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# Prospective Study of Psychological Morbidity and Illness Perceptions in Young People with Inflammatory Bowel Disease

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## ABSTRACT

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

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

**Results:** Among the 121 patients at baseline (median age 19.3 years, 40% female, 62% Crohn's disease, 73% in clinical remission), 55% reported elevated symptoms of anxiety/depression and 83% low HRQoL. Negative illness perceptions at baseline were significantly correlated with greater anxiety, depression and lower HRQoL at baseline and follow-up. In regression analysis at baseline, IPQ-R domain of greater perception of a cyclical nature of IBD was an independent predictor of anxiety, whilst a greater perceived emotional impact of IBD was an independent predictor of anxiety, depression and HRQoL.

Female gender and clinical relapse were also independent predictors of lower HRQoL. After controlling for baseline measures, clinical risk factors and illness perceptions did not explain additional variance in psychological morbidity at follow-up.

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

**Keywords:** inflammatory bowel disease, paediatrics, psychological end points

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## 1 Introduction

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



morbidity, including abdominal pain, sleep dysfunction, use of psychotropic drugs and non-adherence to medication (9).

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

In adults with IBD, limited cross-sectional research exists examining the relationship between illness perceptions and psychological morbidity and other outcomes (12,19–23). Negative illness perceptions regarding consequences (20,23) and emotional representations (19) have been found to correlate with reduced health-related quality of life (HRQoL), depression and anxiety (12,21) in addition to lower work productivity (23). Most recently, in

a larger cross-sectional study in adults with IBD, negative illness perceptions regarding consequences were associated with lower levels of mental and physical health as well as impairment of activity and reduced work activity (22). In addition, a longitudinal study of IBD adult patients found that those with and without arthropathies held significantly different illness perceptions (24), suggesting that symptom or disease-related differences may impact on illness perceptions and, in turn, psychological morbidity. To date, there have been no studies exploring young people's illness perceptions and their relationship with psychological morbidity.

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

## **2 Materials and Methods**

### **2.1 Study design**

Young people aged 16-21 years, with an established diagnosis of IBD (CD, UC or Inflammatory Bowel Disease Unspecified (IBDU)) completed measures of psychological morbidity (anxiety and depression), HRQoL and illness perceptions. The World Health Organisation defines adolescence as the developmental stage between 10–19 years, and

youth as those between 15-24 years. Together, adolescents and youth are referred to as young people. This study examines young people aged 16-21 years.

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

## 2.2. Procedure

Consecutive patients were recruited between March 2014 and March 2015, with follow-up concluded by March 2016. Patients were recruited from two University hospitals (Sheffield Teaching Hospitals NHS Foundation Trust and Sheffield Children's Hospitals NHS Foundation Trust). The study was part of a wider research programme examining the experiences of young people transitioning from child to adult healthcare. The two recruitment centres participate in a formal transition process for young people with IBD from paediatric to adult healthcare with transfer occurring between the ages of 16-18 years. This involves medical and nursing health care professionals attending joint IBD clinics alongside an assessment of readiness for transfer in line with current guidelines and international consensus (26,27).

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

At 12-month follow-up, patients were approached at scheduled appointments (by AJB, AR or EP) or by their chosen preference for follow-up (57% returned follow-up data by post, 42% at clinic appointment, 1% via email). If patients failed to respond to the first invitation for 12-month follow-up they were sent a reminder by their chosen method. Two patients stated they did not wish to participate at the follow-up time point, a further 19 were lost to follow-up during the time period required for completion of the study. At baseline and at 12 months, patients completed measures detailed below alongside demographic measures.

## 2.3 Measures

### 2.3.1 Demographic characteristics

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

### 2.3.2 Clinical characteristics

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

### 2.3.3 Illness Perceptions

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

IBD treatments); *emotional representations* (perceived emotional impact of IBD); and *illness coherence* (personal understanding of IBD) (11).

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

#### **2.3.4 Anxiety and depression**

Anxiety and depression were measured using the Hospital Anxiety and Depression Scale (HADS) (31). Subscale scores were attained by summing the subscale items with higher scores indicating a greater severity (subscale range 0–21) (32). Both measures of depression (alpha = .82) and anxiety (alpha = .85) were found to have a strong internal consistency. Severity of anxiety and depression was interpreted according to existing literature as 0–7 “normal”, 8–10 “mild severity”, 11–15 “moderate severity”, and 16–21 “severe severity” (31,32).

### 2.3.5 Health-related Quality of Life (HRQoL)

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

### 2.4 Statistical analysis

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

outcome variables, both cross-sectionally and prospectively, after controlling for any significant demographic or medical variables.

### 3 Results

#### 3.1 Patient Characteristics

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

One hundred patients also completed the follow-up questionnaire at 12 months (attrition at follow-up of 17%). No significant differences were identified between patients who completed the follow-up questionnaires compared to those who did not, either in clinical (remission vs relapse  $p = .49$ , CD vs UC/IBDU  $p = .99$ , corticosteroids vs no corticosteroids  $p = .45$ ), or demographic details (employment status  $p = .24$ , ethnicity  $p = .12$ , gender  $p = .21$ , age at baseline  $p = .10$ , age at diagnosis  $p = .72$ , IBD related flares/admission in last year  $p = .74$ ). Patients who completed the follow-up at 12 months had significantly lower depression scores at baseline ( $M = 3.21$ ,  $SD = 3.38$ ) compared to those who did not ( $M = 5.13$ ,  $SD = 4.30$ ),  $t(116) = -2.20$ ,  $p = .03$  (CI -3.64 -1.92). No other differences were identified in illness



perceptions or in the outcome measures of anxiety or HRQoL between patients who completed the follow-up compared to those who did not.

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

### 3.2 Prevalence and Severity of Psychological Morbidity over Time

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

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

### 3.3 Associations between Demographic/Clinical Risk Factors and Psychological Morbidity

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

found to have non-significant associations with psychological morbidity at baseline and follow-up.

### **3.4 Associations between Demographic/Clinical Risk Factors and Illness Perceptions**

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

### **3.5 Associations between Illness Perceptions and Psychological Morbidity**

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

control at baseline correlated with follow-up depression and HRQoL, and personal control at baseline correlated with follow-up HRQoL.

### 3.5 Regression Analyses Identifying Predictors of Psychological Morbidity

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

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

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

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

#### 4 Discussion

The current study of young people aged 16-21 years with IBD demonstrated high rates of anxiety/depressive symptoms, with a combined prevalence of (55%). This is greater than the most recently published data in patients between the ages of 10 and 25 years with IBD (47%) (8), and is markedly higher than national UK statistics (19%) reported for 16-24 year olds (35). Of particular concern are high rates of anxiety reported in 42%, compared to 19%

rate reported in a recent systematic review for adults with IBD (36), and 28% in 10-25 year olds with IBD (8). The rate of depressive symptoms observed in the current sample was 13%, lower than the 21% rate that has been reported for adults with IBD (36, 38), but much greater than 3% observed in van den Brink data (8). Furthermore, our data show low HRQoL in young people aged 16-21 years with IBD, with 83% scoring lower than that of the general population.

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

unable to explain additional variance in psychological morbidity and quality of life at follow-up after controlling for baseline morbidity. This may have been due to the lack of change in anxiety, depression and quality of life between baseline and follow-up.

Illness perceptions varied according to disease activity, with a greater perceived emotional impact of IBD observed in disease relapse, and a lower perception of the effectiveness of controlling IBD through patients' own behaviour compared to those in remission.

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

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



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

complete follow-up assessment and they may also be less likely to engage with healthcare services.

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

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### Author Contributions

Guarantor of the article: AJB

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

### Supplementary Data

Supplementary data are available online.

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**TABLE 1** Demographic and clinical characteristics of patients at baseline

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

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

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

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

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

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

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

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

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

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

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

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

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

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

Note. Step 1  $R^2 = 0.35$ ,  $p < 0.001$ .

Step 2  $R^2 = 0.599$ ,  $p < 0.001$ . \*  $p < 0.05$ . \*\*  $p < 0.01$ . \*\*\*  $p < 0.001$