weigh.	0	1	2	3	4
11. I wish I looked like someone else.	0	1	2	3	4
12. People my own age like my looks.	0	1	2	3	4
13. My looks upset me.	0	1	2	3	4
14. I'm as nice looking as most people.	0	1	2	3	4
15. I'm pretty happy about the way I look.	0	1	2	3	4
16. I feel I weigh the right amount for my height.	0	1	2	3	4
17. I feel ashamed of how I look.	0	1	2	3	4

18. Weighing myself depresses me.	0	1	2	3	4
19. My weight makes me unhappy	0	1	2	3	4
20. My looks help me to get dates.	0	1	2	3	4
21. I worry about the way I look.	0	1	2	3	4
22. I think I have a good body.	0	1	2	3	4
23. I'm looking as nice as I'd like to.	0	1	2	3	4

Three subscales: BE-Appearance (1, 6, 7*, 9*, 11*, 13*, 15, 17*, 21*, 23); BE-Weight (3, 4*, 8, 10, 16, 18*, 19*, 22); and BE-Attribution (2, 5, 12, 14, 20). [* negative items, which must be recoded for scoring by reversing the scale (i.e., 0 = 4, 1 = 3, 2 = 2, 3 = 1, 4 = 0).]

Address correspondence, including requests for a copy of the manual for the Body-Esteem Scale for Adolescents and Adults, to Dr. Beverley K. Mendelson at <bev@ego.psych.mcgill.ca>.

APPENDIX 2.11

Demographic Questionnaire

Study Number:

(1) How old are you? _____

(2) Please circle your gender female male

(3) What is your post code? _____

If you don't know your post-code, please write your address and we can look it up

_____

(4) Please circle the option that best describes your family

I live with my mum and dad

I live with my mum

I live with my dad

I live with my mum and stepfather/mum's boyfriend

I live with my dad and stepmother/dad's girlfriend

I live with my grandparents

Other (please explain) _____

_____

(b) How many brothers and sisters do you have? _____

APPENDIX 2.12

Table a: Multiple regression for predictors and outcome self-esteem

Model	B	SE B	β	t	Sig.
(Constant)	22.38	1.90		11.81	0.00
Gender	-4.39	1.53	-0.37	-2.87	0.01*
Early-mid adolescence	-1.28	1.70	-0.11	-0.75	0.46
Early-late adolescence	-0.95	2.20	-0.06	-0.43	0.67
SES	0.00	0.00	0.19	1.48	0.15
Disease type (UC/CD)	-1.85	1.84	-0.13	-1.01	0.32

Note: $R^2 = 0.189$, $p=0.06$ *ns* *$p>0.01$

Table b: Multiple regression for predictors and outcome social functioning

Model	B	SE B	β	t	Sig.
(Constant)	21.19	1.51		13.08	0.00
Gender	-2.10	1.18	-0.25	-1.78	0.08
Early-mid adolescence	-1.76	1.28	-0.21	-1.37	0.18
Early-late adolescence	-2.36	1.77	-0.20	-1.34	0.19
SES	0.00	0.00	0.11	0.77	0.45
Disease type (UC/CD)	-1.54	1.40	-0.15	-1.10	0.28

Note: $R^2 = 0.14$, $p=0.22$ *ns*

Table c: Mean total scores and scores for subscales on measures of psychosocial functioning.

Measure		Early (11-13yrs)		Mid (14-15yrs)		Late (16-18yrs)	
		Mean	*SD*	*Mean*	*SD*	*Mean*	*SD*
YSR							
	Activities scale	9.09	2.41	8.05	2.63	8.53	2.60
	Social scale	8.90	2.48	8.06	2.29	8.17	2.88
	Academic scale	2.15	0.43	2.18	0.57	2.30	0.49
	Total score	20.14	4.09	18.29	4.47	18.99	4.58
	T score	44.16	9.91	39.75	10.17	41.22	10.88
RBES							
	BE-Appearance	26.60	8.62	26.17	10.79	24.78	8.93
	BE-Weight	19.92	8.46	21.00	8.26	19.22	10.70
	BE-Attitudes	9.68	3.79	8.96	2.97	9.89	3.69
	BE-Total	55.89	17.59	55.68	17.50	53.91	24.47
RSES		21.36	4.91	20.29	6.17	21.78	6.70
HADS							
	HADS- Depression	2.33	2.62	2.40	2.31	4.18	3.84
	HADS – Anxiety	6.19	4.51	6.52	3.92	7.82	5.33

APPENDIX 2.13

Major Research Proposal

The impact of Inflammatory Bowel Disease on psychosocial functioning in early, mid and late adolescence.

Sarah Ross

13th July 2009
Version number: 5
Word count: 3226

Academic Supervisor: Dr Sarah Wilson
Clinical Supervisors: Dr Julie Strachan & Dr Janie Donnan

ABSTRACT

Background: The onset of Inflammatory Bowel Disease (IBD) is highest during adolescence, when young people are endeavouring to establish an identity, develop peer and romantic relationships and become autonomous. The symptoms of IBD may make it more difficult for them to make these essential developmental transitions and cause difficulties in psychosocial functioning. While previous research has compared adolescents with IBD to healthy controls, it may be more informative to take a developmental approach, examining psychosocial functioning within the early, mid and late stages of adolescence.

Aims: The primary aim of this study is to investigate whether stage of adolescence has an effect on social functioning, body image and self-esteem in adolescents with IBD. The secondary aims are to determine whether stage of adolescence has an effect on coping post diagnosis, and whether time since diagnosis and disease phenotype have an effect on outcome measures.

Methods: 105 adolescents aged between 11 and 18 years with IBD will be recruited from a gastroenterology outpatient clinic. Each adolescent will complete measures of social functioning, body image, self-esteem and mood. Demographic and disease information will also be gathered. Outcome measures will be compared between the three groups (early, mid and late adolescence).

Applications: Determining whether a particular sub-group of adolescents are more at risk for developing difficulties would allow early intervention of targeted interventions to prevent difficulties becoming entrenched. Additionally, this study may pave the way for other research examining psychosocial functioning within a developmental context.

1. Introduction

Inflammatory Bowel Disease (IBD) is caused by chronic inflammation of the gastrointestinal tract and comprises of three main disorders; Crohn's disease (CD), ulcerative colitis (UC) and intermediate colitis (IC). These result in ongoing or recurring symptoms including frequent diarrhoea, abdominal pain, fatigue, perianal disease, poor appetite, delayed puberty, weight loss, nausea and growth delay. The onset of IBD within childhood years is reported to be highest in adolescence (Sawczenko et al., 2001).

During adolescence, there are a number of biological, psychological and social changes that may make coping with a chronic disease more challenging (Suris et al., 2004). From a psychosocial perspective the tasks of adolescence are to establish an identity, develop peer and romantic relationships and establish greater independence and autonomy (Erikson, 1956). Adolescence can be considered as consisting of three developmental stages; early (11 to 13), middle (14 to 15) and late (16 to 18 years old), although some degree of overlap is inevitable (Berk, 2007). Early adolescence can be characterised by the tremendous assimilation of new experiences; including the physical changes of puberty and social changes such as moving to senior school. This introduces a new set of demands requiring more sophisticated social and cognitive skills. Conflict between young people and their parents tends to increase at the start of puberty, while greater importance is placed on friendships and being part of the crowd.

In mid adolescence there is a peak in the preoccupation with other's view of self (Elkind & Bowen, 1979) and consequently the peer group is considered very

influential. Self-esteem, which can be defined as the discrepancy between one's ideal self and what one perceives to be one's real self (Harter, 1990) has been shown to dip in early to mid adolescence (Seidman et al., 1994). At this stage young people are often concerned with establishing their independence and autonomy, tending to spend more time with their friends, or alone, than with their parents.

In late adolescence rising levels of self-esteem (Harter, 1990) are accompanied by decreasing levels of family conflict. Some young people may have developed formal operational cognitive skills (Piaget, 1952) and be able to solve abstract problems. One of the key tasks of this stage is forming emotionally intimate partnerships, and beginning to develop a clear self-identity. At this stage adolescents may be more future oriented, thinking in terms of further education, jobs and life goals.

The symptoms associated with IBD can make it more difficult for adolescents to complete the essential developmental transitions outlined above. During a 'flare up' when the disease is active, adolescents with IBD may need to spend a great deal of time in the bathroom and fear becoming a target of 'bathroom humour'. The perceived need to be near a bathroom at all times may also limit social activities. Adolescents are likely to miss considerable time off school due to illness and hospital appointments, impacting on both academic work and peer relationships.

There have been mixed outcomes of studies examining social functioning in young people with IBD. Studies using self-report norm-referenced measures of social competence found mean scores in the average range (Gold et al., 2000; Mackner & Crandall, 2005). Whilst studies using comparison groups and parent-report measures,

found lower social competence scores in children and adolescents with IBD than in healthy comparison groups (Engstrom, 1999; Mackner & Crandall, 2006). A recent study reported that a diagnosis of IBD in adolescence, as supposed to in childhood, was associated with greater difficulties in social functioning (Mackner & Crandall, 2006).

Some adolescents with IBD will undergo surgery or have a colostomy bag which can lead to reluctance to engage in peer or intimate relationships, as well as having an impact on body image. Delayed puberty and slowed growth, as well as side effects from steroids, such as weight gain or facial changes, may also impact on body image and self-esteem. There has been little research to date on the impact of IBD on body image, although population based studies show that adolescents with a chronic illness report higher body dissatisfaction than healthy adolescents (Neumark-Sztainer et al., 1995). Loonen and colleagues (2002) found adolescents with IBD had significantly lowered scores on the body complaints domain of a health-related quality of life (HRQOL) measure. Conversely, a more recent study using a norm-based scale to assess feelings about physical appearance found mean scores in the average range, and no difference between young people with IBD and healthy controls (Mackner & Crandall, 2005). It should be noted, however, that to the author's knowledge no specific measures of body image have been administered to adolescents with IBD.

Studies examining self-esteem in this population using norm-based questionnaires report mean scores in the average range (Gold et al., 2000; Mackner & Crandall, 2005; De Boer, 2005*)* and comparable levels of self-esteem to healthy adolescent controls (Lindfred et al., 2008). However, other studies using comparison groups*,*

found that children and adolescents with IBD had significantly lower self-esteem than healthy controls (Engstrom, 1999; Mackner & Crandall, 2005).

While relatively little research has examined the areas mentioned above, more work has investigated the prevalence of mood disorders in this population. A recent review concluded that young people with IBD were more likely to meet criteria for anxiety or depression than healthy peers, but that rates of mood disorder were similar to those associated with other chronic illnesses (Mackner, Crandall & Szigethy, 2006). Research examining depression in the general population, suggests adolescents who have completed puberty have significantly higher rates of depression than their pre-pubertal peers (Lewinsohn et al., 1994). Therefore it may be expected that older, post-pubertal adolescents with IBD will experience more difficulties with mood.

It is difficult to determine the validity of previous studies and to make comparisons between them due to a number of methodological difficulties such as varying measures, small sample sizes and large age ranges. Recently, several studies have used health-related quality of life (HRQOL), encompassing physical, social and psychological functioning, as a primary outcome measure. It is possible that more subtle differences in specific areas of functioning may be missed by such broad measures.

This is a complex population with a number of factors that may be impacting on psychosocial functioning such as gender, time since diagnosis, disease type and severity and age. Most studies of adolescents with IBD have found gender to be negatively associated with HRQOL, with girls scoring lower than boys (Loonen,

2004). However, others have found no sex differences for HRQOL (Otley et al., 2006) or self-esteem (Lindfred et al., 2008). In the adult IBD literature, females have been found to have lower HRQOL than males (e.g. Rubin et al., 2004).

While HRQOL has been found to significantly improve in the first six months post diagnosis and then continue to improve throughout the first year (Otley et al., 2006), further information on more long term functioning is not available. Disease type may have an impact on psychosocial functioning. The adult literature suggests patients with CD have reduced HRQOL compared to those with UC (e.g. Nordin et al., 2002). Loonen and colleagues (2002) reported that young people with CD had lower HRQOL scores than those with UC, although these differences were not significant. CD has been found to have a greater impact on social functioning than UC in one study (Ferry, 1999) although other researchers have found no difference (Lindfred et al., 2008, Mackner & Crandall, 2005).

Recently, increasing age has been shown to be associated with a decrease in HRQOL (Otley et al., 2006) and self-esteem (Lindred et al., 2008) in adolescents with IBD. Similar findings have been reported in other paediatric chronic illnesses. It has been suggested that this could be the result of the adolescent's increasing cognitive ability to appreciate the long-term implications of his or her illness, in addition to the effects of IBD on their attainment of key developmental tasks, such as identity development and establishing autonomy (Loonen et al., 2002).

While research has started to examine the psychosocial sequelae of IBD in adolescents, it has primarily focussed on making comparisons between adolescents

with IBD and their healthy peers. Adolescence is a time of transition, with a huge degree of heterogeneity within the 11 to 18 age group, making it questionable whether examining this population as one group is useful. It may be more valuable to consider the effects of IBD within a developmental context, comparing psychosocial functioning in early, mid and late adolescence in order to determine if one of these sub-groups is at a greater risk.

It is possible that while adolescents with IBD, as a group, have comparable self-esteem to their healthy peers, there may be subsets that have significantly lowered self-esteem. Lindfred and colleagues (2008) found that severity of disease, being female and being in mid adolescence increased the risk of low self-esteem in adolescents with IBD. Research has shown that lowered self-esteem, body dissatisfaction and impaired social functioning can be risk factors for later depression and anxiety (Carr, 1999). Therefore gaining a detailed picture of this population would have important service implications, allowing input to be directed to the most vulnerable group.

2. Aims and hypotheses

Primary aim:

To investigate the impact of IBD on social functioning, body-image and self-esteem in early, mid and late adolescence.

Research questions:

1. Does stage of adolescence have an effect on social functioning, body image and self-esteem in adolescents with IBD?

2. Does stage of adolescence have an effect on mood (specifically anxiety and depression), and does mood correlate with social functioning, body image and self-esteem in adolescents with IBD?
3. Within each stage of adolescence, does length of time since diagnosis have an effect on social functioning, body image and self-esteem in adolescents with IBD?
4. To explore whether type of disease (CD, UC or IC) has an effect on social functioning, body image and self-esteem in adolescents with IBD (subject to numbers achieved for each group)?

Due to the limited relevant research, the following tentative hypotheses are proposed:

1. Younger adolescents will report less impairment in the areas of social functioning, body image and self-esteem than older adolescents.
2. Younger adolescents will report fewer symptoms of anxiety and depression than older adolescents.
3. Adolescents with CD will report greater impairment in the areas of social functioning, body image and self-esteem than adolescents with UC or IC.

3. Plan of investigation

Participants

Adolescents attending the Gastroenterology outpatient clinic at The Royal Hospital for Sick Children, Yorkhill. According to clinical staff, around 170 adolescents attend the clinic each year.

Inclusion and exclusion criteria

Participants must be aged between 11-18 years old, attending senior school, and have a diagnosis of UC, CD or IC. They must be more than six months post-diagnosis in order that the initial shock has reduced and some adjustment has occurred. Participants will be excluded who have a serious comorbid medical condition, a major psychiatric diagnosis or who have a level of impaired cognitive functioning which would prevent them from being able to give informed consent or complete the questionnaires.

Recruitment procedures

Letters containing information about the study will be sent to all adolescents due to attend the outpatient clinic and who fulfil inclusion criteria. Letters will be co-signed by the Consultant Paediatrician in order to encourage participation. Adolescents will be approached at outpatient clinic appointments, given further information about the study and invited to participate. Informed consent will be sought from both the adolescent and their parent. It will be explained that choosing not to take part in the study will not adversely affect their medical treatment. Confidentiality and data-protection procedures will be made clear.

Measures

1. **The Rosenberg Self Esteem Scale (RSES) (Rosenberg, 1965)**

   This is a widely used and well validated brief (10 item) measure of global self esteem for use with adolescents. Participants indicate the extent to which they agree with statements (e.g. "On the whole, I am satisfied with myself") on a four point scale. The RSES takes less than five minutes to complete.

2. **Social competence scale of The Youth Self Report checklist (YSR) (Achenbach, 1991)**

   This is one of the most widely used standardised assessments for measuring social competence in adolescents. The self-report social competence scale measures the young person's participation in hobbies, games, sports, chores, friendships and activities and takes around five minutes to complete. The YSR has adequate psychometric properties (Achenbach, 1991). Additionally, there will be two questions using a Likert scale in order to gather information on the young person's perception of their social life compared to their healthy peers, and the extent to which this is affected by IBD (see Appendix A[5]).

3. **Revised Body-Esteem Scale (Mendelson & White, 1993)**

   This measures adolescents' attitudes and feelings about their body and appearance. There are three subscales: general feelings about appearance, weight satisfaction, and evaluations attributed to others about one's body and appearance. Respondents indicate their degree of agreement with 23 statements (e.g. "I like what I look like in pictures") using a five-point scale (see Appendix B[i]). This takes around five minutes to complete and has been shown to be valid and reliable in a wide age range (Mendelson, Mendelson & White, 2001).

4. **Hospital Anxiety and Depression Scale (HADS) (Zigmond & Snaith, 1983)**

   This is a brief 14 item self-report measure developed for use with adult medical out-patients. However, construct and concurrent validity have now been

[5] Please note that due to space constraints original Appendices have not been included

demonstrated in physically ill adolescents (aged 12-17) (White et al., 1999). The questionnaire has two subscales, one for depression and one for anxiety and takes around two to three minutes to complete. A possible limitation will be the use of the HADS with 11 year olds in this study. However, by including only 11 year olds that have entered senior school, participants should have adequate cognitive skills to complete this measure.

Demographic information including age, gender, socio-economic status (by post code) and family composition will be collected via a brief (four item) questionnaire given to adolescents. Disease information, including current disease severity will be measured using the Pediatric Crohn's Disease Activity Index (PCDAI; Hyams et al., 1991) and the Pediatric Ulcerative Colitis Activity Index (PUCAI; Turner, 2008). The PCDAI and PUCAI have good reliability and validity and are collected routinely by the clinical team. Additionally, information on length of time in hospital, disease duration, current medication, pubertal status and whether the adolescent has undergone resectional or non-resectional surgery will be gathered from patient files.

Design

This study uses a cross-sectional between groups design to compare psychosocial functioning in early, mid and late adolescence.

Research procedures

After gaining consent, participants will be asked to complete the questionnaires in a clinic room. This should take no more than 20 minutes. The main researcher will be present during this time in order to answer any questions and provide assistance in completing questionnaires. Questionnaires will be marked and entered into an SPSS

database where participants will only be identifiable by the number and letter sequence given to them when they attended clinic.

Justification of sample size

Although previous studies have looked at psychosocial functioning in adolescents with IBD as a whole; no studies have been identified which look at differences between stages of adolescence, and in this regard the study is exploratory. Studies comparing psychosocial functioning and HRQOL in adolescents with IBD to healthy controls have reported medium effect sizes (Mackner & Crandall, 2006; Loonen et al., 2002; De Boer et al., 2005). These papers provide the best available indication of likely effect size.

Therefore, in order to calculate sample size (N) the following assumptions were made: significance criterion (alpha) was taken to be 0.05, effect size to be medium ($f = 0.25$ according to Cohen, 1988) giving power of 0.8 if N=159 (53 per group). This was calculated using an online power calculator (G*power, Faul et al., 2007). However, information from the research site regarding the number of possible participants in the available time period, indicated a maximum of 100-110 young people as a realistic target. Thus, with 35 participants per group (N=105); a medium effect size ($f = 0.25$) and significance criterion of 0.05, this study would have power of 0.6. As aspects of this study are exploratory, it will be important to calculate effect sizes from our data, so that future studies can use this as a basis for their research.

Settings and equipment

The setting for the study is the Royal Hospital for Sick Children, Yorkhill NHS Trust, Glasgow. Questionnaires will be administered in a free clinic room at the Gastroenterology outpatient clinic.

Data Analysis

Outcome measures (self-esteem, body-image, social functioning, anxiety and depression scores) will be compared between the three groups (early, mid and late) using ANOVA if data is normally distributed and a non-parametric alternative if data is non-normally distributed. If data suggest these will be informative, some more complex statistical procedures such as multiple regression will be employed.

4. Health and Safety – researcher and participant safety issues

No health and safety issues are anticipated. Questionnaires will be completed in the hospital clinic where, if any medical problems arise, medical staff will be on hand.

5. Ethical issues

Ethical approval will be sought from the Greater Glasgow NHS Trust Ethics Committee as well as the local Research and Development department at Yorkhill hospital. This is a study recruiting young people, so care must be taken to provide information about the study in a developmentally appropriate manner. Informed consent will be sought from both the young person and their parent (even if the young person is over 16). Consideration will be taken if young people are feeling unwell or in pain due to flare ups.

If psychological difficulties are picked up, this information will be fed back to the young person and their parent. They will then have the option of requesting a referral to the dedicated psychology service attached to the Gastroenterology team. Feedback about the study in general may be given to participants who attend the annual IBD information day in the form of a presentation summarising the results of the study.

6. Financial issues

While the authors of the RSES, BES and HADS indicate permission for unlimited photocopying of these forms, the greatest expenditure will be purchasing forms for the YSR. The YSR is the quickest and most reliable questionnaire measuring social functioning in this age group. Furthermore, the YSR has been successfully used to examine social functioning in adolescents with IBD in previous studies (e.g. Mackner and Crandall, 2005). Additionally there will be the cost of sending letters to participants and photocopying information sheets, consent/assent forms and the reproducible questionnaires.

7. Timetable

Submission of proposal for ethical approval – July 2009

Preparation of materials for research – September 2009

Data collection – October 2009 – April 2010

Data analysis and write up – April 2010 – June 2010

Final draft to supervisor – June 2010

8. Practical application

The Gastroenterology team at Yorkhill hospital are currently developing their service and are supportive of this research. They would be able to use the findings of this study in order to direct existing resources into the most clinically appropriate areas and potentially gain more funding for psychology input.

9. References

Achenbach TM. *Manual of the Child Behaviour Checklist (CBCL).* Burlington, VT: University Associates of Psychiatry.

Berk LE. (2007) *Development through the lifespan.* Boston. Allyn and Bacon, p.362.

Carr A. (1999) The *Handbook of Child and Adolescent Clinical Psychology: A Contextual Approach* (2nd ed). Routledge.

Cohen J. (1998) *Statistical power analysis for the behavioural sciences*, (2nd ed). Hillsdale, NJ: Erlbaum.

De Boer M, Grootenhuis M, Derkx B & Last B. (2005) Health-related quality of life and psychosocial functioning in adolescents with inflammatory bowel disease, *Inflammatory Bowel Disease*, 11, 400-406.

Elkind D & Bowen, R. (1979) Imaginary audience behaviour in children and adolescents. *Developmental Psychology*, 15, 38-44.

Engestrom I. (1999) Inflammatory bowel disease in children and adolescents: mental health and family functioning. *J Pediatr Gastroenterol Nutr*, 28, S28-33.

Erickson EH. (1956) The Problem of Ego Identity. *J. Amer. Psychoanal. Assn*, 4, 56-121.

Faul F, Erdfelder E, Lang AG & Buchner A. (2007) G*Power 3: A flexible statistical power analysis program for the social, behavioural, and biomedical sciences. *Behaviour Research Methods,* 39, 175-191.

Ferry GD. (1999) Quality of life in inflammatory bowel disease: background and definitions. *Journal of Pediatric Gasteroentrology and Nutrition,* 28, S15-S18.

Gold N, Issenman R, Roberts J & Watts S. (2000) Well adjusted children: an alternative view of children with inflammatory bowel disease and functional gastrointestinal complaints. *Inflammatory Bowel Disease,* 6 (1), 1-7.

Griffith AM, Nicholas D, Smith C, et al. (1999) Development of a quality of life index for pediatric inflammatory bowel disease: dealing with differences related to age and IBD type. *Journal of Pediatric Gastroenterology and Nutrition*, 28, S46-S52.

Harter S. (1990) Causes, correlates and functional role of global self-worth: A life span perspective. In J. Kolligan & R. Stenberg (Eds.), Perceptions of competence and incompetence across the life span. *New Haven, CT: Yale University Press*.

Hyams JS, Ferry GD, Mandel FS, Gryboski JD, et al. (1991) Development and Validation of a Pediatric Crohn's Disease Activity Index. *Journal of Pediatric Gastroenterology and Nutrition*, 12, 439-447.

Lindfred H, Saalman R, Nilsson S, & Reichenberg K. (2008) Inflammatory bowel disease and self-esteem in adolescence. *Acta Paediatrica, International Journal of Paediatrics*, 97(2), 201-205.

Loonen HJ, Grootenhuis MA, Last BF, Koopman HM & Derkx HHF. (2002) Quality of life in paediatric inflammatory bowel disease measured by a generic and a disease specific questionnaire. *Acta Paediatr,* 91, 348-354.

Van der Zaag-Loonen HJ, Grootenhuis MA, Last BF, et al. (2004) Coping strategies and quality of life of adolescents with inflammatory bowel disease. *Qual Life Res*., 13, 1011-1019.

Mackner LM & Crandall WV. (2003) Gender differences in weight and body image contribute to problematic eating behaviours in inflammatory bowel disease compared to healthy children. *Journal of Pediatric Gastroenterology Nutrition*, 37, 375.

Mackner LM & Crandall WV. (2005) Long-term psychosocial outcomes reported by children and adolescents with inflammatory bowel disease. *American Journal of Gastroenterology*, 100, 1386-1392.

Mackner LM & Crandall WV. (2006) Brief report: psychosocial adjustment in adolescents with inflammatory bowel disease. *Journal of Paediatric Psychology*, 31 (3), 281-285.

Mackner LM, Crandall WV & Szigethy EM. (2006) Psychosocial Functioning in Pediatric Inflammatory Bowel Disease. *Inflammatory Bowel Disease*, 12 (3), 239-244.

Mendelson BK & White D R. (1993) Manual for the Body-Esteem Scale for Children. *Concordia University Research Bulletin, 12* (2), 1–10.

Mendelson BK, Mendelson MJ & White, DR. (2001) Body-Esteem Scale for Adolescents and Adults. *Journal of Personality Assessment*, 76 (1), 90-106.

Neumark-Sztainer D, Story M, Resnick M, et al. (1995) Body dissatisfaction and unhealthy weight-control practices among adolescents with and without chronic illness: a population based study. *Arch Pediatr Adolesc Med*, 149, 1330-5.

Nordin D, Pahlman L, Larsson K, Sundberg-Hjelm M & Loof L. (2002) Health-related quality of life and psychological distress in a population-based sample of Swedish patients with inflammatory bowel disease. *Scand J Gastroenterol*, 37, 450-7.

Ogden CA, Abbott J, Aggett P, Derkx BH, Maity S & Thomas AG. (2008) Pilot evaluation of an instrument to measure quality of life in British children with

inflammatory bowel disease. *Journal of Pediatric Gastroenterology and Nutrition*, 46, 117-120.

Otley A, Smith C, Nicholas, D, Munk M, Avolio J, Sherman PM & Griffiths AM. (2002) The IMPACT questionnaire: A valid measure of health related quality of life in pediatric inflammatory bowel disease. *Journal of Pediatric Gastroenterology and Nutrition*, 35, 557-663.

Otley AR, Griffiths AM, Hale S, Kugathasan S, Pfefferkorn M, Mezoff A, Rosh J et al., (2006) Health-related quality of life in the first year after a diagnosis of pediatric inflammatory bowel disease. *Inflammatory Bowel Disease*, 12, (8), 684-691.

Piaget J. (1952) The origins of intelligence in children. In Berk LE. (2007) *Development through the lifespan.* Boston. Allyn and Bacon.

Richardson G, Griffiths, AM, Miller V & Thomas AG. (2001) Quality of life in inflammatory bowel disease: A cross cultural comparison of English and Canadian children. *Journal of Pediatric Gastroenterology and Nutrition,* 32, 573-578.

Rosenburg M. (1965) *Society and the adolescent self-image*. Princeton, NJ: Princeton University Press.

Rosenburg Self-Esteem Scale, published in Johnston M, Wright S & Weinman J. *Measures in health psychology: a user's portfolio*. The NFER-NELSON publishing Company Ltd.

Rubin GP, Hungin APS, Chinn DJ, & Dwarakanath D. (2004) Quality of life in patients with established inflammatory bowel disease: a UK general practice survey. *Aliment Pharmacol Ther*, 19, 529-35.

Sawczenko A, Sandhu BK, Logan RFA, Jenkins H, Taylor CJ, Mian S & Lynn R. (2001) Prospective survey of childhood inflammatory bowel disease in the British Isles. *Lancet,* 357, 1093-1094.

Seidman E. (1994) The impact of school transitions in early adolescence on the self-system and perceived social context of poor urban youth. *Child Development*, 65 (2), 507-522.

Suris JC, Michaud PA & Viner R. (2004) The adolescent with a chronic condition. Part 1: developmental issues. *Arch. Dis. Child*, 89, 938-942.

Szigethy E, Levy-Warren A, Whitton S, Bousvaros A, Gauvreau K, Leichtner AM & Beardslee WR. (2004) Depressive symptoms and inflammatory bowel disease in children and adolescents: a cross-sectional study. *Journal of Pediatric Gastroenterology and Nutrition*, 39, 395-403.

Turner D. Development, evaluation and application of a pediatric ulcerative colitis activity index (PUCAI). Unpublished.

Varni J, Seid M & Kurtin PS. (2001) PedsQL 4.0: reliability and validity of the Pediatric Quality of Life Inventory version 4.0 generic core scales in healthy and patient populations. *Med Care*, 39, 800-12.

White D, Leach C, Sims R, Atkinson M & Cottrell D. (1999) Validation of the hospital anxiety and depression scale for use with adolescents. *British Journal of Psychiatry,* 175, 452-454.

Zigmond AS, Snaith RP. (1983) The hospital anxiety and depression scale. *Acta Psychiatrica Scandinavica*, 67, 361-370.