University of Alberta

THE PSYCHOSOCIAL FUNCTIONING OF PATIENTS WITH INFLAMMATORY BOWEL DISEASE IN EARLY ADULTHOOD IS IMPAIRED

by

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ABSTRACT

Inflammatory bowel disease is a chronic disease that is often diagnosed in childhood and adolescence. The objective of this study was to assess the impact of a diagnosis of IBD on the psychosocial functioning in early adulthood. This was a questionnaire-based cross-sectional study comparing patients with Crohn's disease and ulcerative colitis to healthy controls. Overall, unlike other childhood illness the milestone development of IBD patients is not hampered compared to healthy controls. IBD patients age 18-30 have higher mean depression scores than healthy controls (9.2 v. 6.0, difference in means =3.2, [1.31, 5.05], p=0.001); this difference was not only due to somatic or physical symptoms, but also due to increased cognitive/affective symptoms. IBD patients report 4X more hours of absenteeism per month than healthy controls (15.7 v. 4.3 hours, difference in means = 11.4, [0.92, 21.9], p=0.03). A younger age of diagnosis is associated with poorer autonomy development.

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List of Abbreviations

ANOVA – Analysis of Variance

BDI-II – Beck Depression Inventory – II

CD – Crohn's disease

Chi-sq – Chi-squared

df – Degrees of freedom

Dx – diagnosed

EPICORE – Epidemiology Coordinating and Research

F – Female

HRQOL – health related quality of life

IBD – inflammatory bowel disease

LSD – lysergic acid diethylamide

M – Male

n – number of subjects or sample size

RDD – random digit dialing

SD – Standard Deviation of the mean

SE – Standard Error of the mean

SIBDQ – Short Inflammatory Bowel Disease Questionnaire

SPSS – Statistical Package for the Social Sciences

TNO-AZL – Netherlands Organization for Applied Scientific Research Academic Medical Centre

UC – ulcerative colitis

US – United States

v. – versus

X^2 – Chi-squared

1. Introduction

1.1. Impact of Inflammatory Bowel Disease on Well Being

Chronic disease has the potential to have a significant impact on the overall well being of individuals, their families, and society as a whole. This impact can be both positive and negative. Examples of positive impact includes societal and researchers motivation to investigate and realize mechanisms of disease and create new treatments and therapies; or families or groups working together to increase resources or advance awareness of the obstacles faced by those affected by these disorders. Examples of negative impact include the direct fiscal costs of care and the indirect costs related to loss of work productivity and the psychological stress imposed by disease. At the individual level, persons with disease or disability are more likely to be unemployed or under-employed, experience depression, and face challenges with daily functioning. In contrast, individuals affected by a chronic disease are also motivated to raise money, search for cures, or provide a helping hand to others with health problems.

Chronic disease takes a toll over time, physically, emotionally, and financially. The impact of chronic disease on these parameters depends on disease severity, disease duration, and the nature of disease. Patients with disease or disability are often restricted physically. Emotionally, chronic disease can be difficult to cope with and lead to altered levels of psychological adjustment. Financially, chronic disease can result in acceptance of under-employment and subsequently lower paying occupations in addition to limited opportunities for financial bonuses or work promotions.

Children and adolescents are especially vulnerable to effects of chronic disease. Chronic disease has the ability to affect physical, intellectual, emotional, and psychosocial growth and development. There is only a short

period of time in which growth and development takes place. Timely physical and sexual development is a part of social acceptance and psychosexual maturation. Finding success and acceptance in one's peer group can affect confidence and the ability to reach their potential. Disease onset and diagnosis during childhood or adolescence is of particular importance because these periods of life include significant other changes – biological, psychological, and social. Youth and young adults are faced with the challenges of adjustment to adult life while learning to cope with a chronic disease or disability. Adolescents with chronic disease perceive a lack of support and feel alienated, isolated and afraid.[1]

1.2. What is Inflammatory Bowel Disease?

Inflammatory bowel disease (IBD) is a chronic inflammatory disease of the intestine that often has its onset in children, adolescents and young adults. Common symptoms of IBD include abdominal cramping, diarrhea, weight loss and blood in the stool. These are embarrassing symptoms, which patients, and especially children often ignore and hope will go away. In addition, patients with inflammatory bowel disease may have extra-intestinal manifestations, which include joint swelling, and stiffness, skin rashes, mouth ulcers, and inflammatory eye disease. Collectively the term IBD refers to Crohn's disease (CD), ulcerative colitis (UC), and IBD-unspecified. Crohn's disease can affect any part of the intestinal tract from the mouth to the anus and patients often experience abdominal pain, diarrhea, weight loss and may develop complications including fistulas (deep ulcerations of the intestine making tracts to other organs or the skin), strictures (narrowing of the intestine), and abscesses. Ulcerative colitis patients have diarrhea, which is often bloody, abdominal cramping, and fecal incontinence. IBD varies in severity and its pattern of presentation is one of flares and remission. The goals of treatment are to induce remission (with medications and/or surgery) and to maintain

remission (with medications). The top concerns of patients with IBD include: the uncertain nature of the disease, having an ostomy bag, having surgery, effect of medications, and energy level.[2,3] The symptoms of IBD are embarrassing and may lead to social isolation, withdrawal and decreased sexual intimacy.[4] Diagnosis of IBD in childhood and adolescence leads to impaired growth and delayed puberty. Furthermore, the psychosocial development of children with IBD may be delayed, perhaps simultaneously as the result of illness and therapy (e.g. corticosteroids).[5,6]

1.3. IBD and Adolescence

Increasing disease severity can negatively impact the psychosocial development of children and young adults. Adolescents (age 10-18) with severe IBD report more emotional problems than controls or those with milder disease.[7] Furthermore, the psychosocial functioning of patients (11-17 years old) with mild IBD have normal psychosocial functioning, one year after their diagnosis.[8] Otley *et al* also reported a significant effect of worsening disease severity negatively impacting health related quality of life (HRQOL).[9,10]

Differences in treatment (e.g. surgery, corticosteroids, or use of biologic therapy) may also impact the psychosocial functioning of young IBD patients. Otley *et al* did not find a difference in IMPACT (an IBD-specific HRQOL questionnaire for children) score amongst children with a history of corticosteroids in the last year.[10] Remission induced by infliximab (a biologic medication used to induce and maintain remission) in adult ulcerative colitis patients, resulted in an improvement in IBDQ (an IBD-specific HRQOL questionnaire) score and improved employment status and productivity.[11] Although, this improved quality of life may simply reflect the treatment outcome and not the treatment *per se*. The relationship between a diagnosis of IBD and type of occupation has been previously discussed in the literature, nevertheless, a clear understanding of cause and effect is lacking.[12] In contrast

analysis of the United States (US) census data demonstrated that only symptomatic and not asymptomatic patients with IBD have a greater rate of workplace nonparticipation.[13]

1.3.1. Gender Differences

Vaisto *et al* have explored the question of the role of gender in the psychosocial functioning in IBD.[7] They discovered that adolescent girls report more emotional problems, anxious/depressed symptoms and had better academic performance compared to adolescent boys. Boys reported less total competence than girls.[7] In a meta-analysis of children with a variety of chronic illnesses, girls had lower self-esteem than boys.[14]

1.3.2. Impact of Age of Diagnosis

Adolescence is a complex transitional process that may be significantly impacted by a diagnosis of inflammatory bowel disease. In a large prospective study by Otley *et al*, new diagnosed pediatric patients with IBD, age of diagnosis was found to be an important factor in determining health related quality of life, as measured by the IMPACT-II questionnaire (a disease-specific HRQOL questionnaire for children with IBD); for each year of age increase, the HRQOL was found to be lower.[10] HRQOL improved over the year after diagnosis, with most improvements being seen in the 1st 6 months, but with ongoing improvement in social/functional score at 12 months as well. Another study using the TNO-AZL (Netherlands Organization for Applied Scientific Research Academic Medical Centre) Children's Quality of Life Questionnaire (a generic pediatric HRQOL questionnaire) has shown that adolescents (age 12-18) but not children (age 8-11) with IBD have decreased autonomy and motor functioning but no difference in social or cognitive functioning compared to healthy controls.[15] When Mackner and Crandall examined psychosocial adjustment in adolescents with IBD, a diagnosis of IBD in adolescence was associated with worse social competence than a diagnosis in childhood (<11

years old).[16] In a study of adolescents with inflammatory bowel disease, a positive correlation was found between age of diagnosis and symptoms of depression.[17]

The finding that age at diagnosis impacts the psychosocial development begs the question of whether these differences are driven by disease duration. Otley *et al* demonstrated that during the 1st year after diagnosis of IBD, there is a statistically significant increase in the health-related quality of life.[10] However, Szigethy *et al* found that IBD duration was not associated with increased depressive symptoms, while age at diagnosis did.[17]

1.4. Success in Life

The impact of a diagnosis of IBD during adolescence and its impact on development have received little attention in IBD research.[18] There is an abundance of literature assessing the medical aspect of IBD; there is little research on the psychosexual impact.[19] Nevertheless, it has been recommended that adults with a chronic illness originating in childhood should have ongoing assessment of the late consequences of childhood illness in regards to their psychosocial needs.[5]

Currently, adult medical care of patients with inflammatory bowel disease is focused primarily on induction and maintenance of disease remission. While this is essential to their care, a holistic approach should include attention also to the patient within the context of life. Indeed, it can be argued that the ultimate goal of medical care of patients with chronic disease, like IBD is success in life. Ideally, we would want patients to achieve their full potential, in spite of their disease.

"Success in life" is a difficult endpoint to define. The definition of success depends on personal and societal values, which are related to cultural and religious mores. Pinquart and Teubert have divided functioning of children and

adolescents with chronic illness into three areas: social, physical and academic as the building blocks for basic life skills.[20] These skills are necessary for the development of supportive peer networks and personal skills to interact in society, have success in school and later life, and to living independently.[20] Maslow and colleagues have studied the educational, vocational and social outcomes of young adults with chronic illness.[21] Success in this study was measured in terms of marriage, having children, romantic relationship quality, living with parents, educational attainment, employment and income.[21] In Canadian society, the attainment of developmental milestones, relationships with family and friends, employment, and financial and social independence are also reasonable measures of success.

1.5. Purpose of the Study

The purpose of this study was to measure the psychosocial functioning of emerging and young adults (aged 18-30), with a diagnosis of IBD, and compare them to healthy, age and gender-matched individuals without IBD.

1.5.1. Primary Objective

The primary objective of this study is to compare the psychosocial functioning of emerging and young adults with IBD to healthy, age and gender-matched individuals without IBD using assessments of:

- Developmental milestones and risk behavior,
- Depression,
- Work performance status

1.5.2. Secondary Objective

The secondary objective is to determine the impact of gender, type of IBD, and age at diagnosis on these measures of psychosocial functioning.

1.6. Significance of the Study

There is limited data on the long-term impact a diagnosis of IBD will have on the emerging and young adult's ability to function in society. Identification of the specific domains that affect psychosocial development of patients with IBD and their subsequent functioning in society is the first step in developing cost-effective therapeutic programs that will positively intervene and ensure a well-rounded and productive member of society.

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2. Methods and Study Population

2.1. Methods

2.1.1. Study Design

A questionnaire-based cross-sectional study design was chosen for this project. The main advantage of cross-sectional studies is their efficiency for investigating chronic conditions that often go undetected. For such conditions, it may not be feasible to identify all cases at the time of onset in a target population and screening for prevalent cases may be the only option. While cross-sectional studies cannot measure disease incidence, which is the preferred frequency measure for investigating causal hypotheses, they can identify potentially important associations in a relatively shorter time period and relatively lower cost. The limitations of cross-sectional studies can be reduced if assumptions can be made about the timing of the outcome with respect to other study factors. Another advantage of cross-sectional studies is that they can be designed and analyzed like case-control studies for greater efficiency. Self-administered questionnaires have the advantages over interviewer-administered questionnaires of being less expensive[1], so self-administered questionnaires were chosen to increase the number of potential participants at a lower cost. Because the hypothesis under investigation pertains to the effect of IBD on psychosocial functioning, IBD diagnosis is the main independent in this study and measures of psychosocial functioning are the dependent variables. To examine the effect of IBD on individuals with this diagnosis, it is necessary to compare them to people without the diagnosis on psychosocial outcomes. For an unbiased comparison, the non-cases should be chosen from the same base population as the diagnosed IBD cases.[2] Selection bias is important to consider for both case and control groups, as ideally they should be chosen from the same base population.[2] It is best to capture data

on all known potential confounders, since the analysis can control for confounders that are measured.[2]

2.1.2. *Measurement Tools*

A number of questionnaires were reviewed for their merits and appropriateness for this study. A list of the excluded questionnaires and the reason for their exclusion is listed in Table 2.1.

Table 2.1. List of excluded questionnaires reviewed and reason for exclusion

Questionnaire Name/Description	**Reason for exclusion**
Behavior Assessment Scale for Children (BASC)	For children only
Schedule for Non-adaptive and Adaptive Personality (SNAP)	Specific for personality disorders; not within the scope of this project
Social Adjustment Scale-Self Report (SAS-SR)	Assessment tool for satisfaction with social roles; beyond the scope of this project
Adult Self Report (ASR)	126 questions; licensed; many questions overlap with other questionnaires
Adult Behavior Checklist (ABCL)	Needs to be completed by someone other than participant
Child Behavior Checklist (CBCL)	For age 6-18 only; completed by parent
Youth Self Report (YSR)	For age 11-18 only
Student Adjustment to College Questionnaire (SACQ)	For students only
Short Form (SF-12; SF-36)	12 or 36 questions; generic tool for health and well-being; non-specific,

	overlaps with other surveys
Inflammatory Bowel Disease Questionnaire (IBDQ)	32 questions; licensed; correlates well with SIBDQ
Revised Illness Perception Questionnaire (IPQ-R)	Developed for use in 8 diseases; none of them GI disease

To measure psychosocial functioning, the following 4 questionnaires were chosen for inclusion in the study.

1. Course of Life Questionnaire – this questionnaire was developed by the Psychosocial Department of the Emma Children's Hospital in the Netherlands. It is designed to assess milestone development and risk behavior in young adults aged 18-30 with chronic illness. It assesses the achievement of developmental milestones and risk behavior.[3, 4] It is a 75-item questionnaire that has recently been translated from Dutch into English, but has not been used previously in patients with inflammatory bowel disease. Dr. Helene Stam generously provided the English version and scoring guide (Appendix 1).

2. Beck Depression Inventory II (BDI-II) – The BDI-II is a 21 question patient-administered questionnaire that was created by Dr. Aaron Beck. This second version was published in 1996. It measures the severity of self-reported depression in adults and adolescents.[5,6] The BDI-II is a multiple-choice, self-report inventory. It is designed for use in persons 13 years of age and older. It is a well-established measurement tool with cut-offs for mild, moderate and severe depression. Higher scores indicate more depression symptoms. This was purchased from Pearson Canada Assessment, Incorporated (Appendix 2).

3. Short Inflammatory Bowel Disease Questionnaire (Short IBDQ) – This is a 10-item health related quality of life (HRQOL) questionnaire specific to

inflammatory bowel disease.[7] Each question is reported on a 7-point scale (1=poor HRQOL; 7=optimal HRQOL). As this questionnaire is designed for patients with IBD, it was measured only in IBD participants (Appendix 3).

4. World Health Organization Health and Performance Questionnaire – this is a 13-item questionnaire about work performance – designed to estimate the workplace costs of illness and assess individual performance relative to their peers[8] (Appendix 4).

2.1.3. Definition of Study Groups

2.1.3.1. Cases

Subjects with IBD are referred to in this study as "cases" although IBD is not the study outcome variable. The patient population of interest was male and female patients with a known diagnosis of Crohn's disease or ulcerative colitis. Due to the age limits in the Course of Life Questionnaire, only patients aged 18-30 years were recruited. Two sub-populations of the patient group were recruited based upon age at diagnosis: pediatric (diagnosed age 17 and younger) and adult (diagnosed age 18 plus). The adult diagnosed group was felt to be an important comparator to the pediatric diagnosed group.

Inclusion Criteria - Cases

1. Male or female, age 18-30;
2. A known diagnosis of Crohn's disease or ulcerative colitis of at least 1 year duration, as confirmed by endoscopic and/or radiological studies;
3. Willing to participate and able to give consent

Exclusion Criteria - Cases

1. Serious underlying disease or chronic illness other than inflammatory bowel disease;

2. Unable to read and write in English;

3. Inability or unwillingness to complete the questionnaires

2.1.3.2. Controls

Subjects without IBD are referred to in this study as "controls", although IBD status is not the dependent variable in this study. Healthy, age-matched individuals were chosen as a comparison group. The definition of "healthy" was largely at the discretion of the participant, although information regarding health problems, surgeries, and medications was collected for each participant.

Inclusion Criteria - Controls

1. Male or female, age 18-30;

2. Willing to participate and able to give consent

Exclusion Criteria - Controls

1. Serious underlying disease or chronic illness, including inflammatory bowel disease;

2. Unable to read and write in English;

3. Inability or unwillingness to complete the questionnaires

Matching

Controls were age-matched because the "normal" general well being and societal functioning of individuals is dependent on their stage in life (childhood, adolescence, early adulthood, adulthood, retirement). Gender has been shown to be less important in determining differences in the general well-being and societal functioning of adolescents with IBD,[9] therefore specific attempts to recruit gender-matched controls were not employed.

Blinding and avoiding bias:

The questionnaires were self-administered and so blinding was not required for data collection. Controls were recruited differently than IBD patients, which raise the possibility of confounding due to different distributions of factors that influence psychosocial functioning. Gift certificates were used to aid in the recruitment of the control group; in addition all IBD participants were also provided gift certificates to reduce potentially relevant differences between the groups.

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Patients diagnosed in adulthood were used as a second comparison group in order to reduce the potential of confounding due to the manner in which the non-IBD group was recruited. The field of IBD research is rapidly growing, thus there may be differences in IBD diagnosis over time; limiting the age range of the participants minimizes the bias that may result from this.

2.1.4. Sample Size Calculation

The primary outcome measure of this study is the proportion of individual who have reached developmental milestones by a certain age. Estimates for this population group are unknown; however proportions are known for Dutch patients that are survivors of childhood and controls.[3]

For the purposes of sample size calculation, a single domain of the Course of Life Questionnaire was chosen. Ideally, we would have liked to use an overall score from this Questionnaire, however all previous publications with this assessment tool have reported scores for each domain separately.

The sample size required for a balanced 3-way ANOVA with 80% power, and a 5% Type I error is 79 per group. Therefore, we therefore aimed to recruit 100

patients per group (IBD diagnosed<18 years, IBD diagnosed>18 years, and healthy controls) to give a 20% buffer.

2.1.5. *Study Procedures*

2.1.5.1. Identification and Recruitment of Subjects

The University of Alberta Gastroenterology patient care database was searched to identify eligible patients based upon age and diagnosis. Consent to contact patients was obtained from the gastroenterologists at the University of Alberta to comply with the ethical standards of the University of Alberta. A letter of recruitment was sent to each potential participant (Appendix 5). A follow-up phone call to patients who did not respond to the letter of invitation was employed to improve response rate. In addition, eligible patients attending clinic or biologic infusion clinic were approached and invited to participate. Interested participants were given a package in person or by mail. Packages for patient participants contained a letter of consent, patient demographic sheet (Appendix 6), the four questionnaires, and instructions on how to receive the gift certificate. Packages were returned in-person or with the supplied pre-addressed stamped envelopes.

The surveys were piloted to 6 IBD patients. Of these, 4 returned the surveys. No issues with clarity or survey completion were identified. Therefore, no changes were made to the questionnaire packages.

Controls were recruited through advertisements in "free newspapers". This included one-time advertisements in the University newspapers (Folio and Gateway) and multiple advertisements in Edmonton's Metro (Appendix 7). Interested parties could either call or email for more information. Respondents were screened for inclusion criteria (age and health status) and were mailed packages. Packages for control participants contained a letter of consent, healthy control demographic sheet (Appendix 8), the three

questionnaires, and instructions on how to receive the gift certificate. The SIBDQ was not sent to healthy controls, as it is designed for use in patients with IBD only. Packages were returned with the supplied pre-addressed, stamped envelope.

Bookstore gift certificates ($20) were mailed to participants once they returned the completed packages.

2.1.5.2. Data Management

Upon return of the completed packages, each participant was assigned an identification (ID) code. This number was marked on each questionnaire or information sheet returned by that participant. Data was then entered into a password-protected Microsoft Access database. Compiled data was exported into a Statistical Package for the Social Sciences (SPSS 2010) data file with the study-defined ID code being the only unique identifier. SPSS (Version 19.0) was used for data analysis; Microsoft Excel was used for data figure generation. In regards to post-secondary training, data was collected on type of training and whether or not a degree was obtained. Due to the wide age range, a combined variable of "attending any post-secondary" was created to account for the proportion that attended any type of post-secondary training, from auction school to graduate studies.

2.1.5.3. Statistical Analysis

Data was summarized with descriptive statistics (mean $\pm$ standard error [SE] or standard deviation [SD] for interval data; frequencies and percentages for categorical data). For interval data, differences in means are reported along with 95% confidence intervals (CI) and p-values; differences in the mean were tested using the student t-test and Analysis of Variance (ANOVA). For categorical data, chi-squared (X^2) tests were used to test differences in frequencies between groups. Data from Chi-squared analysis is reported in the

following format: X^2[df,n]=test statistic, where df=degrees of freedom and n=sample size. To compare frequencies to known data, the one-sample binomial test was used.

2.2. Recruitment

2.2.1. *Patients with Inflammatory Bowel Disease*

Letters of recruitment were mailed to 386 potentially eligible IBD patients identified in the patient care database. Patients attending biologic infusion clinic or IBD outpatient clinic were invited to participate by their physician or other study personal. Packages were sent to 286 packages IBD patients. This may not account for all of the packages distributed, as packages were available in clinic to be distributed to interested patients. This includes four packages collected in the pilot phase of the project. One person responded to the advertisement for healthy controls for this study indicated that he has IBD and so was included in the IBD group after providing the additional information required by IBD patients. Recruitment of IBD patients began in December 2009 and continued through December 2010.

2.2.2. *Healthy Controls*

The recruitment of healthy controls began in January 2010 and continued throughout 2010. One hundred and twenty-four surveys were mailed to persons who responded to the advertisement. Interested persons could respond by either email or telephone. The distribution of age and gender of control participants was reviewed periodically during the recruitment process. The gender distribution was found to be similar between control and IBD groups. Interim analysis of the age of healthy participants found they tended to be younger, therefore the final phases of healthy control recruitment was limited to persons 25-30 years old.

2.3. Ethical Considerations

This study was approved by Health Research Ethics Board at the University of Alberta (Protocol 00009686). Each participant provided written consent to participate in this study (Appendices 9, 10).

2.4. Demographic Results

2.4.1. Health Status of IBD and Control Groups

A total of 312 participants were recruited for this study; 108 healthy controls and 204 patients with inflammatory bowel disease. The package return rate for healthy controls was 87.1% (108/124) and 71.3% (204/286) for IBD patients.

Past medical and surgical history was collected from both groups. Dental surgery (most commonly wisdom tooth extraction) was the most common non-IBD surgery in both groups. However, a higher proportion of healthy controls indicated that had dental surgery than IBD patients (23.1 v. 9.3%; (X^2[1, 312]=11.2, p=0.001). The rate of tonsillectomy (and/or adenoidectomy) was similar in the IBD and control groups compared to controls (19/204; 9.3% versus 5/108; 4.6%; (X^2[1, 312]=1.4, p=0.25). Asthma was the most common other medical condition in both IBD and control group; 7/108 (6.5%) of healthy controls reported some history of asthma and 19/204 (9.3%) of IBD patients; frequency was similar between groups (X^2[1, 312]=0.7, p=0.39). A history of depression was reported by 2 (1.1%) IBD patients and just 1 (0.9%) healthy control. In total, 64% of IBD patients had Crohn's disease. IBD surgery or surgeries were reported by 52/204 (25.6%) of patients. More CD patients had IBD related surgery then UC patients (35.4% v. 8.2%, (X^2[1, 203]=18.1, p<0.0001).

2.4.2. Socio-Demographic Characteristics of IBD and Control Groups

The demographic characteristics for IBD and control groups are shown in Table 2.2. The IBD and control groups were similar in regards to the mean age

(24.7 v. 24.1 years, difference in mean = 0.58, [-0.31, 1.47], p=0.22) and gender distribution (39.7% v. 35.2% male, (X^2[1, 312]=0.6, p=0.43). In regards to living situation, the control groups was more likely to be living in their parent's home (45.8% v. 34.3%; X^2[4, 308]=12.8, p=0.01), more likely to be single (75.9% v. 56.7%, X^2[2, 311]=12.6, p=0.002), and less likely to have children (5.6% v. 18.7%, X^2[1, 311]=11.2, p=0.001). Birth order of IBD and control groups was similar (only child 5.5% v. 10.5%, oldest 36.3% v. 37.1%, middle 20.9% v. 17.1%, youngest 36.8% v. 35.2%, (X^2[3, 306]=3.0, p=0.39).

In regards to education, the IBD group was less likely to have graduated from high school (93.5% v. 99.0%, (X^2[1, 305]=4.8, p=0.03). However the IBD group had 12 patients under age 19 and the control group had only one participant under 19, which may confound the results. When participants under 19 were removed, there was a trend toward a lower rate of graduation from high school in the IBD patients but the difference was smaller (94.8% v. 99.0%, X^2[1, 295]=3.4, p=0.06) but still notable. A smaller proportion of IBD patients attended post-secondary training (77.9% v. 97.2%, X^2[1, 312]=20.2, p<0.001) and this difference persisted even when those under 19 were excluded (81.7% v. 97.1%, X^2[1, 295]=14.3, p>0.001).

In female participants, there were similar proportions of IBD patients and controls that were currently pregnant (6.6% v. 5.9%, X^2[1, 190]=0.03, p=0.86). The control group was more likely to not have carried any full-term pregnancies (92.6% v. 76.2%, X^2[3, 190]=8.6, p=0.04). There was a higher frequency of miscarriage rate in female IBD participants, (10.7% v. 2.9%, X^2[1, 190]=3.6, p=0.06) and history of abortion (9.8% v. 4.4%, X^2[1, 190]=1.8, p=0.18) in IBD participants, but the small numbers leave some uncertainty about these distinctions.

Table 2.2. Socio-demographic data of the IBD and control groups

Characteristic	IBD	Control	p-value
n	204	108	
Age (years; mean ± SE)	24.7 ± 0.28	24.1 ± 0.32	0.21
Gender (M/F) n (%)	81/123 (40/60)	38/70 (35/65)	0.43
Living Situation			0.01
Parents' home	69/201 (34.3%)	49/107 (45.8%)	
School dorm	1/201 (0.5%)	4/107 (3.7%)	
With roommates	18/201 (9.0%)	11/107 (10.3%)	
On my own	30/201 (14.9%)	17/107 (15.9%)	
With partner/spouse	83/201 (41.3%)	26/107 (24.3%)	
Marital Status			0.002
Single	115/203 (56.7%)	82/108 (75.9%)	
Married/living together	86/203 (42.4%)	24/108 (22.2%)	
Divorced	2/203 (1.0%)	2/108 (1.9%)	
Have children	40/203 (19.7%)	6/108 (5.6%)	0.001
Birth Order			0.39
Only child	11/201 (5.5%)	11/105 (10.5%)	
Oldest	73/201 (36.3%)	39/105 (37.1%)	
Middle	42/201 (20.9%)	18/105 (17.1%)	

Youngest	75/201 (36.8%)	37/105 (35.2%)	
Education level			
Graduated High school	187/200 (93.5%)	104/105 (99.0%)	0.03
Post-secondary			
Any	159/204 (77.9%)	105/108 (97.2%)	<0.001
Type of post-secondary			
Technical school	33/204 (16.2%)	10/108 (9.3%)	
Apprenticeship	12/204 (5.9%)	4/108 (3.7%)	
College	52/204 (25.5%)	23/108 (21.3%)	
University	87/204 (42.6%)	83/108 (76.9%)	
Graduate School	13/204 (6.4%)	17/108 (15.7%)	
Other Post-secondary	3/204 (1.5%)	0/108 (0%)	
Female Participants Only			
Currently Pregnant	8/122 (6.6%)	4/68 (5.9%)	0.86
# Pregnancies			0.04
0	93/122 (76.2%)	63/68 (92.6%)	
1	16/122 (13.1%)	3/68 (4.4%)	
2	8/122 (6.6%)	2/68 (2.9%)	
>2	5/122 (4.1%)	0/68 (0%)	

Miscarriage	13/122 (10.7%)	2/68 (2.9%)	0.06
Abortion	12/122 (9.8%)	3/68 (4.4%)	0.18

2.4.3. Socio-Demographic Data and Gender

Socio-demographic status for male and female study participants is presented in Table 2.3. Male participants were younger than the females (23.9 v. 24.8 years, difference in means = 0.88, [0.01, 1.76], p=0.05) and were more likely to be living in their parents' home (47.0% v. 33.0%, X^2[4, 308]=16.3, p=0.003), while female participants were more likely to be living with a partner or spouse (41.9% v. 24.8%, X^2[4, 308], p=0.003). Females were more likely to be married (42.5% v. 23.7%, X^2[2, 311]=14.7, p=0.001), and to have children (19.2% v. 7.6%, X^2[1, 311]=7.7, p=0.005) than males. However, birth order was similar between male and female participants (only child 6.1% v. 7.9%, oldest 37.4% v. 36.1%, middle 22.6% v. 17.8%, and youngest 33.9% v. 38.2%, X^2[3, 306]=1.6, p=0.67). Of the IBD patients, mean SIBDQ scores were similar between males and females (52.6 v. 51.4, difference in mean = 1.17, [-1.68, 4.03], p=0.42).

Education was similar between male and female participants with the majority graduating from high school (98.2% v. 95.1%, X^2[1, 295]=1.8, p=0.18) and attending post-secondary training (82.4% v. 86.0%, X^2[1, 312]=0.76, p=0.38).

Table 2.3 Socio-demographic data by gender, for all participants combined

Characteristic	**Male**	**Female**	**p-value**
n	119	193	
Age (mean $\pm$ SE)	23.9 $\pm$ 0.34	24.8 $\pm$ 0.28	0.40
Living Situation			0.003

Parents' home	55/117 (47.0%)	63/191 (33%)	
School dorm	2/117 (1.7%)	3/191 (1.6%)	
With roommates	17/117 (14.5%)	12/191 (6.3%)	
On my own	14/117 (12.0%)	33/191 (17.3%)	
With partner/spouse	29/117 (24.8%)	80/191 (41.9%)	
Marital Status			0.001
Single	90/118 (76.3%)	107/193 (55.4%)	
Married/living together	28/118 (23.7%)	82/193 (42.5%)	
Divorced	0/118 (0%)	4/193 (2.1%)	
Have children	9/118 (7.6%)	37/193 (19.2%)	0.01
Birth Order			0.67
Only child	7/115 (6.1%)	15/191 (7.9%)	
Oldest	43/115 (37.4%)	69/191 (36.1%)	
Middle	26/115 (22.6%)	34/191 (17.8%)	
Youngest	39/115 (33.9%)	73/191 (38.2%)	
HRQOL			
SIBDQ (mean $\pm$ SE)	52.6 $\pm$ 1.08	51.4 $\pm$ 0.94	0.42
Education level			
Graduated High school	109/111 (96.5%)	175/184 (94.7%)	0.18

Post-secondary			
Any	98/119 (82.4%)	166/193 (86.0%)	0.38
Type of post-secondary			
Technical school	21/119 (17.6%)	22/193 (11.4%)	
Apprenticeship	9/119 (7.6%)	7/193 (3.6%)	
College	24/119 (20.2%)	51/193 (26.4%)	
University	63/119 (52.9%)	107/193 (55.4%)	
Graduate School	10/119 (8.4%)	20/193 (10.4%)	
Other Post-secondary	2/119 (1.7%)	1/193 (0.5%)	

2.4.4. Socio-Demographic Data of IBD Patients by Type of IBD

Inflammatory bowel disease comprises both Crohn's disease and ulcerative colitis as distinct diagnoses. To determine if the type of IBD affects psychosocial functioning, patients with Crohn's disease and ulcerative colitis were compared. The Crohn's and UC participants in this study were similar in regards to age (24.6 v. 24.8 years, difference in means = 0.19, [-0.98, 1.35], p=0.75), gender (39.2% male v. 39.7%; (X^2[1, 203]=0.01, p=0.95), living situation (37.5% v. 43.1% living in parents' home and 40.6% v. 43.1% living with a partner or spouse, X^2[4, 200]=4.3, p=0.36), marital status (42.3% married v. 43.1%, X^2[2, 202]=0.2, p=0.90), having children (20.8% v. 18.1%, X^2[1, 202]=0.2, p=0.64), and birth order (only child 5.5% v. 5.6%, oldest 34.4% v. 38.9%, middle 25.0% v. 13.9%, and youngest 35.2% v. 41.7%, X^2[3, 200]=3.5, p=0.32). The current health related quality of life, as measured by SIBDQ was also similar for CD and UC patients (51.7 v. 52.2, difference in means = 0.51, [-2.39, 3/43], p=0.73).

A similar proportion CD and UC patients graduated high school (93.8% v. 93.0%, $X^2[1, 199]=0.05$, p=0.83) and attended post-secondary school (79.2% v. 75.3%, $X^2[1, 2.03]=0.4$, p=0.52).

The proportion of females with CD and UC being pregnant currently (5.1% v. 9.3%, $X^2[1, 122]=0.8$, p=0.37) was similar. Approximately three-quarters of CD and UC patients had never carried a full-term pregnancy (77.5% v. 74.4%, $X^2[2, 123]=2.5$, p=0.48). The proportion of CD and UC patients reporting having miscarriages (11.4% v. 9.3%, $X^2[1, 122]=0.1$, p=0.72), or abortions (10.1% v. 9.3%, $X^2[1, 122]=0.02$, p=0.88) were similar (Table 2.4).

Table 2.4 Socio-demographic data by type of IBD

Characteristic	Crohn's	UC	p-value
n	130	73	
Age (mean $\pm$ SE)	24.6 $\pm$ 0.36	24.8 $\pm$ 0.47	0.75
Gender (M/F) n (%)	51/79 (39/61)	29/44 (40/60)	0.95
Living Situation			0.36
Parents' home	48/128 (37.5%)	31/72 (43.1%)	
School dorm	0/128 (0%)	1/72 (1.4%)	
With roommates	9/128 (7.0%)	9/72 (12.5%)	
On my own	19/128 (14.8%)	10/72 (13.9%)	
With partner/spouse	52/128 (40.6%)	31/72 (43.1%)	
Marital Status			0.90
Single	74/130 (56.9%)	40/72 (55.6%)	

Married/living together	55/130 (42.3%)	31/72 (43.1%)	
Divorced	1/130 (0.8%)	1/72 (1.4%)	
Have children	27/130 (20.8%)	13/72 (18.1%)	0.64
Birth Order			0.32
Only child	7/128 (5.5%)	4/72 (5.6%)	
Oldest	44/128 (34.4%)	28/72 (38.9%)	
Middle	32/128 (25.0%)	10/72 (13.9%)	
Youngest	45/128 (35.2%)	30/72 (41.7%)	
HRQOL			
SIBDQ (mean $\pm$ SE)	51.7 $\pm$ 0.88	52.2 $\pm$ 1.21	0.73
Education level			
Graduated High school	120/128 (93.8%)	66/71 (93.0%)	0.83
Post-secondary			
Any	103/130 (79.2%)	55/73 (75.3%)	0.52
Type of post-secondary			
Technical school	19/130 (14.6%)	14/73 (19.2%)	
Apprenticeship	7/130 (5.4%)	5/73 (6.8%)	
College	34/130 (26.2%)	18/73 (24.7%)	
University	54/130 (41.5%)	32/73 (43.8%)	

Graduate School	9/130 (6.9%)	4/73 (5.5%)	
Other Post-secondary	3/130 (2.3%)	0 (0%)	
Female Participants Only			
Currently Pregnant	4/79 (5.1%)	4/43 (9.3%)	0.37
# Pregnancies			
0	61/79 (77.2%)	32/43 (74.4%)	
1	8/79 (10.1%)	8/43 (18.6%)	
2	6/79 (7.6%)	2/43 (9.3%)	
>2	4/79 (5.1%)	1/43 (2.3%)	
Miscarriage	9/79 (11.4%)	4/43 (9.3%)	0.72
Abortion	8/79 (10.1%)	4/43 (9.3%)	0.88

2.4.5. Socio-Demographic Data of IBD Patients by Age of Diagnosis

In order to look at the association between study outcomes and age of diagnosis, it was decided *a priori* to recruit 2 groups of IBD patients, those diagnosed as a child/adolescent and those diagnosed in adulthood. The socio-demographic data is shown in Table 2.5. Those diagnosed under age 18 were younger (22.4 v. 26.7 years, difference in mean = 4.2, [3.29, 5.19], p<0.001), more likely to be male (48.4% male v. 31.8%, X^2[1, 204]=5.9, p=0.02), living at home (51.6% v. 18.9% living at home and 26.3% v. 54.7% living with a partner or spouse, X^2[4, 201]=34.3, p<0.001), and less likely to be married (25.8% married v. 57.5%, X^2[2, 203]=21.1, p<0.001), or have children (7.2%, v. 31.1%, X^2[1, 203]=18.3, p<0.001) than those diagnosed in adulthood. There was no

difference in birth order by age of diagnosis (only child 6.2% v. 4.8%, oldest 34.0% v. 38.5%, middle 22.7% v. 19.2%, and youngest 37.1% v. 37.5%, X^2[3, 201]=0.7, p=0.87). The mean SIBDQ score was similar for these groups (51.6 v. 52.1, difference in means = 0.51, [-2.30, 3.31], p=0.72).

In terms of education, adult diagnosed patients were more likely to have graduated from high school (98.1% v. 88.3%, X^2[1, 200]=7.9, p=0.005). Even with IBD participants under the age of 19 excluded, less of the pediatric diagnosis group graduated from high school than those diagnosed in adulthood (90.6% v. 98.1%, X^2[1, 191]=5.4, p=0.02). There proportion of participants with post-secondary education was similar, with 74.0% of IBD patients diagnosed under age 18 attending post-secondary compared to 81.3% of those diagnosed older (X^2[1, 203]=1.6, p=0.21). With the participants less than 19 years excluded, 81.2% and 82.1% of pediatric and adult diagnosed patients went on to post-secondary training (X^2[1, 191]=0.03, p=0.87).

The proportion of females with an age of diagnosis under 18 and 18 years or older who were currently pregnant was similar (4.0% v. 8.3%, X^2[1, 122], p=0.34). However fewer patients diagnosed under 18 reported a history of miscarriage (2.0% v. 16.7%, X^2[1, 122]=6.7, p=0.01). The history of having an abortion was similar between groups (14.0% v. 6.9%, X^2[1, 122]=1.7, p=0.20).

Table 2.5. Socio-demographic data of the IBD participants, by age of diagnosis

Characteristic	Diagnosed<18	Diagnosed 18+	p-value
n	97	107	
Age (mean $\pm$ SE)	22.4 $\pm$ 0.35	26.7 $\pm$ 0.33	<0.001
Gender (M/F) n (%)	47/50 (48/52)	34/73 (32/68)	0.02

Living Situation			<0.001
Parents' home	49/95 (51.6%)	20/106 (18.9%)	
School dorm	1/95 (1.1%)	0/106 (0%)	
With roommates	12/95 (12.6%)	6/106 (5.7%)	
On my own	8/95 (8.4%)	22/106 (20.8%)	
With partner/spouse	25/95 (26.3%)	58/106 (54.7%)	
Marital Status			<0.001
Single	71/97 (73.2%)	44/106 (41.5%)	
Married/living together	25/97 (25.8%)	61/106 (57.5%)	
Divorced	1/97 (1.0%)	1/106 (1.0%)	
Have children	7/97 (7.2%)	33/106 (31.1%)	<0.001
Birth Order			0.87
Only child	6/97 (6.2%)	5/104 (4.8%)	
Oldest	33.97 (34.0%)	40/104 (38.5%)	
Middle	22/97 (22.7%)	20/104 (19.2%)	
Youngest	36/97 (37.1%)	39/104 (37.5%)	
HRQOL			
SIBDQ (mean $\pm$ SE)	51.5 $\pm$ 1.10	52.1 $\pm$ 0.91	0.72
Education level			

Graduated High school	83/94 (88.3%)	104/106 (98.1%)	0.005
Post-secondary			
Any	71/96 (74.0%)	87/107 (81.3%)	0.21
Type of post-secondary			
Technical school	14/96 (14.6%)	19/107 (17.8%)	
Apprenticeship	7/96 (7.3%)	5/107 (4.7%)	
College	23/96 (24.0%)	29/107 (27.1%)	
University	40/96 (41.7%)	47/107 (43.9%)	
Graduate School	5/96 (5.2%)	8/107 (7.5%)	
Other Post-secondary	3/96 (6.3%)	0/108 (0%)	
Female Participants Only			
Currently Pregnant	2/50 (4.0%)	6/72 (8.3%)	0.34
# Pregnancies			
0	45/50 (90.0%)	48/72 (66.7%)	
1	4/50 (8.0%)	12/72 (16.7%)	
2	1/50 (2.0%)	7/72 (9.7%)	
>2	0/50 (0%)	5/72 (6.9%)	
Miscarriage	1/50 (2.0%)	12/72 (16.7%)	0.01
Abortion	7/50 (14.0%)	2/72 (6.9%)	0.20

2.5. Discussion

Clinic-based studies have an important role in epidemiologic research. The selection of an appropriate comparison group is vital to the value of the study. Ideally, comparison groups should be representative of the same "base experience",[2] and chosen from the same population. Unfortunately, the "ideal" comparison group rarely exists.[10] Although this study is not essentially a case-control study because subjects were not selected based on their outcome status, the clinic-based identification of IBD cases raises similar considerations for identifying a valid comparison group. Because this is not a case-control study, differences in distributions of risk factors in the comparison groups increase the potential for confounding rather than selection bias.

The types of controls that can be used include population controls, hospital or disease registry controls, controls from a medical practice, friend and family controls.[11] Each type of control group has advantages and disadvantages. For this study, friend and family controls were not chosen due to the possibility of overmatching. Hospital and medical practice controls were not chosen, since we have a highly specialized gastroenterology practice, which are unlikely to represent healthy controls. Many studies have used a family practice registry or asked the patients family physicians to identify controls. However, due to the time and budget constraints of this project, this type of control group was deemed not feasible. Therefore, we chose to use a population based control group. A disadvantage of a population control group is a lower motivation level. Therefore, we provided an incentive to participate in the form of a $20 bookstore gift certificate. To limit differences that might be enhanced by this incentive, this incentive was also offered to the IBD group. A disadvantage of a population comparison group is the inconvenience and cost of identifying and recruiting this group of subjects.

Population based control groups can be recruited via a number of strategies. The use of a roster (e.g. citizen or registered voters) is often used. Alternatively, random-digit dialing (RDD) has also been used. The cost and time of RDD increases when you are targeting subsets of the population, as we did in this study.[11] Neighborhood controls have also been used; however this approach was estimated to be too costly and time-consuming for this project. Instead, we chose to advertise in local "free newspapers". Initially, we placed advertisements in 3 papers – 2 University-based papers and 1 free citywide daily paper. For subsequent, recruitment advertisements were placed only in the non-university paper only. Advertisement in university-based newspapers for the control group may have increased the potential for confounding, given that 76.9% of healthy controls indicating that they attended university versus only 42.6% of IBD participants. The rates of attending university were similar for CD and UC, as well as for those diagnosed as children or adults.

This strategy was successful in recruiting >100 healthy controls. Participants were screened for age and health status prior to having a package mailed to them. The return rate of nearly 90% likely reflects the pre-selection of participants. The self-defined "healthy" status of volunteers was also effective in selecting those without significant health problems. The one participant with a chronic illness other than asthma who responded to the advertisement for "healthy volunteers had inflammatory bowel disease. One might speculate that this participant may have been interested due to the nature of the study as the words "inflammatory bowel disease" were used in the recruitment advertisement (Appendix 7).

Previous studies of population-based controls, recruited through RDD have shown that those with higher socioeconomic status[12] and high school graduates[13] are more likely to participate. According to Statistics Canada, in

2009/2010 only 5.6% of 16-17 year old Albertans had graduated from high school compared to 73.7% of 18-19 year olds, and 89.0% of 20-24 year olds.[14] Both the cases and controls in this study have a higher rate of high school graduation than the provincial average for 20-24 year olds ($p=0.03$ and $p=0.01$, respectively). In a study of seniors, volunteers were more likely to be women and more educated than a random sample.[15] For this study, both cases and controls were required to volunteer to participate and the proportion of female participants was 60-65% in both groups.

A number of socio-demographic variables differed between the IBD and control groups. The control group was more likely to be single, childless, and living at home compared to the IBD group. Education levels also differed between the IBD groups with the healthy control group being more likely to have graduated from high school and attended post-secondary training. We can adjust for these differences in the analysis, given sufficient data.

Categorization of the IBD participants by their age of diagnosis allows us to consider the impact of a childhood diagnosis of IBD, and also infer whether the diagnosis preceded typical ages for achieving particular milestones. However, the pediatric (diagnosed <18 years) and adult (diagnosed 18+ years) groups differed on several socio-demographic factors. The pediatric group was younger, more likely to be childless, single, and living in their parents' home. The adult group was more likely to be living with a partner or spouse, have graduated from high school and had a miscarriage. Interestingly, despite the higher rate of graduation from school in the adult diagnosis group, the rates of attending post-secondary training were similar to the pediatric group (81.3% versus 74.0%, respectively).

Consideration must be given to differences on the basis of gender. The male and female participants were similar in regards to age, birth order, graduating from high school, and post-secondary education. Females were more likely to

be married, have children, and live with their partner or spouse, while males were more likely to live in their parents' home. It appears that gender may impact living situation, marital status, and having children.

The socio-demographic results of the Crohn's disease and ulcerative colitis groups were remarkable similar, with no precise differences found for any of the socio-demographic variables measured. The groups did differ in the proportion of patients with IBD-related surgery. The absence of clear differences between the CD and UC groups means that we can combine them to enhance statistical precision in this analysis.

In summary, this study compares IBD and healthy controls in regards to overall well being and societal functioning. The use of free-newspapers (some of them being university-based) to recruit a comparison group introduces potential confounding due to a higher than average education level in subjects without IBD. It logically follows that the higher rate of university attendance in the control group would mean that a higher proportion completed high school , since you generally require a high school diploma to enter university. The only other group where graduation from high school is different is in the groups divided by age of diagnosis. It is possible that this difference is driven by the younger average age of this group, however this difference persisted even with the <19 years old participants being excluded.

Differences in marital status, living situation and having children were seen between IBD and control groups, males and females, and pediatric- compared to adult-diagnosed IBD. The differences in these outcomes in the pediatric- and adult-diagnosed IBD groups may be driven by sex, since these groups also differed in proportion of males and females. However, the pediatric-diagnosed group was also significantly younger which may also explain these differences. Birth order was not notably different in any of the sub-groups and therefore is unlikely a potential confounder.

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3. Attainment of Developmental Milestones in Young Adults with Inflammatory Bowel Disease

3.1. Background

Chronic illness in childhood and adolescence is known to impact the normal growth and development in areas of biological, psychological, and social domains.[1] The biological effects of inflammatory bowel disease include delayed or stunted growth and puberty. Impaired growth velocity and linear growth affects 35-46% of patients Crohn's disease, compared to only 10% of those with ulcerative colitis.[2] A diagnosis of inflammatory bowel disease during adolescence is known to have a negative impact on the psychosocial functioning of adolescents compared to those who are diagnosed in childhood.[3,4] Furthermore, increasing age at diagnosis is positively correlated to worse health related quality of life of adolescents with IBD.[5] The social functioning of young people (mean age 20 years) with IBD has been shown to be negatively affected compared to controls in areas of school absences, having a paid job, reliance on benefits for main source of income, and going out.[4] Parents of children with IBD perceive significantly less social competence in their children than do parents of healthy children.[6] A previous studies have identified that patients with childhood cancer, end-stage renal disease, anorectal malformation, Hirschsprung's disease, and esophageal atresia have impaired or delayed milestone development using the Course of Life Questionnaire.[7]

Given this evidence of the effect of IBD on the physical and psychosocial wellbeing of individuals we sought to extend the literature by examining what effect a childhood diagnosis of IBD would have on development and well being. Previous studies have looked at the impact of a childhood diagnosis of IBD on children and adolescents but not on emerging or young adults. We hypothesized that having a childhood diagnosis of IBD would negatively

impact the development of emerging and young adults with IBD. Specifically, we examined the impact of gender, age of diagnosis, and type of IBD on its relationship to psychosocial development.

3.2. Methods

3.2.1. Course of Life Questionnaire

The English version of the "Course of Life Questionnaire for Young Adults" was used for assessment of developmental milestones in our study. This questionnaire was developed and validated by a Dutch group. Through personal communication Dr. Heleen Stam provided an English version, along with the scoring system free of charge. It divides development into 5 domains: autonomy development, psychosexual development, social development, anti-social behavior, and substance use and gambling. Responses to questions evaluating each domain are scored as a 1 or 2, and the sum of these scores compose the scores for each individual domain. A higher score for the three developmental domains indicates the accomplishment of more milestones; a lower score indicates that either the milestones have not been met or the timing has been delayed.[7] Higher scores for anti-social behavior and substance use and gambling indicates the participant has more high-risk behavior.[7] Study participants under the age of 19 were excluded from this analysis since some questions in each domain used age 19 as a cut-off. For each domain, participants were included only if they completed all questions for that domain.

To gain insight into the impact of gender, type of IBD (Crohn's disease or ulcerative colitis), and age of diagnosis, mean domain scores were calculated for each sub-group. Age of diagnosis was coded into categorical variables: pediatric (<18 years) and adult (18+ years). When differences were found between the pediatric and adult groups, the pediatric age group was further

divided into childhood (<12 years) and adolescent (12-17 years). Results from the individual questions comprising each domain score are reported as percent of respondents choosing that response.

3.2.2. Statistical Analysis

Differences in mean domain scores are reported along with 95% confidence intervals (CI). Independent sample t-tests and ANOVA were used to test differences between mean scores.

Linear regression models for overall domain scores comparing IBD patients versus healthy controls were generated to test and adjust for confounding variables. A simple linear regression was fitted for each a diagnosis of IBD, age, gender, marital status, and post-secondary education. Variables that were significant at a p=0.20 level of significant in simple linear regression were considered as candidates for the multivariate linear regression model. (Ibrahim Quazi, MSc from Epidemiology Coordinating and Research [EPICORE] Centre performed linear regression analysis.)

A measure of the difference in means divided by the pooled standard deviation has been reported in previous papers using the Course of Life questionnaire, with values of 0.2 interpreted as indicating small differences, 0.5 as medium differences, and 0.8 as large differences.[8] A pooled standard deviation was used as the denominator for calculating effect size to try to avoid over estimating this measure of difference in means.[9]

The results of individual questions for each domain are reported as percentages of respondents. Groups are compared using Chi-squared (X^2) tests with p-values reported. Mean overall scores, standard deviation, t-tests, ANOVA, and Chi-squared analysis were calculated using SPSS (Version 19). Linear regression analysis was calculated using STATA (Version 11).

3.3. Results

3.3.1. Demographic Data of IBD and Patient Groups

After excluding the 13 IBD patients and 1 healthy control participant that were under 19, 298 patients were included in the milestone data analysis. Demographic data is displayed in Table 3.1. There were small differences in gender distribution (60.7% male v. 64.5%, $X^2[1, 298]=0.4$, p=0.52) but the mean age of the IBD patients was almost 1 year greater than the control group (25.1±0.27 v. 24.2±0.33, difference in mean = 0.96, [0.10, 1.82], p=0.03). Differences were also seen in marital status, with more controls being single (44.6% v. 21.4%) and more IBD patients being married (76.7% v. 21.4%, $X^2[2, 289]=15.6$, p<0.001). The control group was also more likely to have some post-secondary training (97.2% versus 81.2%, $X^2[1, 198]=18.0$, p<0.001). These variables (age, gender, marital status, having post-secondary training) were subsequently used in linear regression analysis to adjust for possible confounding.

Table 3.1 Demographics of IBD and control participants over age 18 years old

Characteristic	IBD	Control	p-value
n	191	107	
Age (mean ± SE)	25.1 ± 0.27	24.2 ± 0.33	0.03
Gender (M/F) n (%)	75/116 (39.3/60.7)	38/69 (35.5/64.5)	0.52
Marital Status			0.0004
Single	101/186 (54.3%)	79/103 (76.7%)	
Married/living together	83/186 (44.6%)	22/103 (21.4%)	

Divorced	2/186 (1.1%)	2/103 (1.9%)	
Post-secondary			
Any	155/191 (81.2%)	104/107 (97.2%)	0.00008

3.3.2. Autonomy Development, Male and Female Participants Combined

3.3.2.1. Overall Autonomy Development Score

The IBD group had higher mean autonomy scores than controls (8.1 v. 7.7, difference in means = 0.45, [0.16, 0.73], p=0.002), with male and female participants grouped together. This suggests that the IBD patients have better autonomy development than the healthy controls. After adjusting for age and marital status, having IBD is associated with significantly higher autonomy scores than healthy controls. The linear regression model is shown in Table 3.2. While the constant variance assumption was violated in this analysis, it was felt that this model was still valid in adjusting for differences between the two groups.

Table 3.2 Multivariable linear regression model for autonomy score

	Adjusted Coefficient (95% CI)	p-value
Disease Status		
Healthy Control		
IBD	0.31 (0.03, 0.059)	0.03
Age	0.06 (0.01, 0.10)	0.008
Marital Status		

Single		
Married	0.39 (0.07, 0.71)	0.02
Constant	6.20 (5.19, 7.20)	<0.001

For the overall model p-value < 0.0001; R^2=0.11. In the model, the constant variance assumption is violated.

Responses of IBD patients and healthy controls to individual questions measuring autonomy development are shown in Table 3.3.

3.3.2.2. Regular chores and tasks

The majority of IBD and non-IBD participants groups reported having regular chores in elementary or junior or high school.

3.3.2.3. Paid employment

A higher proportion of IBD patients reported having a paid job in both elementary school and junior or high school, as compared to healthy controls

3.3.2.4. Vacation without parents

Approximately one-third, of participants in each group reported going on vacation without adults by the age of 18 years old.

3.3.2.5. Living with parents

Almost twice as many healthy controls reported still living with their parents than IBD patients.

Table 3.3 Individual question responses to autonomy questions for IBD patients and controls, male and female participants combined

	IBD	**Controls**	

	%	n	%	n	p-value
Regular chores/tasks, elementary school					
Yes	82.0	155	76.0	79	0.21
No	18.0	34	24.0	25	
Paid job, elementary school					
Yes	33.3	63	21.2	22	0.03
No	66.7	126	78.8	82	
Regular chores/tasks, junior or high school					
Yes	85.2	161	78.8	82	0.17
No	14.8	28	21.2	22	
Paid job, junior or high school					
Yes	86.8	164	74.0	77	0.006
No	13.2	25	26.0	27	
First time vacation without adults					
Age 18 or younger	33.0	62	32.4	33	0.91
Age 19 or older/never	67.0	126	67.6	69	
Leaving your parents home					

Not living with your parents	78.3	148	60.6	63	0.001
Living with your parents	21.7	41	39.4	41	

3.3.3. Autonomy Development, Male Participants Only

3.3.3.1. Overall Autonomy Development Score

The mean autonomy score was similar between male IBD patients and healthy controls (8.0 v. 7.7, difference in means = 0.30, [0.18, 0.77], p=0.22).

3.3.3.2. Regular chores and tasks

Over 80% of males with IBD and healthy males reported having regular chores in junior/senior high. Males with IBD were less likely to report having regular chores in elementary school than healthy males.

3.3.3.3. Paid employment

Over twice as many male IBD patients had a paid job in elementary school than healthy male controls. Similar proportion of male participants reported having a paid job in junior or high school in each group.

3.3.3.4. Vacation without parents

Approximately 40% of males with IBD and healthy controls went on vacation without adults by the age of 18.

3.3.3.5. Living with parents

Half of the healthy control males reported still living at home, as compared to one-quarter of male IBD patients.

Table 3.4 Responses of male participants to individual autonomy questions for IBD patients and controls

	IBD Patients		Controls		
	%	n	%	n	p-value
Regular chores/tasks, elementary school					
Yes	74.0	54	83.8	31	0.25
No	26.0	19	16.2	6	
Paid job, elementary school					
Yes	30.1	22	13.5	5	0.06
No	69.9	51	86.5	32	
Regular chores/tasks, junior or high school					
Yes	84.9	62	83.8	31	0.88
No	15.1	11	16.2	6	
Paid job, junior or high school					
Yes	84.9	62	81.1	30	0.61
No	15.1	11	18.9	7	
First time vacation without adults					
Age 18 or younger	35.6	26	40.5	15	0.61

Age 19 or older/never	64.4	47	59.5	22	
Leaving your parents home					
Not living with your parents	75.3	55	48.6	18	0.005
Living with your parents	24.7	18	51.4	19	

3.3.4. Autonomy Development, Female Participants Only

3.3.4.1. Overall Autonomy Development Score

Female IBD patients had higher a mean autonomy score than the female controls (8.2 v. 7.6, difference in means = 0.54, [0.18, 0.90], p=0.004). Responses to individual questions assessing autonomy development in females only are shown in Table 3.5.

3.3.4.2. Regular tasks and chores

More female IBD patients indicated that they had regular chores in elementary school than female controls. This difference in regular chores was less prominent in junior and high school.

3.3.4.3. Paid employment

Girls with IBD were more likely to have a paid job in junior or high school compared to controls.

3.3.4.4. Vacation without parents

Approximately 30% female IBD patients and controls reported going on vacation without adults at the age of 18 or earlier.

3.3.4.5. Living with parents

Females with IBD also were more likely to not live with their parents.

Table 3.5 Responses of female participants to individual autonomy scores for IBD patients and controls

	IBD Patients		Controls		
	%	n	%	n	p-value
Regular chores/tasks, elementary school					
Yes	87.1	101	71.6	48	0.01
No	12.9	15	28.4	19	
Paid job, elementary school					
Yes	35.3	41	25.4	17	0.16
No	64.7	75	74.6	50	
Regular chores/tasks, junior or high school					
Yes	85.3	99	76.1	51	0.12
No	14.7	17	23.9	16	
Paid job, junior or high school					
Yes	87.9	102	70.1	47	0.003
No	12.1	14	29.9	20	
First time vacation without					

adults					
Age 18 or younger	31.3	36	27.7	18	0.61
Age 19 or older/never	68.7	79	72.3	47	
Leaving your parents home					
Not living with your parents	80.2	93	67.2	45	0.05
Living with your parents	19.8	23	32.8	22	

3.3.5. Autonomy Development, IBD Patients, by Type of IBD

3.3.5.1. Overall Autonomy Development Score

The mean autonomy scores were similar for patients with Crohn's disease and patients with ulcerative colitis (8.1 v. 8.2, difference in means = 0.15, [-0.19, 0.50], p=0.38). Responses to individual autonomy questions are shown in Table 3.6; the groups were similar with respect to all questions.

Table 3.6 Differences in responses to individual autonomy questions of IBD patients, by type of IBD

	CD Patients		**UC Patients**		
	%	**n**	%	**n**	**p-value**
Regular chores/tasks, elementary school					
Yes	82.9	102	80.3	53	0.65
No	17.1	21	19.7	13	

Paid job, elementary school					
Yes	29.3	36	40.9	27	0.11
No	70.7	87	59.1	39	
Regular chores/tasks, junior or high school					
Yes	86.2	106	83.3	55	0.60
No	13.8	17	16.7	11	
Paid job, junior or high school					
Yes	86.2	106	87.9	58	0.74
No	13.8	17	12.1	8	
First time vacation without adults					
Age 18 or younger	32.0	39	34.8	23	0.69
Age 19 or older/never	68.0	83	65.2	43	
Leaving your parents home					
Not living with your parents	76.4	94	81.8	54	0.39
Living with your parents	23.6	29	18.2	12	

3.3.6. Autonomy Development, IBD Patients, by Age at Diagnosis

3.3.6.1. Overall Autonomy Development Score

Younger age at diagnosis is associated with lower autonomy development scores. Patients diagnosed under age 18 years have lower autonomy scores

than those diagnosed in adulthood (7.8 v. 8.4, difference in means = 0.56, [0.24,0.89], p=0.001). Of the patients diagnosed under age 18, those diagnosed in childhood (under age 12) have a trend toward lower scores than those diagnosed between 12 and 17 (7.4 v. 7.9, difference in means = 0.49 [-0.28, 1.27], p=0.32). When compared to patients diagnosed in adulthood, those diagnosed in childhood and adolescence have lower mean autonomy scores (7.4 v. 8.4, difference in means = 0.93, [0.19, 1.68], p=0.01; 7.9 v. 8.4, difference in means = 0.44, [0.01. 0.87], p=0.04).

The responses of IBD patients to individual autonomy questions by age of diagnosis are shown in Tables 3.7 and 3.8.

3.3.6.2. Regular chores and tasks

Patients diagnosed under 18 were less likely to have regular chores at home in elementary school and junior or senior high. Patients diagnosed under age 12 were even less likely to have regular chores compared to those diagnosed between 12 and 17 in both elementary school and junior or senior high.

3.3.6.3. Paid employment

Approximately one-third of IBD participants diagnosed in childhood or adulthood had a paid job in elementary school while over 80% of IBD patients in each group had a paid job in junior or high school.

3.3.6.4. Vacation without parents

Similar proportion of IBD patients diagnosed under and over 18 reported going on vacation without adults by the age of 18 or earlier.

3.3.6.5. Living with parents

Those diagnosed under 18 were more almost three times more likely to still live with their parents. Those diagnosed under 12 were even more likely to live with their parents than those diagnosed in adolescence.

Table 3.7 Responses to autonomy development questions for IBD patients, by age of diagnosis

	Pediatric Dx < 18		**Adult Dx 18 +**		
	%	**n**	**%**	**n**	**p-value**
Regular chores/tasks, elementary school					
Yes	76.2	64	86.7	91	0.06
No	23.8	20	13.3	14	
Paid job, elementary school					
Yes	29.8	25	36.2	38	0.35
No	70.2	59	63.8	67	
Regular chores/tasks, junior or high school					
Yes	77.4	65	91.4	96	0.007
No	22.6	19	8.6	9	
Paid job, junior or high school					
Yes	84.5	71	88.6	93	0.41

No	15.5	13	11.4	12	
First time vacation without adults					
Age 18 or younger	29.8	25	35.6	37	0.40
Age 19 or older/never	70.2	59	64.4	67	
Leaving your parents home					
Not living with your parents	66.7	56	87.6	92	0.001
Living with your parents	33.3	28	12.4	13	

Table 3.8 Comparison of responses of IBD patients to autonomy development questions, by age of diagnosis, (childhood, adolescence and adulthood)

	Childhood Dx <12		**Adolescence Dx 12 – 17**		**Adulthood Dx 18+**		
	%	**n**	**%**	**n**	**%**	**n**	**p-value**
Regular chores/tasks, elementary school							
Yes	61.9	13	81.0	51	86.7	91	0.03
No	38.1	8	19.0	12	13.3	14	
Paid job, elementary school							
Yes	33.3	7	28.6	18	36.2	38	0.60

No	66.7	14	71.4	45	63.8	67	
Regular chores/tasks, junior or high school							
Yes	71.4	15	79.4	50	91.4	96	0.02
No	28.6	6	20.6	13	8.6	9	
Paid job, junior or high school							
Yes	76.2	16	87.3	55	88.6	93	0.31
No	23.8	5	12.7	8	11.4	12	
First time vacation without adults							
Age 18 or younger	14.3	3	34.9	22	35.6	37	0.15
Age 19 or older/never	85.7	18	65.1	41	64.4	67	
Leaving your parents home							
Not living with your parents	61.9	13	68.3	43	87.6	92	0.002
Living with your parents	38.1	8	31.7	20	12.4	13	

3.3.7. Psychosexual Development, Male and Female Participants Combined

3.3.7.1. Overall Psychosexual Development Score

Overall, the IBD patients had higher psychosocial development scores than the healthy controls (6.7 v. 6.1, difference in means = 0.60, [0.24, 0.97], p=0.001; effect size = 0.40). Linear regression analysis demonstrates that after adjusting for marital status and age, a diagnosis of IBD is significantly associated with an increase in psychosexual development score (Table 3.9).

Table 3.9 Multivariable linear regression model for psychosexual development score

	Adjusted Coefficient (95% CI)	p-value
Disease Status		
Healthy Control		
IBD	0.49 (0.13, 0.86)	0.007
Age	0.02 (-0.03, 0.07)	0.47
Marital Status		
Single		
Married	0.41 (0.002, 0.82)	0.05
Constant	5.55 (4.27, 6.83)	<0.001

For the overall model, p-value = 0.0004; R^2=0.06. In the model, normality and constant variance assumptions are violated.

Detailed responses to individual psychosexual questions comparing IBD patients and controls are shown in Table 3.10.

3.3.7.2. First girl/boyfriend

Overall, IBD patients were more likely to have a girl or boyfriend by age 17 as compared to healthy controls.

3.3.7.3. First time falling in love

IBD and control groups were similar in regards to falling in love by age 18.

3.3.7.4. First sexual intimacy

A greater proportion of IBD patients reported their first sexual intimacy to occur by age 18 or younger than healthy controls.

3.3.7.5. First sexual intercourse

More IBD patients reported having sexual intercourse by age 18 or younger than healthy controls.

Table 3.10 Comparison of responses to individual psychosexual development questions between IBD patients and healthy controls

	IBD Patients		**Controls**		
	%	**n**	**%**	**n**	**p-value**
First girlfriend/boyfriend					
Age 17 or younger	73.5	139	57.9	62	0.006
Age 18 or older/never	26.5	50	42.1	45	
For the first time falling in love					
Age 18 or younger	58.1	108	49.5	53	0.16
Age 19 or older/never	41.9	78	50.5	54	

For the first time sexual intimacy					
Age 18 or younger	80.3	151	63.6	68	0.002
Age 19 or older/never	19.7	37	36.4	39	
For the first time sexual intercourse					
Age 18 or younger	63.0	119	40.2	59.8	0.0002
Age 19 or older/never	37.0	70	43	64	

3.3.8. Psychosexual Development, Male Participants Only

3.3.8.1. Overall Psychosexual Development Score

The psychosexual development scores of male IBD patients were similar to healthy controls (6.3 v. 6.5, difference in means = 0.23, [-.037, 0.82], p=0.45). Results of individual questions assessing psychosexual development are shown in Table 3.11; no differences are seen for any of the individual items.

Table 3.11 Responses to individual psychosexual development questions for male IBD patients and healthy controls

	IBD Patients		**Controls**		
	%	**n**	**%**	**n**	**p-value**
First girlfriend/boyfriend					
Age 17 or younger	64.4	47	71.1	27	0.48
Age 18 or older/never	35.6	26	28.9	11	

For the first time falling in love					
Age 18 or younger	51.4	37	52.6	20	0.90
Age 19 or older/never	48.6	35	47.4	18	
For the first time sexual intimacy					
Age 18 or younger	68.1	49	78.9	30	0.23
Age 19 or older/never	31.9	23	21.1	8	
For the first time sexual intercourse					
Age 18 or younger	47.9	35	47.4	18	0.95
Age 19 or older/never	52.1	38	52.6	20	

3.3.9. Psychosexual Development, Female Participants Only

3.3.9.1. Overall Psychosexual Development Score

The psychosexual development of females with IBD was markedly greater than the healthy controls (7.0 v. 5.9, difference in means = 1.09, [0.63, 1.56], p<0.001).

3.3.9.2. First girl/boyfriend

Nearly 80% of female IBD patients had their first girl/boyfriend by age 17, compared to only half of healthy controls.

3.3.9.3. First time falling in love

The proportion of females with IBD reported falling in love for the first time by age 17 or younger tended to be higher than the proportion of healthy controls.

3.3.9.4. First sexual intimacy

Female IBD patients were more 50% more likely to report first sexual intimacy by the age of 18 or younger than healthy females.

3.3.9.5. First sexual intercourse

Twice as many female IBD patients reported first sexual intercourse by age 18 than healthy females.

Table 3.12 Responses to individual psychosexual development questions for female IBD patients and healthy controls

	IBD Patients		**Controls**		
	%	**n**	**%**	**n**	**p-value**
First girlfriend/boyfriend					
Age 17 or younger	79.3	92	50.7	35	0.00005
Age 18 or older/never	20.7	24	49.3	34	
For the first time falling in love					
Age 18 or younger	62.3	71	47.8	33	0.06
Age 19 or older/never	37.3	43	52.2	36	
For the first time sexual intimacy					

Age 18 or younger	87.9	102	55.1	38	0.0000005
Age 19 or older/never	12.1	14	44.9	31	
For the first time sexual intercourse					
Age 18 or younger	72.4	84	36.2	25	0.000001
Age 19 or older/never	27.6	32	63.8	44	

3.3.10. Psychosexual Development of IBD Patients, by Type of IBD

3.3.10.1. Overall Psychosexual Development Score

The mean psychosexual score was moderately lower for patients with Crohn's disease compared to those with UC (6.6 v. 7.0, difference in means = 0.44, [0.02, 0.85], p=0.04; effect size = 0.31). Differences between IBD groups in overall psychosexual score are similar for males with CD and UC (difference in means = 0.17, [-0.59, 0.94], p=0.66). Females with CD have lower psychosexual development scores than female UC patients (6.8 v. 7.4, mean difference = 0.63, [0.19, 1.07], p=0.01; effect size = 0.49).

Table 3.13 Differences in mean psychosexual score by type of IBD and gender

	CD	**UC**	**Difference in means (95% CI)**	**p-value**	**Difference in mean divided by SD**
All	6.6 ± 1.47	7.0 ± 1.33	0.44 (0.02, 0.85)	0.04	0.31

Males only	*6.2 ±1.56*	*6.4 ±1.58*	*0.17 (-0.59, 0.94)*	*0.66*	*0.11*
Females only	*6.8 ±1.37*	*7.4 ±0.97*	*0.63 (0.19, 1.07)*	*0.005*	*0.49*

3.3.10.2. First girl/boyfriend

Patients with Crohn's disease were slightly less likely to report having a boy/girlfriend at age 17 or younger.

3.3.10.3. First time falling in love

Crohn's disease and ulcerative colitis patients were similar in regards to first time falling in love.

3.3.10.4. First sexual intimacy

The proportion of Crohn's patients reporting sexual intimacy before age 19 was slightly smaller than UC patients.

3.3.10.5. First sexual intercourse

A smaller proportion of CD patients reported having sexual intercourse before age 19 than patients with UC.

Table 3.14. Responses to individual psychosexual questions of IBD patients, by type of IBD

	CD Patients		**UC Patients**		
	%	**n**	**%**	**n**	**p-value**
First girlfriend/boyfriend					

Age 17 or younger	69.4	86	81.5	53	0.07
Age 18 or older/never	30.6	38	18.5	12	
For the first time falling in love					
Age 18 or younger	57.4	70	59.4	38	0.79
Age 19 or older/never	42.6	52	40.6	26	
For the first time sexual intimacy					
Age 18 or younger	76.4	94	87.7	57	0.07
Age 19 or older/never	23.6	29	12.3	8	
For the first time sexual intercourse					
Age 18 or younger	57.3	71	73.8	48	0.03
Age 19 or older/never	42.7	53	26.2	17	

3.3.11. Psychosexual Development of IBD Patients, by Age of Diagnosis

3.3.11.1. Overall Psychosexual Development Score

The mean psychosexual score was somewhat lower for IBD patients diagnosed under age 18 years compared to those diagnosed later (6.5 v. 6.9, difference in means = 0.39, [-0.03, 0.80], p=0.07; effect size = 0.27).

3.3.11.2. First girl/boyfriend

Similar proportions of IBD patients with a pediatric diagnosis and adult diagnosis reported having a girl or boyfriend by the age of 17.

3.3.11.3. First time falling in love

Patients diagnosed under 18 were less likely to report falling in love by age 18 than those diagnosed 18 years or older.

3.3.11.4. First sexual intimacy

The proportions of IBD patients reporting sexual intimacy by age 18 were similar regardless of a pediatric or adult diagnosis of IBD.

3.3.11.5. First sexual intercourse

Fewer IBD patient diagnosed under age 18 reported having intercourse by age 18 than those diagnosed 18 years or older. When the pediatric group was further divided into childhood and adolescence groups, there was a trend for less IBD patients diagnosed in childhood reporting first intercourse by age 18 than those diagnosed in adolescence.

Table 3.15 Responses to individual psychosexual questions for IBD patients, by age of diagnosis

	Pediatric Dx < 18		**Adult Dx 18+**		
	%	**n**	**%**	**n**	**p-value**
First girlfriend/boyfriend					
Age 17 or younger	69.0	58	77.1	81	0.21
Age 18 or older/never	31.0	26	22.9	24	

For the first time falling in love					
Age 18 or younger	50.6	42	64.1	66	0.06
Age 19 or older/never	49.4	41	35.9	37	
For the first time sexual intimacy					
Age 18 or younger	77.4	65	82.7	86	0.36
Age 19 or older/never	22.6	19	17.3	18	
For the first time sexual intercourse					
Age 18 or younger	54.8	46	69.5	73	0.04
Age 19 or older/never	45.2	38	30.5	32	

Table 3.16 Psychosexual development scores for IBD patients with a diagnosis of IBD in childhood, adolescence or adulthood

	Childhood Dx <12		**Adolescence Dx 12 – 17**		**Adulthood Dx 18+**		
	%	**n**	**%**	**n**	**%**	**n**	**p-value**
First girlfriend/boyfriend							
Age 17 or younger	71.4	15	68.3	43	77.1	81	0.44
Age 18 or older/never	28.6	6	31.7	20	22.9	24	

For the first time falling in love							
Age 18 or younger	52.4	11	50.0	31	64.1	66	0.18
Age 19 or older/never	47.6	10	50.0	31	35.9	37	
For the first time sexual intimacy							
Age 18 or younger	76.2	16	77.8	49	82.7	86	0.65
Age 19 or older/never	23.8	5	22.2	14	17.3	18	
For the first time sexual intercourse							
Age 18 or younger	47.6	10	57.1	36	69.5	73	0.08
Age 19 or older/never	52.4	11	42.9	27	30.5	32	

3.3.12. Social Development, Male And Female Participants Combined

3.3.12.1. Overall Social Development Score

The mean social development scores were similar between IBD patients and controls (20.7 v. 20.4, difference in means = 0.31, [-0.23, 0.85]). Linear regression analysis indentified no variables associated with the social development score.

3.3.12.2. Participation in competitive sports

A higher proportion of IBD patients reporting being involved in competitive sports in elementary school compared to controls. Similar proportions IBD

patients and controls were involved in competitive sports in junior or high school and after high school.

3.3.12.3. Friendship

The majority of IBD patients and controls reported having a best friend in Grade 1-3, Grade 4-6, and junior high or high school. The vast majority of IBD and controls report having a best friend in elementary school, however more IBD patients report having a best friend in junior or high school than controls. Almost 90% of participants in each group indicated that they belonged to a group of friends in junior or high school.

3.3.12.4. Leisure time

Similar proportions of IBD and control patients spent the majority of their leisure time with friends in elementary school and in junior or high school. Nearly 40% IBD patients and controls reported going to a bar or disco in junior or high school.

Table 3.17 Responses to individual questions about social development, IBD patients and controls

	IBD Patients		**Controls**		
	%	**n**	**%**	**n**	**p-value**
At least 1 year of competitive sports, elementary school					
Yes	79.7	145	63.7	65	0.003
No	20.3	37	36.3	37	
Number of friends, Grade 1-3					

Less than 4	24.7	44	27.5	28	0.62
4 or more	75.3	134	72.5	74	
Number of friends, Grade 4-6					
Less than 4	22.1	40	14.7	15	0.13
4 or more	77.9	141	85.3	87	
Best friend, elementary school					
Yes	89.0	162	90.2	92	0.76
No	11.0	20	9.8	10	
Most of the time playing with…, elementary school					
Friends	67.0	122	58.8	60	0.17
Brothers/sisters, parents, on your own	33.0	60	41.2	42	
At least 1 year competitive sports, junior or high school					
Yes	69.8	127	68.6	70	0.84
No	30.2	55	31.4	32	
Number of friends, junior or high school					
Less than 4	12.6	23	12.7	13	0.98
4 or more	87.4	159	87.3	89	

Best friend, junior or high school					
Yes	87.4	159	75.5	77	0.01
No	12.6	23	24.5	25	
Belonging to a group of friends, junior or high school					
Yes	87.9	160	88.2	90	0.94
No	12.1	22	11.8	12	
Leisure time mainly with…, junior or high school					
Friends	86.3	157	82.4	84	0.38
Brothers/sisters, parents, on your own	13.7	25	17.6	18	
Going to a bar or disco, junior or high school					
Occasionally, often	39.0	71	36.6	37	0.69
Never	61.0	111	63.4	64	
At least 1 year competitive sports, after high school					
Yes	30.2	55	33.3	34	0.59
No	69.8	127	66.7	68	

3.3.13. Social Development, Male Participants Only

3.3.13.1. Overall Social Development Score

The average social development score was similar for male IBD patients and controls (20.8 v. 20.9, difference in means = -0.14, [--1.11, 0.83], p=0.78).

Male IBD patients had similar responses to all social development questions as compared to controls (Table 3.18).

Table 3.18 Responses to social development questions, male participants only

	IBD Patients		Controls		
	%	n	%	n	p-value
At least 1 year of competitive sports, elementary school					
Yes	86.1	62	77.1	27	0.25
No	13.9	10	22.9	8	
Number of friends, Grade 1-3					
Less than 4	24.3	17	25.7	9	0.87
4 or more	75.7	53	74.3	26	
Number of friends, Grade 4-6					
Less than 4	18.1	13	11.4	4	0.38
4 or more	81.9	59	88.6	31	
Best friend, elementary school					
Yes	86.1	62	82.9	29	0.66

No	13.9	10	17.1	6	
Most of the time playing with…, elementary school					
Friends	68.1	49	60.0	21	0.41
Brothers/sisters, parents, on your own	31.9	23	40.0	14	
At least 1 year competitive sports, junior or high school					
Yes	72.2	52	85.7	30	0.12
No	27.8	20	14.3	5	
Number of friends, junior or high school					
Less than 4	15.3	11	8.6	3	0.33
4 or more	84.7	61	91.4	32	
Best friend, junior or high school					
Yes	81.9	59	74.3	26	0.36
No	18.1	13	25.7	9	
Belonging to a group of friends, junior or high school					
Yes	87.5	63	85.7	30	0.80

No	12.5	9	14.3	5	
Leisure time mainly with…, junior or high school					
Friends	83.3	60	80.0	28	0.67
Brothers/sisters, parents, on your own	16.7	12	20.0	7	
Going to a bar or disco, junior or high school					
Occasionally, often	38.9	28	40.0	14	0.91
Never	61.1	44	60.0	21	
At least 1 year competitive sports, after high school					
Yes	33.3	24	48.6	17	0.13
No	66.7	48	51.4	18	

3.3.14. Social Development, Female Participants Only

3.3.14.1. Overall Social Development Score

Female IBD patients had similar mean social development scores when compared to female healthy controls (20.7 v. 20.2, difference in means = 0.54, [-0.11, 1.19], p=0.11). Responses to individual social development questions for female participants are shown in Table 3.19.

3.3.14.2. Participation in competitive sports

Three-quarters of female IBD patients participated in competitive sports in elementary school compared to just 57% healthy controls. Approximately two-thirds of female IBD patients and controls reported participating in competitive sports in junior or high school. After high school, approximately one-third of female IBD patients and controls indicated they participate in competitive sports.

3.3.14.3. Friendship

Over 90% of female IBD patients and controls reported having a best friend in elementary school. However, more female IBD patients reported having a best friend in junior or high school than female healthy controls. The majority of female IBD patients and controls reported have at least 4 friends in primary and secondary school. Almost 90% of female IBD patients and controls indicated that they belonged to a group of friends in junior or high school.

3.3.14.4. Leisure time

The proportion of females reporting spending the majority of their time playing with friends was similar for IBD patients and controls in both elementary and junior or high school. The proportion of female participants that went to a bar during junior or high school was similar between groups.

Table 3.19 Responses of female IBD patients and controls to individual social development questions

	IBD Patients		Controls		
	%	n	%	n	p-value
At least 1 year of competitive sports, elementary school					

Yes	75.5	83	56.7	38	0.009
No	24.5	27	43.3	29	
Number of friends, Grade 1-3					
Less than 4	25.0	27	28.4	19	0.62
4 or more	75.0	27	71.6	48	
Number of friends, Grade 4-6					
Less than 4	24.8	27	16.4	11	0.19
4 or more	75.2	82	83.6	56	
Best friend, elementary school					
Yes	90.9	100	94.0	63	0.46
No	9.1	10	6.0	4	
Most of the time playing with…, elementary school					
Friends	66.4	73	58.2	39	0.28
Brothers/sisters, parents, on your own	33.6	37	41.8	28	
At least 1 year competitive sports, junior or high school					
Yes	68.2	75	59.7	40	0.25
No	31.8	35	40.3	27	

Number of friends, junior or high school					
Less than 4	10.9	12	14.9	10	0.43
4 or more	89.1	98	85.1	14.9	
Best friend, junior or high school					
Yes	90.9	100	76.1	51	0.007
No	9.1	10	23.9	16	
Belonging to a group of friends, junior or high school					
Yes	88.2	97	89.6	60	0.78
No	11.8	13	10.4	7	
Leisure time mainly with…, junior or high school					
Friends	88.2	97	83.6	56	0.39
Brothers/sisters, parents, on your own	11.8	13	16.4	11	
Going to a bar or disco, junior or high school					
Occasionally, often	39.1	43	34.8	23	0.57
Never	60.9	67	65.2	43	

At least 1 year competitive sports, after high school					
Yes	28.2	31	25.4	17	0.68
No	71.8	79	74.6	50	

3.3.15. Social Development of IBD Patients, by Type of IBD

3.3.15.1. Overall Social Development Score

Patients with Crohn's disease had lower mean social development scores than patients with UC (20.5 v. 21.2, difference in means = 0.70, [0.04, 1.36]).

3.3.15.2. Participation in competitive sports

UC patients were somewhat more likely have participated in competitive sports in elementary school than Crohn's patients. This difference was not seen in junior and high school or after high school.

3.3.15.3. Friendship

Crohn's disease and ulcerative colitis patients were similar with respect to the number of friends, having a best friend, and belonging to a group of friends. In grades 1-3, 4-6, and junior or senior high the majority of Crohn's patients and UC patients reported having at least 4 friends and the majority reported having a best friend.

3.3.15.4. Leisure time

Approximately two-thirds of CD and UC patients indicated that they spent they majority of their time with friends in elementary school. However, patients with Crohn's disease were three times more likely to report spending

the majority of their leisure time in junior or high school with siblings, parents or on their own than UC patients who spent time with friends. Approximately CD and UC patients reported going to a bar occasionally or frequently in junior high and high school.

Table 3.20 Responses to individual social development questions, by type of IBD

	CD Patients		**UC Patients**		
	%	**n**	%	**n**	**p-value**
At least 1 year of competitive sports, elementary school					
Yes	75.9	88	86.4	57	0.09
No	24.1	28	13.6	9	
Number of friends, Grade 1-3					
Less than 4	28.1	32	18.8	12	0.17
4 or more	71.9	82	81.3	52	
Number of friends, Grade 4-6					
Less than 4	25.0	29	16.9	11	0.21
4 or more	75.0	87	83.1	54	
Best friend, elementary school					
Yes	86.2	100	93.9	62	0.11
No	13.8	16	6.1	4	

Most of the time playing with…, elementary school					
Friends	68.1	79	65.2	43	0.68
Brothers/sisters, parents, on your own	31.9	37	34.8	23	
At least 1 year competitive sports, junior or high school					
Yes	69.8	81	69.7	20	0.99
No	30.2	35	30.3	20	
Number of friends, junior or high school					
Less than 4	15.5	18	7.6	5	0.12
4 or more	84.5	98	92.4	61	
Best friend, junior or high school					
Yes	84.5	98	92.4	61	0.12
No	15.5	18	7.6	5	
Belonging to a group of friends, junior or high school					
Yes	85.3	99	92.4	61	0.16
No	14.7	17	7.6	5	
Leisure time mainly with…,					

junior or high school					
Friends	81.9	95	93.9	62	0.02
Brothers/sisters, parents, on your own	18.1	21	6.1	4	
Going to a bar or disco, junior or high school					
Occasionally, often	37.1	43	42.4	28	0.48
Never	62.9	73	57.6	38	
At least 1 year competitive sports, after high school					
Yes	29.3	34	31.8	21	0.73
No	70.7	82	68.2	45	

3.3.16. Social Development of IBD Patients, by Age of Diagnosis

3.3.16.1. Overall Social Development Score

The mean social development scores were the same for IBD patients with a pediatric or adult diagnosis of IBD (20.7 v. 20.7, difference in means = 0.03, [-0.62, 0.67], p=0.94). Detailed responses of IBD patients to social development questions, by age of diagnosis are shown in tables 3.21 and 3.22.

3.3.16.2. Participation in competitive sports

Patients with a pediatric diagnosis of IBD were more likely to have participated in competitive sports in elementary school, but not in junior or

high school or after high school. More patients diagnosed under age 12 played competitive sports in elementary compared to those diagnosed in adolescence and adulthood.

3.3.16.3. Friendship

Patients diagnosed in childhood were just as likely as those diagnosed in adulthood to have at least 4 friends in elementary school but slightly less likely to have at least 4 friends in junior or high school. Those diagnosed under age 18 were also less likely to report belonging to a group of friends in junior or high school. IBD patients diagnosed in adolescence were less likely to belong to a group of friends than either those diagnosed in childhood or adulthood. The proportions of patients having a best friend were similar for these groups in both elementary and high school.

3.3.16.4. Leisure time

Similar proportions of IBD patients diagnosed under and over 18 report spending the majority of their leisure time with friends in elementary school but those diagnosed under 18 were less likely to report this in junior or high school. Approximately 40% of each group report going to a bar or disco in junior or high school.

Table 3.21 Responses to social development questions by age of diagnosis

	Pediatric Dx < 18		**Adult Dx 18+**		
	%	**n**	**%**	**n**	**p-value**
At least 1 year of competitive sports, elementary school					
Yes	87.2	68	74.0	77	0.03

No	12.8	10	26.0	27	
Number of friends, Grade 1-3					
Less than 4	22.1	17	26.7	27	0.48
4 or more	77.9	60	73.3	74	
Number of friends, Grade 4-6					
Less than 4	20.5	16	23.3	24	0.65
4 or more	79.5	62	76.7	79	
Best friend, elementary school					
Yes	87.2	68	90.4	94	0.49
No	12.8	10	9.6	10	
Most of the time playing with…, elementary school					
Friends	71.8	56	63.5	66	0.24
Brothers/sisters, parents, on your own	28.2	22	36.5	38	
At least 1 year competitive sports, junior or high school					
Yes	71.8	56	68.3	71	0.61
No	28.2	22	31.7	33	
Number of friends, junior or high school					

Less than 4	17.9	14	8.7	9	0.06
4 or more	82.1	64	91.3	95	
Best friend, junior or high school					
Yes	84.6	66	89.4	93	0.33
No	15.4	12	10.6	11	
Belonging to a group of friends, junior or high school					
Yes	82.1	64	92.3	96	0.04
No	17.9	14	7.7	8	
Leisure time mainly with…, junior or high school					
Friends	80.8	63	90.4	94	0.06
Brothers/sisters, parents, on your own	19.2	15	9.6	10	
Going to a bar or disco, junior or high school					
Occasionally, often	41.0	32	37.5	39	0.63
Never	59.0	46	62.5	65	
At least 1 year competitive sports, after high school					
Yes	26.9	21	32.7	34	0.40

No	73.1	57	67.3	70	

Table 3.22 Social development scores for IBD patients with a diagnosis in childhood, adolescence, or adulthood

	Childhood Dx <12		**Adolescence Dx 12 – 17**		**Adulthood Dx 18+**		
	%	**n**	**%**	**n**	**%**	**n**	**p-value**
At least 1 year of competitive sports, elementary school							
Yes	95.2	20	84.2	48	74.0	77	0.05
No	4.8	1	15.8	9	26.0	27	
Number of friends, Grade 1-3							
Less than 4	14.3	3	25.0	14	26.7	27	0.48
4 or more	85.7	18	75.0	42	73.3	74	
Number of friends, Grade 4-6							
Less than 4	23.8	5	19.3	11	23.3	24	0.83
4 or more	76.2	16	80.7	46	76.7	79	
Best friend, elementary school							

Yes	90.5	19	86.0	49	90.4	94	0.68
No	9.5	2	14.0	8	9.6	10	
Most of the time playing with…, elementary school							
Friends	71.4	15	71.9	41	63.5	66	0.50
Brothers/sisters, parents, on your own	28.6	6	28.1	16	36.5	38	
At least 1 year competitive sports, junior or high school							
Yes	71.4	15	71.9	41	68.3	71	0.88
No	28.6	6	28.1	16	31.7	33	
Number of friends, junior or high school							
Less than 4	19.0	4	17.5	10	8.7	9	0.17
4 or more	81.0	17	82.5	47	91.3	95	
Best friend, junior or high school							
Yes	85.7	18	84.2	48	89.4	93	0.62
No	14.3	3	15.8	9	10.6	11	
Belonging to a group							

of friends, junior or high school							
Yes	90.5	19	78.9	45	92.3	96	0.04
No	9.5	2	21.1	12	7.7	8	
Leisure time mainly with…, junior or high school							
Friends	76.2	16	82.5	47	90.4	94	0.14
Brothers/sisters, parents, on your own	23.8	5	17.5	10	9.6	10	
Going to a bar or disco, junior or high school							
Occasionally, often	47.6	10	63.2	36	37.5	39	0.41
Never	52.4	11	36.8	21	62.5	65	
At least 1 year competitive sports, after high school							
Yes	23.8	5	28.1	16	32.7	34	0.66
No	76.2	16	71.9	41	67.3	70	

3.3.17. Antisocial Behavior, Male and Female Participants Combined

3.3.17.1. Overall Score for Antisocial Behavior

The mean antisocial score was similar for IBD patients compared to healthy controls (4.9 v. 4.8, difference in means = 0.10, [-0.13, 0.34], p=0.40). In linear regression analysis, the two factors that are associated with a lower antisocial behavior score are being female and having any post-secondary training (Table 3.23). Having IBD was not associated with a change in anti-social behavior score.

Table 3.23 Linear regression model for antisocial behavior score

	Adjusted Coefficient (95% CI)	p-value
Gender		
Male		
Female	-0.59 (-0.82, -0.36)	<0.001
Post-Secondary Training		
None		
Any	-0.39 (-0.72, -0.06)	0.02
Constant	5.55 (5.22, 5.89)	<0.001

For the overall model, p-value < 0.0001; R^2=0.10. In the model, normality and constant variance assumptions are violated.

There are no differences seen in the responses to individual questions assessing antisocial behavior between IBD patients and healthy controls (Table 3.24). Suspension for misbehavior was similar for IBD patients and

controls in elementary school and junior or high school. Approximately 40% of IBD patients and controls reported being asked to leave class due to misbehavior in junior or high school. Trouble with the law was reported by less than 20% of participants in each group.

Table 3.24 Responses to questions about antisocial behavior for IBD patients and healthy controls

	IBD Patients		**Controls**		
	%	**n**	**%**	**n**	**p-value**
Suspended/expelled for misbehavior, elementary school					
Yes	13.8	26	10.3	11	0.38
No	86.2	162	89.7	96	
In trouble with the police or other law enforcement, junior or high school					
Yes	17.0	32	14.2	15	0.52
No	83.0	156	85.8	91	
Been suspended/expelled for misbehavior, junior or high school					
Yes	19.1	36	12.1	13	0.12
No	80.9	152	87.9	94	
Been asked to leave class by a teacher due to misbehavior,					

junior or high school					
Yes	37.8	71	42.1	45	0.47
No	62.2	117	57.9	62	

3.3.18. Anti-social Behavior, Male Participants Only

The mean anti-social behavior scores of male IBD patients and controls were similar as were the responses to individual questions assessing anti-social behavior (Table 3.25).

Table 3.25 Responses to individual questions regarding anti-social behavior for male IBD patients and controls

	IBD Patients		**Controls**		
	%	**n**	**%**	**n**	**p-value**
Suspended/expelled for misbehavior, elementary school					
Yes	21.1	8	26.0	19	0.56
No	78.9	30	74.0	54	
In trouble with the police or other law enforcement, junior or high school					
Yes	21.1	8	20.5	15	0.95
No	78.9	30	79.5	58	

Been suspended/expelled for misbehavior, junior or high school					
Yes	24.7	18	18.4	7	0.46
No	75.3	55	81.6	31	
Been asked to leave class by a teacher due to misbehavior, junior or high school					
Yes	49.3	36	63.2	24	0.17
No	50.7	37	36.8	14	

3.3.19. Anti-social Behavior, Female Participants Only

Female IBD patients had similar mean anti-social scores as female healthy controls (4.8 v. 4.5, difference in means = 0.15, [-0.10, 0.40], p=0.25). The groups were similar for any of the individual questions measuring anti-social behavior (Table 3.26).

Table 3.26 Responses to individual anti-social behavior questions for female IBD patients and controls

	IBD Patients		**Controls**		
	%	**n**	**%**	**n**	**p-value**
Suspended/expelled for misbehavior, elementary school					

Yes	6.1	7	4.3	3	0.61
No	93.9	108	95.7	66	
In trouble with the police or other law enforcement, junior or high school					
Yes	14.8	17	10.3	7	0.39
No	85.2	98	89.7	61	
Been suspended/expelled for misbehavior, junior or high school					
Yes	15.7	18	8.7	6	0.18
No	91.3	63	84.3	97	
Been asked to leave class by a teacher due to misbehavior, junior or high school					
Yes	30.4	35	30.4	21	1.00
No	69.6	80	69.6	80	

3.3.20. Anti-social behavior for IBD Patients, by Type of IBD

Patients with Crohn's disease had similar mean anti-social behavior scores compared to patients with UC (4.84 v. 4.95, difference in means = 0.12, [-0.18, 0.42], p=0.44). The proportion of IBD patients reporting trouble with law enforcement in junior or high school was almost twice as high in UC patient

than Crohn's patients. Crohn's and UC patients were similar with respect to all other antisocial questions (Table 3.27).

Table 3.27 Responses to individual questions assessing anti-social behavior, by type of IBD

	CD Patients		UC Patients		
	%	n	%	n	p-value
Suspended/expelled for misbehavior, elementary school					
Yes	12.3	15	16.7	11	0.41
No	87.7	107	83.3	55	
In trouble with the police or other law enforcement, junior or high school					
Yes	13.1	16	24.2	16	0.05
No	86.9	106	75.8	50	
Been suspended/expelled for misbehavior, junior or high school					
Yes	18.9	23	19.7	13	0.89
No	81.1	99	80.3	53	
Been asked to leave class by a teacher due to misbehavior, junior or high school					

Yes	39.3	48	34.8	23	0.54
No	60.7	74	65.2	43	

3.3.21. Anti-social Behavior of IBD Patients, by Age of Diagnosis

Patients diagnosed under age 18 and 18 and older have similar mean anti-social scores (5.0 v. 4.8, difference in means = 0.18, [-0.11, 0.47], p=0.23). There is a trend toward IBD patients diagnosed under age 18 years being more likely to be suspended/expelled for misbehavior in junior or high school. No other differences in individual anti-social behavior questions were seen between the groups by age of diagnosis (Tables 3.28 and 3.29).

Table 3.28 Responses to Individual questions assessing anti-social behavior for IBD patients, by age of diagnosis

	Pediatric Dx < 18		**Adult Dx 18 +**		
	%	**n**	**%**	**n**	**p-value**
Suspended/expelled for misbehavior, elementary school					
Yes	14.5	12	13.3	14	0.82
No	85.5	71	86.7	91	
In trouble with the police or other law enforcement, junior or high school					
Yes	15.7	13	18.1	19	0.66

No	84.3	70	81.9	86	
Been suspended/expelled for misbehavior, junior or high school					
Yes	25.3	21	14.3	15	0.06
No	74.7	62	85.7	90	
Been asked to leave class by a teacher due to misbehavior, junior or high school					
Yes	42.2	35	34.3	36	0.27
No	57.8	48	65.7	69	

Table 3.29 Anti-social development questions for IBD patients with a diagnosis in childhood, adolescence, or adulthood

	Childhood Dx <12		**Adolescence Dx 12 – 17**		**Adulthood Dx 18+**		
	%	**n**	**%**	**n**	**%**	**n**	**p-value**
Suspended/expelled for misbehavior, elementary school							
Yes	9.5	2	16.1	10	13.3	14	0.73
No	90.5	19	83.9	52	86.7	91	

In trouble with the police or other law enforcement, junior or high school							
Yes	19.0	4	14.5	9	18.1	19	0.81
No	81.0	17	85.5	53	81.9	86	
Been suspended/expelled for misbehavior, junior or high school							
Yes	23.8	5	25.8	16	14.3	15	0.16
No	76.2	16	74.2	46	85.7	90	
Been asked to leave class by a teacher due to misbehavior, junior or high school							
Yes	38.1	8	43.5	27	34.3	36	0.49
No	61.9	13	56.5	43.5	65.7	69	

3.3.22. Substance Use and Gambling, Male and Female Participants Combined

3.3.22.1. Overall Substance Use and Gambling Score

IBD patients had higher mean substance use and gambling scores compared to healthy controls (14.5 v. 13.9, difference in means = 0.67, [0.11, 1.22], p=0.01; effect size = 0.29). However, after adjusting for gender, age and post-

secondary training with multivariable linear regression analysis, having IBD is not associated with a change in substance use and gambling score (Table 3.30). Increasing age is associated with an increase in substance use and gambling score, while being female and having any post-secondary training was associated with a lower substance use and gambling score.

Table 3.30 Multivariable linear regression model for substance use and gambling score

	Adjusted Coefficient (95% CI)	p-value
Gender		
Male		
Female	-0.62 (-1.16, -0.09)	0.02
Age	0.12 (0.05, 0.19)	0.001
Post-Secondary Training		
None		
Any	-1.53 (-2.29, -0.76)	<0001
Constant	13.01 (11.13, 14.89)	<0.001

For the overall model, p-value < 0.0001; R^2=0.10). In the model, constant variance assumption is violated.

Detailed results of individual questions assessing substance use and gambling are shown in Table 3.31.

3.3.22.2. Alcohol use

IBD patients were more likely report they drank alcohol often or very often in junior or high school compared to controls. However, after high school similar

proportions of IBD patients and healthy controls reported they drank alcohol often or very often.

3.3.22.3. Soft drug use

IBD patients were more likely to report they used soft drugs like marijuana or hashish compared to healthy controls in junior or high school and after high school.

3.3.22.4. Psychedelic drug use

The proportions of IBD patients and controls reporting use of psychedelic drugs, like ecstasy or lysergic acid diethylamide (LSD) was similar in junior or high school and after high school.

3.3.22.5. Hard drug use

Very few of IBD patients and no controls reported using hard drugs like cocaine or heroin in junior or high school. After high school, more IBD patients reported using hard drugs compared to controls, although use was uncommon.

3.3.22.6. Smoking

IBD patients were more likely to report they smoked cigarettes compared to healthy controls in junior or high school and after high school.

3.3.22.7. Gambling for money

Similar proportions of IBD patients and controls indicated that they gambling for money during junior high or high school and after high school.

Table 3.31 Frequencies of responses to individual substance use and gambling questions, IBD patients and controls

	IBD Patients		Controls		
	%	n	%	n	p-value
Drink alcohol, junior or high school					
Never, occasionally	78.7	148	87.6	92	0.06
Often, very often	21.3	40	12.4	13	
Soft drugs (marijuana or hashish), junior or high school					
Never	60.5	115	74.3	78	0.02
Occasionally, often, very often	39.5	75	25.7	27	
Psychedelic drugs (LSD or Ecstasy), junior or high school					
Never	93.2	177	94.3	99	0.71
Occasionally, often, very often	6.8	13	5.7	6	
Hard drugs (cocaine or heroin), middle or high school					
Never	98.9	188	100.0	105	0.29
Occasionally, often, very often	1.1	2	0.0	0	
Smoking cigarettes, junior or high school					

No	73.2	139	83.8	88	0.04
Yes	26.8	51	16.2	17	
Gambling for money, junior or high school					
Never	95.3	181	94.3	99	0.71
Occasionally, often, very often	4.7	9	5.7	6	
Drink alcohol, after high school					
Never, occasionally	65.4	123	64.8	68	0.90
Often, very often	34.6	65	35.2	37	
Soft drugs, after high school					
Never	57.4	109	70.5	74	0.03
Occasionally, often, very often	42.6	81	29.5	31	
Psychedelic drugs, after high school					
Never	91.1	173	95.2	100	0.19
Occasionally, often, very often	8.9	17	4.8	5	
Hard drugs, after high school					
Never	93.2	177	98.1	103	0.07
Occasionally, often, very often	6.8	13	1.9	2	
Smoking, after high school					

No	72.1	137	81.7	85	0.07
Yes	27.9	53	18.3	19	
Gambling for money, after high school					
Never	64.5	122	66.7	70	0.67
Occasionally, often, very often	35.8	68	33.3	35	

3.3.23. Substance Use and Gambling, Male Participants Only

3.3.23.1. Overall Substance Use and Gambling Score

The mean substance use and gambling score is not different between IBD patients and healthy controls (14.8 v. 14.4, difference in means = 0.46, [-0.49, 1.42], p=0.35).

3.3.23.2. Alcohol use

The proportion of male IBD patients and controls that reported drinking alcohol often or very often were similar for junior or high school and after high school.

3.3.23.3. Soft drug use

Male IBD patients were nearly twice as likely to report soft drug use after high school compared to healthy males. The proportions of male IBD and non-IBD participants reporting soft drug use in junior or high school were similar.

3.3.23.4. Psychedelic drug use

The proportions of male IBD patients and controls reporting use of psychedelic drugs were similar in junior or high school and after high school.

3.3.23.5. Hard drug use

Similar proportions of male IBD patients and controls reported using hard drugs in junior or high school. However, after high school more male IBD patients report hard drug use, although these proportions are still small.

3.3.23.6. Smoking

Male IBD patients and healthy males had similar proportions of smoking in junior or high school and after high school.

3.3.23.7. Gambling for money

The proportions of male IBD patients and healthy controls that reported gambling for money were similar in junior or high school and after high school.

Table 3.32 Frequency of responses to individual substance use and gambling questions for IBD patients and controls, male participants only

	IBD Patients		Controls		
	%	n	%	n	p-value
Drink alcohol, junior or high school					
Never, occasionally	82.2	60	81.1	30	0.89
Often, very often	17.8	13	18.9	7	
Soft drugs (marijuana or hashish), junior or high school					
Never	58.1	43	73.0	27	0.13
Occasionally, often, very often	41.9	31	27.0	10	

Psychedelic drugs (LSD or Ecstasy), junior or high school					
Never	94.6	70	97.3	36	0.52
Occasionally, often, very often	5.4	4	2.7	1	
Hard drugs (cocaine or heroin), middle or high school					
Never	98.6	73	100.0	37	0.48
Occasionally, often, very often	1.4	1	0.0	0	
Smoking cigarettes, junior or high school					
No	83.8	62	83.8	31	1.00
Yes	16.2	12	16.2	6	
Gambling for money, junior or high school					
Never	87.8	65	86.5	32	0.84
Occasionally, often, very often	12.2	9	13.5	5	
Drink alcohol, after high school					
Never, occasionally	63.5	47	54.1	20	0.34
Often, very often	36.5	27	45.9	17	
Soft drugs, after high school					
Never	47.3	35	70.3	26	0.02

Occasionally, often, very often	52.7	39	29.7	11	
Psychedelic drugs, after high school					
Never	85.1	63	89.2	33	0.56
Occasionally, often, very often	14.9	11	10.8	4	
Hard drugs, after high school					
Never	89.2	66	97.3	36	0.14
Occasionally, often, very often	10.8	8	2.7	1	
Smoking, after high school					
No	74.3	55	83.3	30	0.29
Yes	25.7	19	16.7	6	
Gambling for money, after high school					
Never	52.7	39	45.9	17	0.50
Occasionally, often, very often	47.3	35	54.1	20	

3.3.24. Substance Use and Gambling, Female Participants Only

3.3.24.1. Overall Score for Substance Use and Gambling

The mean substance use and gambling score was higher for female IBD patients compared to controls (14.4 v. 13.6, difference in means = 0.75, [0.11, 1.39], p=0.02).

3.3.24.2. Alcohol use

Female IBD patients were more likely than female non-IBD participants to report drinking alcohol in junior or high school, but this difference was smaller after high school.

3.3.24.3. Soft drug use

Female IBD patients were likely to report more use of soft drugs in junior or high school compared to controls. After high school, the proportions of females reporting soft drug use were similar for IBD patients and controls.

3.3.24.4. Psychedelic drug use

Similar proportions of female IBD patients and controls reported psychedelic drug use in junior or high school and after high school.

3.3.24.5. Hard drug use

Hard drug use was uncommon in female participants during junior or high school, with only 1 IBD patient and no healthy controls reporting use. After high school the proportions of female IBD patients and controls reporting use were similar.

3.3.24.6. Smoking

Female IBD patients were twice as likely to report smoking cigarettes in junior or high school than controls. After high school, the proportions were similar.

3.3.24.7. Gambling for money

Gambling for money was uncommon in female participants during junior or high school; no IBD patients and just one healthy control reported this. Gambling after high school was more common but the proportions of females reporting this was similar between IBD patients and controls.

Table 3.33 Responses to individual substance use and gambling questions, IBD patients and controls, female participants only

	IBD Patients		Controls		
	%	n	%	n	p-value
Drink alcohol, junior or high school					
Never, occasionally	76.5	88	91.2	62	0.01
Often, very often	23.5	27	8.8	6	
Soft drugs (marijuana or hashish), junior or high school					
Never	62.1	72	75.0	51	0.07
Occasionally, often, very often	37.9	44	25.0	17	
Psychedelic drugs (LSD or Ecstasy), junior or high school					
Never	92.2	107	92.6	63	0.92
Occasionally, often, very often	7.8	9	7.4	5	
Hard drugs (cocaine or heroin), middle or high school					
Never	99.1	115	100.0	68	0.44
Occasionally, often, very often	0.9	1	0.0	0	
Smoking cigarettes, junior or high school					

No	66.4	77	83.8	57	0.01
Yes	33.6	39	16.2	11	
Gambling for money, junior or high school					
Never	100.0	116	98.5	67	0.19
Occasionally, often, very often	0.0	0	1.5	1	
Drink alcohol, after high school					
Never, occasionally	66.7	76	70.6	48	0.58
Often, very often	33.3	38	29.4	20	
Soft drugs, after high school					
Never	63.8	74	70.6	48	0.35
Occasionally, often, very often	36.2	42	29.4	20	
Psychedelic drugs, after high school					
Never	94.8	110	98.5	67	0.21
Occasionally, often, very often	5.2	6	1.5	1	
Hard drugs, after high school					
Never	95.7	111	98.5	67	0.30
Occasionally, often, very often	4.3	5	1.5	1	
Smoking, after high school					

No	70.7	82	80.9	55	0.13
Yes	29.3	34	19.1	13	
Gambling for money, after high school					
Never	71.6	53	77.9	53	0.34
Occasionally, often, very often	28.4	33	22.1	15	

3.3.25. Substance Use and Gambling in IBD Patients, by Type of IBD

The mean substance use and gambling score was similar for CD and UC patients (14.5 v. 14.7, difference in means = 0.21, [-0.53, 0.96], 1 p=0.57). UC patients were nearly three times more likely to report using psychedelic drugs after high school than CD patients. No other differences were seen between CD and UC patients in regards to individual items assessing substance use and gambling (Table 3.34).

Table 3.34 Responses to individual substance use and gambling questions, by type of IBD

	CD Patients		**UC Patients**		
	%	**n**	**%**	**n**	**p-value**
Drink alcohol, junior or high school					
Never, occasionally	78.0	96	80.0	52	0.76
Often, very often	22.0	27	20.0	13	

Soft drugs (marijuana or hashish), junior or high school					
Never	62.1	77	57.6	38	0.54
Occasionally, often, very often	37.9	47	42.4	28	
Psychedelic drugs (LSD or Ecstasy), junior or high school					
Never	93.5	116	92.4	61	0.77
Occasionally, often, very often	6.5	8	7.6	5	
Hard drugs (cocaine or heroin), middle or high school					
Never	98.4	122	100.0	66	0.30
Occasionally, often, very often	1.6	2	0.0	0	
Smoking cigarettes, junior or high school					
No	73.4	91	72.7	48	0.92
Yes	26.6	33	27.3	18	
Gambling for money, junior or high school					
Never	96.8	120	92.4	61	0.18
Occasionally, often, very often	3.2	4	7.6	5	
Drink alcohol, after high school					

Never, occasionally	66.7	82	63.1	41	0.62
Often, very often	33.3	41	36.9	24	
Soft drugs, after high school					
Never	55.6	69	60.6	40	0.51
Occasionally, often, very often	44.4	55	39.4	26	
Psychedelic drugs, after high school					
Never	94.4	117	84.8	56	0.03
Occasionally, often, very often	5.6	7	15.2	10	
Hard drugs, after high school					
Never	95.2	118	89.4	59	0.13
Occasionally, often, very often	4.8	6	10.6	7	
Smoking, after high school					
No	71.8	89	72.7	48	0.89
Yes	28.2	35	27.3	18	
Gambling for money, after high school					
Never	65.3	81	62.1	41	0.66
Occasionally, often, very often	34.7	43	37.9	25	

3.3.26. Substance Use and Gambling in IBD Patients, by Age of Diagnosis

3.3.26.1. Overall Substance Use and Gambling Score

Pediatric diagnosed IBD patients had similar mean substance use and gambling scores to adult diagnosed participants (14.4 v. 14.7, difference in means = 0.35, [-0.36, 1.07], p=0.33).

3.3.26.2. Alcohol use

Patients diagnosed under age 18 were somewhat less likely to drink alcohol in junior or high school than those diagnosed over age 18. After high school, of the proportions of patients diagnosed under 18 and after age 18 reporting drinking alcohol were similar.

3.3.26.3. Soft drug use

Approximately 40% IBD patients reported using marijuana or hashish in junior or high school and after high school, regardless of age of diagnosis.

3.3.26.4. Psychedelic drug use

Less than 10% IBD patients diagnosed under or over 18, reported psychedelic drug use in junior or high school or after high school.

3.3.26.5. Hard drug use

No patients diagnosed under age 18 reported using hard drugs, like cocaine or heroin, in junior or high school compared to 2% of those diagnosed at age 18 or older. Hard drug use after high school was slightly higher in those diagnosed before age 18.

3.3.26.6. Smoking

Patients diagnosed under age 18 were less likely to smoke cigarettes in junior or high school than those diagnosed over age 18. This difference is less pronounced in smoking after high school.

3.3.26.7. Gambling for money

The proportion of IBD patients that reported gambling for money was similar for those diagnosed under and over age 18 in junior or high school and after high school.

Table 3.35 Responses to individual course of life questions of IBD patients, by age of diagnosis

	Dx < 18		**Dx 18 +**		
	%	**n**	**%**	**n**	**p-value**
Drink alcohol, junior or high school					
Never, occasionally	84.3	70	74.3	78	0.09
Often, very often	15.7	13	25.7	27	
Soft drugs (marijuana or hashish), junior or high school					
Never	61.9	52	59.4	63	0.73
Occasionally, often, very often	38.1	32	40.6	43	
Psychedelic drugs (LSD or Ecstasy), junior or high school					

Never	91.7	77	94.3	100	0.47
Occasionally, often, very often	8.3	7	5.7	6	
Hard drugs (cocaine or heroin), junior or high school					
Never	100.0	84	98.1	104	0.21
Occasionally, often, very often	0.0	0	1.9	2	
Smoking cigarettes, junior or high school					
No	81.0	68	67.0	71	0.03
Yes	19.0	16	33.0	35	
Gambling for money, junior or high school					
Never	94.0	70	96.2	102	0.48
Occasionally, often, very often	6.0	5	3.8	4	
Drink alcohol, after high school					
Never, occasionally	69.9	58	61.9	65	0.25
Often, very often	30.1	25	38.1	40	
Soft drugs, after high school					
Never	54.8	46	59.4	63	0.52
Occasionally, often, very often	45.2	38	40.6	43	

Psychedelic drugs, after high school					
Never	90.5	76	91.5	97	0.80
Occasionally, often, very often	9.5	8	8.5	9	
Hard drugs, after high school					
Never	90.5	76	95.3	101	0.19
Occasionally, often, very often	9.5	8	4.7	5	
Smoking, after high school					
No	77.4	65	67.9	72	0.15
Yes	22.6	19	32.1	34	
Gambling for money, after high school					
Never	66.7	56	62.3	66	0.53
Occasionally, often, very often	33.3	28	37.7	40	

Table 3.36 Responses to substance use and gambling questions for IBD patients with a diagnosis in childhood, adolescence or adulthood

	Childhood Dx <12		**Adolescence Dx 12 – 17**		**Adulthood Dx 18+**		
	%	**n**	**%**	**n**	**%**	**n**	**p-value**
Drink alcohol, junior or							

high school							
Never, occasionally	85.7	18	83.9	52	74.3	78	0.24
Often, very often	14.3	3	16.1	10	25.7	27	
Soft drugs (marijuana or hashish), junior or high school							
Never	66.7	14	60.3	38	59.4	63	0.84
Occasionally, often, very often	33.3	7	39.7	25	40.6	43	
Psychedelic drugs (LSD or Ecstasy), junior or high school							
Never	85.7	18	93.7	59	94.3	100	0.35
Occasionally, often, very often	14.3	3	6.3	4	5.7	6	
Hard drugs (cocaine or heroin), middle or high school							
Never	100.0	21	100.0	63	98.1	104	0.45
Occasionally, often, very often	0.0	0	0.0	0	1.9	2	
Smoking cigarettes, junior or high school							

No	81.0	17	81.0	51	67.0	71	0.10
Yes	19.0	4	19.0	12	33.0	35	
Gambling for money, junior or high school							
Never	100.0	21	92.1	58	96.2	102	0.26
Occasionally, often, very often	0.0	0	7.9	5	3.8	4	
Drink alcohol, after high school							
Never, occasionally	75.0	15	68.3	43	61.9	65	0.45
Often, very often	25.0	5	31.7	20	38.1	40	
Soft drugs, after high school							
Never	61.9	13	52.4	33	59.4	63	0.61
Occasionally, often, very often	38.1	8	47.6	30	40.6	43	
Psychedelic drugs, after high school							
Never	81.0	17	93.7	59	91.5	97	0.20
Occasionally, often, very often	19.9	4	6.3	4	8.5	9	
Hard drugs, after high							

school							
Never	90.5	19	90.5	57	95.3	101	0.43
Occasionally, often, very often	9.5	2	9.5	6	4.7	5	
Smoking, after high school							
No	81.0	17	76.2	48	67.9	72	0.32
Yes	19.0	4	23.8	15	32.1	34	
Gambling for money, after high school							
Never	52.4	11	71.4	45	74.3	78	0.24
Occasionally, often, very often	47.6	10	28.6	18	25.7	27	

3.4. Discussion

3.4.1. Overall Psychosocial Development of IBD Patients

Overall, IBD patients are similar to their healthy peers in regards to social development, and antisocial behavior and substance use and gambling. Unlike other chronic diseases, IBD patients have better autonomy and psychosexual development than healthy controls. This improved autonomy and psychosexual development in IBD patients holds true only for female IBD patients with male IBD patients having similar scores in all domains to the healthy male controls.

Patients with Crohn's disease have similar autonomy development, antisocial behavior and substance use and gambling scores as patients with ulcerative colitis. However, a diagnosis of Crohn's disease appears to impair both psychosexual and social development when compared to patients with ulcerative colitis.

IBD patients that are diagnosed in childhood are more likely to still be living at home with their parents in early adulthood. Despite that fact that they are just as likely to have employment outside the home during childhood and adolescence, they are less likely to have regular chores or tasks in these same time periods. They are less likely to smoke cigarettes or consume alcohol in junior high or high school. Socially, they function similarly to their peers but they tend to be at higher risk of being suspended or expelled in junior or high school. They also tend to have delayed psychosexual development compared to those diagnosed in adulthood.

3.4.2. Developmental Milestones

The Course of Life Questionnaire has been used in young adults, age 18-30 years to assess whether groups of patients accomplish milestones in domains of autonomy, psychosexual, and social development. In a study of adolescents with chronic disease including childhood cancer, chronic kidney disease, Hirschsprung's, anorectal malformations and esophageal atresia, chronic disease patients achieved fewer milestones (or at a later age) than healthy controls in all 5 domains.[7] However, this study does not report overall mean scores for each domain. In a large Dutch study of survivors of childhood cancer, survivors had lower developmental scores for all domains compared to healthy controls with mean autonomy scores of 9.16 and 9.43, respectively.[10]

We found that IBD patients have higher autonomy development and psychosexual development scores than healthy controls, with no clear

difference in social development. The autonomy scores of both IBD patients and healthy controls in this study (8.1 and 7.7) are lower than the scores reported for healthy controls in literature from numerous Dutch studies (9.4 – 9.5)[10-12]. The psychosexual development scores of our IBD patients (6.7) are similar to those seen by Dutch survivors of childhood cancer (6.5) and patients with biliary atresia (6.5 – 7.2).[10,11] However, the psychosexual development scores of our Canadian control group (6.1) are lower than those seen in the Dutch control groups (6.1 v. 7.2).[10,11]

Comparison of this study's scores to the Dutch studies raises the question about potential cultural differences in autonomy and psychosexual development between Canada and the Netherlands. Prior to concluding that IBD patients reach milestones of autonomy and psychosexual development before healthy controls, we must consider the possibility of confounding, due to the control group having a non-comparable distribution of factors that influence psychosocial development. We attempted to adjust for potential confounders with our linear regression analysis. However, we know from our work place data that of the subset of working participants, twice as many controls as IBD patients were full-time students. The assessment of autonomy does include a question about living with your parents in which 39% v 21% controls and IBD patients indicated they still lived with their parents. However this does not explain the lower psychosexual scores of our control group.

Male IBD patients in this study are similar to healthy controls with respect to attainment of the developmental milestones of autonomy, psychosexual, and social development. However, the relatively low autonomy and psychosexual scores of our healthy control group means we should interpret these results cautiously before concluding that male IBD patients are not at risk of delayed autonomy development.

We show that female IBD patients have "better" autonomy and psychosexual development and similar social development compared to healthy controls. Sexuality of adolescents has been explored in a number of studies with concern that young female patients may be more likely have early sexual debut and be sexually active.[13] In a study of adolescents with chronic illness (not including IBD) the average age of 1st intercourse was similar between those with chronic illness and controls; however females with chronic illness were more likely to be sexually active.[13] We show that male IBD patients are similar to controls in regards to sexual activity, however female IBD patients are twice as likely have 1st sexual intercourse by age 18 than healthy controls (72% v. 36%). In a survey of female high school students in the US, students with a physical disability or long-term health problem were more than twice as likely report having been physically forced to have sexual intercourse.[14] This study does not ask about whether the sexual behavior is consensual, and so we must consider the possibility of non-consensual sexual activity in this population.

Generally, it is believed that Crohn's is a worse disease than ulcerative colitis, however little is known about the differences in the impact of the type of IBD on the milestone development. Patients with Crohn's disease have lower psychosexual and social development scores than ulcerative colitis patients. However, autonomy development is not notably different between Crohn's disease and ulcerative colitis patients. Patients with Crohn's disease were just as likely as UC patients to spend leisure time mainly with friends in elementary school but were less likely to do so in high school. This suggests that having Crohn's may have a more significant impact socially in adolescence than childhood.

Younger age of diagnosis is associated with lower autonomy and psychosexual development. For autonomy development only, those

diagnosed in childhood had even lower scores than those diagnosed in adolescence. In this analysis of IBD patients, patients diagnosed in adulthood serve as an internal control as you would expect that milestone development to be relatively complete prior to diagnosis. By using an internal control group within the IBD patients, we minimize of the potential of confounding in interpreting our results.

Patients diagnosed in childhood and adolescence were less likely to have regular chores at home in both elementary and junior/senior high school but just as likely to have paid jobs. This suggests that patients with IBD may not be able to participate in both activities inside and outside the home, either due to perception of their abilities or actual ability. Patients diagnosed younger are more likely to live with their parents than those diagnosed later with up to 40% of childhood diagnosed IBD patients still living with their parents.

3.4.3. High Risk Behavior

The Course of Life Questionnaire assesses high-risk behavior in terms of anti-social behavior and substance use and gambling. Survivors of childhood cancer had significantly lower anti-social scores than healthy controls.[10] Having a diagnosis of IBD was not associated with a change in the anti-social development score. While female gender was associated with a lower anti-social score, there were no differences when male or female IBD patients were compared to healthy controls of the same gender.

In regards to patients with IBD, neither type of IBD or age of diagnosis was associated with a change in anti-social behavior score. The only difference seen was a trend toward patients diagnosed under 18 being more likely to be suspended or expelled in high school for misbehavior (25% v. 14%, p=0.06).

A diagnosis of IBD was not associated with an increase or decrease in substance use and gambling, after adjusting for age, gender, and post-

secondary training. Male IBD participants had similar substance use and gambling scores as the male controls. However, 53% male IBD patients said they used soft drugs (marijuana/hashish) after high school compared to 30% controls. Cannabis use is known to be common in patients with IBD, with approximately 50% IBD patients reporting lifetime use.[15] Females with IBD had higher substance use and gambling score compared to healthy controls. Female IBD patients were more likely to report drinking alcohol "often" or "very often" in junior or high school. In regards to cannabis use, 38% used cannabis in junior or high school compared to 25% female controls; this difference was not seen after high school as more controls used cannabis then with similar percentage of IBD patients. Female IBD patients also differed from controls in regards to smoking in junior or high school; 1/3 female IBD patients said they smoked which is twice that of healthy controls.

Neither type of IBD or age of diagnosis was associated with substance use and gambling mean overall score. As seen in the literature, cannabis use was similar in Crohn's disease and UC patients.[15] There was no difference in smoking rates between Crohn's and UC patients, however more IBD patients diagnosed in adulthood smoked cigarettes in junior or high school.

3.4.4. Summary

In summary using the Course of Life questionnaire, we have identified that patients with Crohn's disease were more at risk for delayed psychosexual and social development, but are not more likely to engage in high-risk behaviors or have delayed autonomy development when compared to UC patients. A younger age of diagnosis was associated with slower attainment of milestones in the domains of autonomy and psychosexual development with no difference in social development. In regards to high risk behavior, patients diagnosed under 18 were less likely to smoke or consume alcohol but tended to be at increased risk of being suspended in school.

Overall, unlike other chronic illness and childhood cancer, a diagnosis of IBD was not associated with delayed development compared to healthy controls. However, we cannot rule out a confounding variable since the autonomy and psychosexual scores were lower than reported in the literature. It is possible that this difference may reflect a cultural difference in development, as all the published studies to date are based on a Dutch population.

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4. Depression in Young Adults with Inflammatory Bowel Disease

4.1. Background

Chronic medical illnesses, like inflammatory bowel disease (IBD) are known to be associated with higher levels of depression.[1] Depression levels of IBD patients have been shown to be higher than the general population, but lower than patients with chronic liver disease.[2] Depression and anxiety are common in patients with inflammatory bowel disease and increased during periods of active disease.[1] In a study of structured interviews to assess depression in IBD patients, there were no differences in rates of depression between patients with Crohn's disease (CD) and ulcerative colitis.[3] Corticosteroids are known to cause depressive symptoms and are also often used to induce remission patients with active IBD. It is therefore important to consider the potential role that steroids may play in causing depression in patients with IBD. It is important to understand that corticosteroids should not be seen as a confounding variable and adjusted for in the analysis. Rather, since they are used to treat active IBD, the depression associated with corticosteroids is also part of the overall disease process.

Adults with IBD are known to have higher rates of depression and anxiety compared to healthy controls.[1,4-6] In a meta-analysis of psychosocial adjustment of adolescents with IBD, youths with IBD were at higher risk of depressive disorders but were similar to healthy youth and youth with other chronic illness in terms of depressive symptoms.[7] In a study of youths with inflammatory bowel disease, diagnosis at a later age was associated with higher rates of depression. Furthermore, disease severity, use of corticosteroids was correlated with higher rates of a positive depression screen.[8]

It is often difficult to accurately measure depression in medical illness. This is in part due to illness causing somatic or vegetative symptoms that are also seen in depression. Furthermore, symptoms of depression may also be viewed as a "normal" reaction to medical illness.[9] While previous studies have claimed that depression symptom scores that include somatic symptoms sometimes over estimate depression in medical illness, a recent study in acute myocardial infarction patients did not find this to be true.[10]

4.2. Methods

To assess depression, IBD patients and healthy controls were given the Beck Depression Inventory–II. In order to assess the association of depression and health related quality of life HRQOL, IBD patients were given an IBD-specific HRQOL questionnaire.

4.2.1. Beck Depression Inventory–II Questionnaire

The Beck Depression Inventory–II (BDI-II) is a 21 question patient-administered questionnaire that was created by Dr. Aaron Beck (Appendix 2). This version was published in 1996. It is designed for use in persons 13 years of age and older. It is a valid and reliable tool for assessing depression in non-psychiatric populations.[11,12] Each of the 21 multiple-choice questions contains 4 statements scored 0-3; higher scores in indicate higher symptom severity. Scores are based upon how the participant has been feeling over the past 2 weeks.

4.2.1.1. Overall scores

The range of possible scores for the BDI-II is 0-63. The BDI-II scores are categorized in regards to levels of depression; minimal (0-13), mild (14-19), moderate (20-28) and severe (29-63).[13] BDI-II scores <4 have been used in previous studies as a cut-off for very low symptoms.[14]

4.2.1.2. Somatic and cognitive sub-scores

A number of different models for evaluating the BDI-II have been examined in the literature, which divide it into the cognitive and somatic symptoms of depression.[14] The model chosen for this paper is described by Thomas *et al* in which BDI-II items 1-14 (sadness, pessimism, past failure, loss of pleasure, guilty feelings, self-dislike, self-criticalness, suicidal ideation, crying, agitation, loss of interest, indecisiveness, and worthlessness) are summed to create a cognitive/affective score. BDI-II items 15-21 (loss of energy, sleep problems, irritability, appetite problems, concentration, fatigue, and loss of interest in sex) are summed to create a somatic symptom score.[10]

4.2.1.3. Participant safety

As required but the University of Alberta Heath Research Ethics Board, all participants were contacted in person or by letter if they had a BDI-II score of 29 or greater, indicating severe depression. Participants were encouraged to see their family practitioner or refer themselves to an outpatient self-referral psychiatric clinic in the city.

4.2.2. Short Inflammatory Bowel Disease Questionnaire

The Short Inflammatory Bowel Disease Questionnaire (SIBDQ) was also administered to IBD patients (Appendix 3). This is a 10-item health related quality of life questionnaire (HRQOL) specific to inflammatory bowel disease (Irvine 2006). Each question is reported on a 7-point scale (1=poor HRQOL; 7=optimal HRQOL); therefore higher scores correspond to better HRQOL. Respondents are asked to respond to the questions on the basis of how they felt over the last 2 weeks. Two of the 10 questions overlap with the BDI-II as they ask about fatigue and depression/discouragement.

4.2.3. *Statistical Analysis*

Independent sample t-tests were used to determine statistical significance between BDI-II and SIBDQ scores. Data is reported as mean scores ± standard error (SE). Differences in mean scores, along with 95% confidence intervals (CI) are reported alongside p-values to highlight differences. Differences in proportions are determined using the Chi-squared tests; results are reported with the X^2(df,n)=statistic and p-value. The association between BDI-II and SIBDQ scores was determined using linear regression analysis. SPSS (version 19) was used for statistical analysis; graphs were created using Microsoft Office Excel.

4.3. Results

4.3.1. *IBD Patients and Healthy Controls*

4.3.1.1. Beck Depression Inventory-II scores

IBD patients had higher mean BDI-II scores compared to healthy controls (9.2 v. 6.0, difference in means = 3.18, [1.31, 5.05], p=0.001). Fewer IBD patients had "very low" BDI-II scores (<4) than healthy controls (27.0% v. 48.1%, X^2(1, 304)=13.5, p<0.001). Sub-score analysis found that IBD patients had both higher cognitive (4.8 v. 3.5, p=0.04) and somatic scores (4.4 v. 2.5, p<0.001) compared to healthy controls, although the difference in means was greater for somatic symptoms (1.87, [1.11, 2.63]) than for cognitive symptoms (1.31, [0.04, 2.58]). Detailed data for the BDI-II scores for IBD patients and healthy controls are shown in Table 4.1. Only 5.4% (11/204) IBD patients were on corticosteroids at the time of the study. The overall BDI-II score was slightly higher in IBD patients on corticosteroids (9.8 v. 9.2. difference in means = 0.66, [-4.31, 5.63], p=0.79). However, the overall mean score is unchanged with those patients on corticosteroids removed.

4.3.1.2. Depression and marital status

The IBD and control groups were found to be different in regards to marital status; therefore results are presented for married/living together and single subgroups. The 5 participants that were divorced or did not indicate marital status were excluded. There was a trend toward lower overall BDI-II (8.6 v. 6.4, difference in means = 2.23, [-1.61, 6.08], p=0.25), cognitive (4.2 v. 3.3, difference in means = 0.91, [-1.56, 3.37], p=0.47 and somatic (4.4 v. 3.1, difference in means = 1.33, [-0.31, 2.97], p=0.11) sub-scores in the married participants, but these did not reach statistical significance. This is likely due to a lack of power with only 22 married healthy controls in the study. The depression scores (9.6 v. 6.0, difference in means = 3.62, [1.35, 5.88], p=0.002) and cognitive (5.2 v. 3.6, difference in means = 1.62, [0.05, 3.20], p=0.04) and somatic (4.4 v. 2.4, difference in means = 1.99, [1.11, 2.87], p<0.001) sub-scores were significantly higher in the single IBD group when compared to the single healthy controls.

Table 4.1. Beck Depression Inventory-II scores of the IBD and control groups

Characteristic	**IBD** (mean ± SE)	**Control** (mean ± SE)	**Difference in means** (95% CI)	**p-value**
n	200	104	-	-
Overall BDI-II	9.2 ± 0.57	6.0 ± 0.73	3.18 (1.31, 5.05)	0.001
Cognitive	4.8 ± 0.39	3.5 ± 0.49	1.31 (0.04, 2.58)	0.04
Somatic	4.4 ± 0.23	2.5 ± 0.28	1.87 (1.11, 2.63)	0.0000018
BDI-II < 4 (n; %)	54 (27.0%)	50 (48.1%)	-	0.0003

Married only (n)	84	22	-	-
Overall BDI-II	8.6 ± 0.90	6.4 ± 1.52	2.23 (-1.61, 6.08)	0.25
Cognitive	4.2 ± 0.58	3.3 ± 0.98	0.91 (-1.56, 3.37)	0.47
Somatic	4.4 ± 0.39	3.1 ± 0.65	1.33 (-0.31, 2.97)	0.11
Single only (n)	113	80		
Overall BDI-II	9.6 ± 0.75	6.0 ± 0.85	3.62 (1.36, 5.88)	0.002
Cognitive	5.2 ± 0.54	3.6 ± 0.58	1.62 (0.05, 3.20)	0.04
Somatic	4.4 ± 0.30	2.4 ± 0.32	1.99 (1.11, 2.87)	0.00001

When the data of the IBD and control groups were combined, the mean BDI-II score of married and single participants combined were identical (8.1 ± 0.79 v. 8.1 ± 0.58, difference in means = 0.04, [-1.87, 1.95], p=0.968); however in married participants this was equally determined by somatic (4.1 ± 0.34) and cognitive (4.0 ± 0.05) components, while in single participants ~55% was from cognitive (4.5 ± 0.40) and 45% from somatic (3.5 ± 0.23) symptoms.

4.3.1.3. Level of depression for IBD and control groups

The groups were also different in regards to the levels of depression (Table 4.2), with IBD groups having more mild (11.5% v. 1.9%), moderate (8.0% v. 5.8%) and severe depression (3.5% v. 1.9%, $X^2(3, 304)=10.2$, p=0.02) than healthy controls.

Table 4.2 Proportion of IBD and control participants with each level of depression

Level of Depression	IBD	Control
n	200	104
Minimal (<14)	154 (77%)	94 (90.4%)
Mild (14-19)	23 (11.5%)	2 (1.9%)
Moderate (20-28)	16 (8.0%)	6 (5.8%)
Severe (29-63)	7 (3.5%)	2 (1.9%)

4.3.2. Depression and Gender

Male and female participants from each group were combined and mean BDI-II total (7.8 v. 8.3, difference in means = 0.57, [-1.29, 2.43], p=0.55) and cognitive (4.2 v. 4.5, difference in means = 0.29, [-0.96, 1.54], p=0.65) and somatic (3.6 v. 3.9, difference in means = 0.28, [-0.49, 1.04], p=0.47) sub-scores; along with rates of very low depression scores (34.5% v. 34.0%, (X^2[1, 304]=0.01, p=0.94) were similar. The results are shown in Table 4.3. There was a trend toward higher scores in females but this was not statistically different.

Table 4.3. Beck Depression Inventory-II scores for all participants, by gender

Characteristic	Male (mean ± SE)	Female (mean ± SE)	Difference in means (95% CI)	p-value
n	116	188	-	-
Overall BDI-II	7.8 ± 0.72	8.3 ± 0.59	0.57 (-1.29, 2.43)	0.55
Cognitive	4.2 ± 0.50	4.5 ± 0.39	0.29 (-0.96, 1.54)	0.65
Somatic	3.6 ± 0.31	3.9 ± 0.24	0.28	0.47

			(-0.49, 1.04)	
BDI-II < 4 (n; %)	40 (34.5%)	64 (34.0%)	-	0.94

4.3.3. IBD Patients Alone

While the numerical value of the mean BDI-II scores and subscores are higher in female IBD patients, the confidence intervals are large and so significant differences are not seen (Table 4.4). The mean BDI-II scores were similar between male and female IBD patients (8.5 v. 9.7, difference in mean = 1.24, [-1.08, 3.56], p=0.29. Cognitive and somatic subscores were also similar between male and female IBD patients (4.5 v. 5.0, difference in means = 0.51, [-1.08, 2.09], p=0.53, 4.0 v. 4.7, difference in means = 0.73, [-0.21, 1.68], p=0.13). The proportion of male and female IBD patients with very-low BDI-II scores are similar (37.0% v. 40.0%, X^2[1, 199]=0.1, p=0.70).

Table 4.4. Beck Depression Inventory-II scores for IBD participants only, by gender

Characteristic	**Male** (mean ± SE)	**Female** (mean ± SE)	**Difference in means** (95% CI)	**p-value**
n	78	121	-	-
Overall BDI-II	8.5 ± 0.79	9.7 ± 0.80	1.24 (-1.08, 3.56)	0.29
Cognitive	4.5 ± 0.57	5.0 ± 0.53	0.51 (-1.08, 2.09)	0.53
Somatic	4.0 ± 0.36	4.7 ± 0.31	0.73 (-0.21, 1.68)	0.13
BDI-II < 4	20 (37.0%)	58 (40.0%)	-	0.70

(n; %)				

4.3.3.1. Beck Depression Inventory-II and SIBDQ scores

The association of mean BDI-II scores and SIBDQ score is depicted in Figure 4.1. The BDI-II and SIBDQ scores are inversely related; higher SIBDQ scores are associated with improved HRQOL and higher BDI-II scores indicate more depressive symptoms. The average decrease in BDI-II score associated with each increase in SIBDQ is estimated to be 0.73 ± 0.072 ($t=10.2$, $p<0.001$). The SIBDQ score of patients on corticosteroids was lower than those patients not on corticosteroids (46.2 v. 52.2, difference in means = 6.0, [-0.12, 12.14], $p=0.06$).

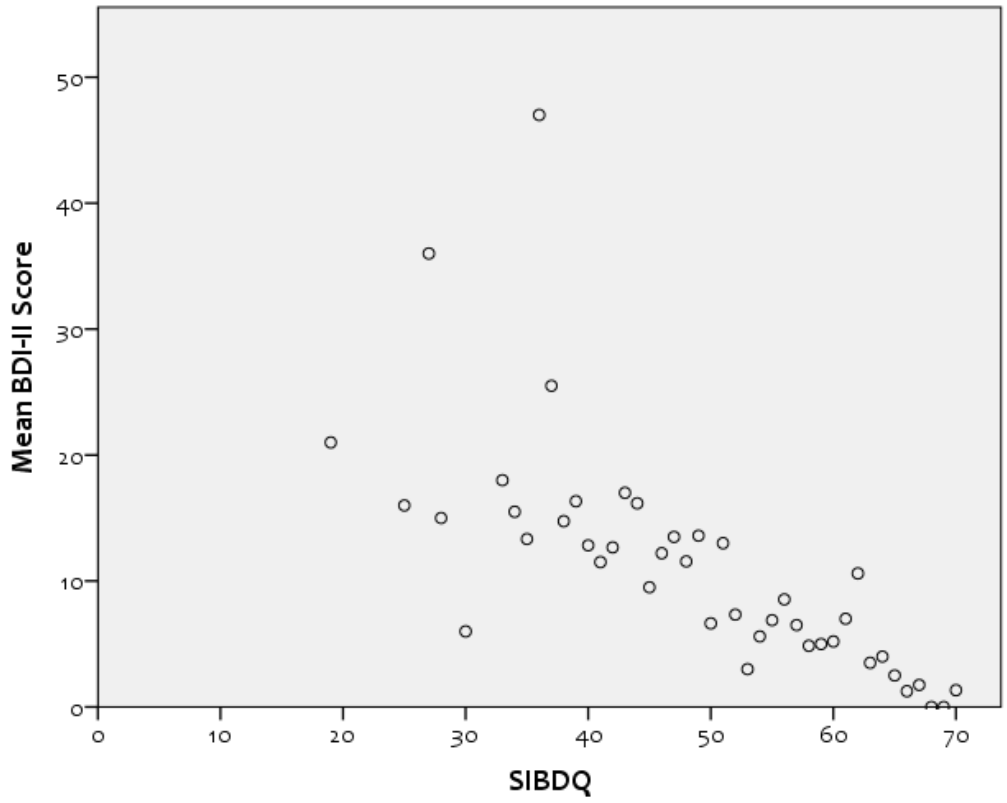


Figure 4.1 Mean Beck Depression Inventory – II score by SIBDQ score

4.3.3.2. Depression and type of IBD

The results for mean depression scores and rates of very low depression scores for patients with Crohn's disease and ulcerative colitis are shown in Table 4.5. Comparison of depression scores for patients with Crohn's disease and UC found the total BDI-II (9.2 v. 9.2, difference in mean = 0.03, [-2.33, 2.38], p=0.98), along with cognitive (4.8 v. 4.9, difference in mean = 0.08, [-1.52, 1.69], p=0.92) and somatic (4.4 v. 4.4, difference in mean = -0.59, [-10.2, 0.90], p=0.90) sub-scores to be similar. The proportion of CD and UC patients with very low BDI-II scores were similar (27.8% v. 26.0%, (X^2[1, 199]=0.1, p=0.79).

Table 4.5. Beck Depression Inventory-II scores for IBD patients by type of IBD

Characteristic	Crohn's (mean ± SE)	UC (mean ± SE)	Difference in means	p-value

			(95% CI)	
n	126	73	-	-
Overall BDI-II	9.21 ± 0.75	9.23 ± 0.90	0.03 (-2.33, 2.38)	0.98
Cognitive	4.8 ± 0.51	4.9 ± 0.60	0.08 (-1.52, 1.69)	0.92
Somatic	4.4 ± 0.30	4.4 ± 0.39	-0.59 (-1.02, 0.90)	0.90
BDI-II < 4 (n; %)	35 (27.8%)	19 (26.0%)	-	0.79

4.3.3.3. Depression and age of diagnosis

Table 4.6 shows the BDI-II results by IBD patients by age of diagnosis. There were no differences in mean BDI-II (9.2 v. 9.2, difference in mean = -0.001, [-2.27, 2.29], p=1.00), cognitive (5.0 v. 4.6, difference in mean = 0.46, [-1.08, 2.00], p=0.56), or somatic (4.1 v. 4.6, difference in mean = -0.46, [-1.39, 0.46], p=0.33) sub-scores between the adult and pediatric diagnosed groups. The proportion of IBD patients with very low BDI-II scores (25.3% v. 28.6%, $X^2(1,200)=0.3$, p=0.60) and the various levels of depression (mild [11.6% v. 11.4%], moderate [7.4% v. 8.6%], and severe [4.2% v. 2.9%]) were similar for between those diagnosed before and after the age of 18, respectively (Tables 4.6 & 4.7). This provides evidence that level of depression in young adults (aged 18-30) is not associated with younger age of diagnosis.

Table 4.6. BDI-II scores for IBD patients by age of diagnosis

Characteristic	**Diagnosed<18** (mean ± SE)	**Diagnosed 18+** (mean ± SE)	**Difference in means** (95% CI)	**p-value**

n	95	105	-	-
Overall BDI-II	9.2 ± 0.75	9.2 ± 0.90	-0.001 (-2.27, 2.27)	1.00
Cognitive	5.0 ± 0.58	4.6 ± 0.52	0.46 (-1.08, 2.00)	0.56
Somatic	4.1 ± 0.32	4.6 ± 0.33	-0.46 (-1.39, 0.46)	0.33
BDI-II < 4 (n; %)	24 (25.3%)	30 (28.6%)	-	0.60

Table 4.7 Proportion of IBD with each level of depression by age of diagnosis

Level of Depression	Diagnosed<18	Diagnosed 18+
Minimal (<14)	73 (76.8%)	81 (77.1%)
Mild (14-19)	11 (11.6%)	12 (11.4%)
Moderate (20-28)	7 (7.4%)	9 (8.6%)
Severe (29-63)	4 (4.2%)	3 (2.9%)

4.3.4. Individual BDI-II Scores for IBD Patients and Controls

The results for the individual Beck Depression Inventory – II items for IBD patients versus controls are depicted in Figure 4.2. A score of zero represents a "normal" response with 1,2, and 3 representing increasing severity of symptoms.

4.3.4.1. Sadness

Differences were found between the IBD and control groups in sadness (X^2[2, 312]=6.0, p=0.05). More IBD patients than healthy controls indicated that were sad much or all of the time (24.5% and 2.5% v. 13.9% and 0.9%). None of the participants indicated that they were so sad that they could not stand it.

4.3.4.2. Pessimism

Approximately ¼ of IBD and control participants indicated that they were more discouraged about their future than they used to be. Five percent of IBD patients, but no controls indicated that they feel their future is hopeless and will only get worse. However, overall the IBD groups and controls are similar in regards to pessimism (X^2[3, 311]=1.6, p=0.65).

4.3.4.3. Past failure

IBD and control groups are similar in their response to questions about past failure (X^2[3, 312]=3.1, p=0.38). Approximately 75% of each group indicated that they do not feel like a failure. Slightly more IBD patients indicated that they have failed more than they should have (17.6% v. 13.0%), while slightly more controls indicated that when they looked back they saw a lot of failures (8.3% v. 6.4%).

4.3.4.4. Loss of pleasure

IBD patients tended to be more likely to indicate that they do not enjoy things as much as they used to (32.4% v. 21.3%), and more controls indicated that they get as much pleasure as they used to from things they enjoy (75.9%, v. 61.8%; X^2[3, 312]=6.8, p=0.08).

4.3.4.5. Guilty feelings

IBD patients were marginally more likely than controls said they felt guilty over many things they have done or should have done (26.0% v. 22.2%), however approximately ¾ of each group indicated that they did not feel particularly guilty (X^2[3, 312]=3.3, p=0.34).

4.3.4.6. Punishment feelings

Over 80% of both groups indicated that they do not feel like they are being punished with a few participants in each group indicating that they feel like they may be punished, expect to punished, or feel they are being punished ($X^2[3, 312]=2.9$, p=0.41).

4.3.4.7. Self-dislike

Twenty-three percent of IBD patients indicated that had lost confidence in their self compared to 9.3% of controls; more controls indicating that there was no change in how they felt about themselves (82.4% v. 70.6%; $X^2[3, 312]=8.5$, p=0.04).

4.3.4.8. Self-criticalness

IBD patients were slightly more likely to indicate that they are more critical of themselves than they used to be (26.5% v. 23.1%) or that they criticize themselves for all of their faults (8.3% v. 2.8%) than controls. Overall, the groups were similar in this area ($X^2[3, 312]=4.5$, p=0.21).

4.3.4.9. Suicidal thoughts or wishes

IBD and controls groups were similar with respect to their responses about suicidal thoughts or wishes (p=0.30). No participant indicated that they would kill themselves if they had the chance.

4.3.4.10. Crying

IBD patients were more likely to indicate that they cry more than they used to (19.6% v. 11.1%), cry over every little thing (4.4% v. 1.9%), or feel like crying but be unable to (2.0% v. 0%) than healthy controls ($X^2[3, 312]=8.0$, p=0.05).

4.3.4.11. Agitation

While IBD and controls had similar responses to the question about agitation, slightly more IBD patients indicated that they were more restless or wound up than usual (34.7% v. 25.5%) or they were so restless or agitated that it is difficult to stay still (4.5% v. 1.9%; $X^2[3, 308]=5.7$, p=0.13).

4.3.4.12. Loss of interest

IBD and control participants were similar in regards to their interest in people or things ($X^2[3, 308]=5.3$, p=0.15). However, IBD were slightly more likely to indicate that they were less interested than before (29.7% v. 19.8%) or had lost most of their interest in other people or things (5.4% v. 2.8%).

4.3.4.13. Indecisiveness

Almost 80% of IBD and control participants indicated that they make decisions as well as ever, with similar proportions of each group indicating that they found it more difficult to make decisions (18.8% v. 16.0%), have much greater difficulty in making decisions (4.5% v. 3.8%), or have trouble making any decisions (1.0% v. 1.9%; $X^2[3, 308]=0.9$, p=0.83).

4.3.4.14. Worthlessness

Approximately 80% of IBD and controls indicated that they do not feel they are worthless. However slightly more IBD patients indicated that they do not consider themselves to be as worthwhile as before (12.9% v. 6.6%) while slightly more controls indicated that they feel more worthless than others (7.5% v. 4.5%) or feel utterly worthless (1.0% v. 0%; $X^2[3, 308]=4.9$, p=0.18).

4.3.4.15. Loss of energy

IBD patients and controls are markedly different in regards to energy ($X^2[3, 308]=34.7$, p<0.001). While 67.9% of controls indicate that they have as much

energy as ever, only 33.2% of IBD patients chose this response. Fifty-seven percent of IBD patients indicated that they have less energy than they used to have compared to only 28.3% of controls.

4.3.4.16. Changes in sleeping pattern

Differences were found between the IBD and control groups in changes in sleeping pattern (X^2[6, 308]=12.7, p=0.048). IBD patients are more likely than controls to report they sleep a lot more (7.4% v. 1.9%) or a lot less (8.9% v. 3.8%) than usual. IBD patients are more likely to report they sleep a little more (20.8% v. 15.1%), while controls are more likely to report they sleep a little less (26.4% v. 18.8%).

4.3.4.17. Irritability

IBD patients were more likely to report irritability than healthy controls (X^2[3, 308]=9.4, p=0.02). Thirty-five percent of IBD patients indicated that they are more irritable than usual, compared to just 19.8% of controls.

4.3.4.18. Changes in appetite

Differences were found between the IBD and control groups in changes in appetite (X^2[6, 306]=22.4, p=0.001). Seventy-two percent of control participants indicated they have not experienced a change in their appetite, compared to just 49.0% of IBD patients. Twenty-five percent of IBD patients indicated that their appetite is somewhat less than usual, compared to just 8.5% of controls. While no controls indicated that they crave food all the time, 4.0% of IBD patients chose this response.

4.3.4.19. Concentration difficulty

IBD patients were slightly more likely to indicate that they can't concentrate as well as usual (29.7% v. 18.1%), while controls were more likely to indicate that they can concentrate as well as ever (74.3% v. 64.9%; X^2[3, 307]=6.6, p=0.09).

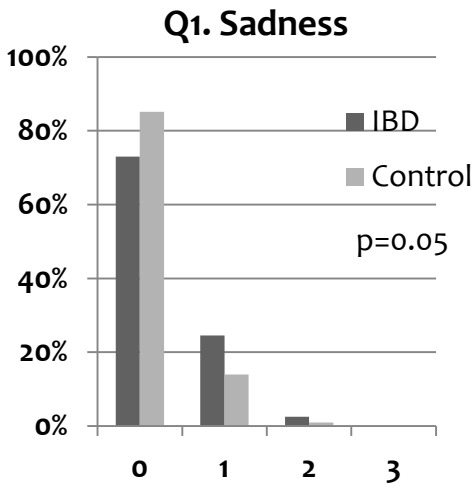
4.3.4.20. Tiredness or fatigue

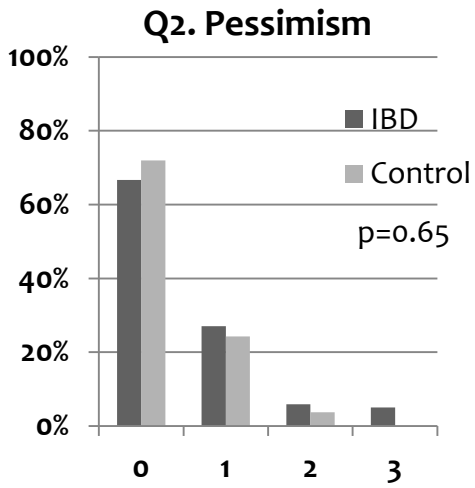
Differences were found between the IBD and control groups in tiredness or fatigue (X^2[3, 308]=18.4). Sixty percent of controls indicated that they were no more tired or fatigued than usual, compared to just 35.6% of IBD patients. More IBD patients than controls indicated that they get tired or fatigued more easily than usual (52.0% v. 34.0%), are too tired or fatigued to do a lot or most of the things they used to do (10.4% and 2.0% v. 5.7% and 0%).

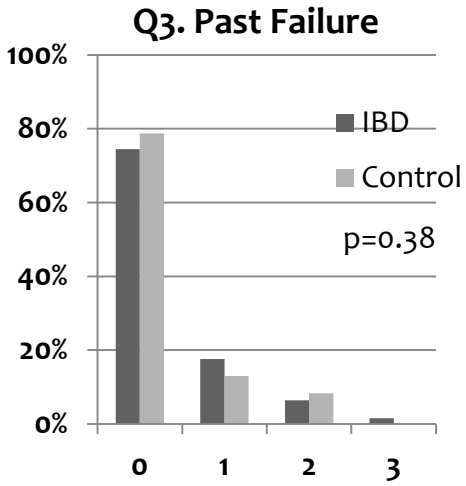
4.3.4.21. Loss of interest in sex

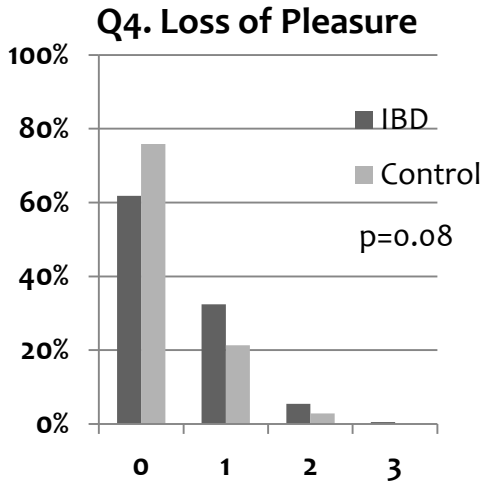
Eighty-six percent of healthy controls indicated that they had not noticed any recent change in their interest in sex, compared to just 66.3% of IBD patients (X^2[3, 308]=14.1, p=0.003). More IBD patients than controls indicated that they are less interested or much less interested in sex than they used to be (24.8% and 6.9% v. 11.3% and 2.8%). Two percent of IBD patients indicated that they had lost interest in sex completely.

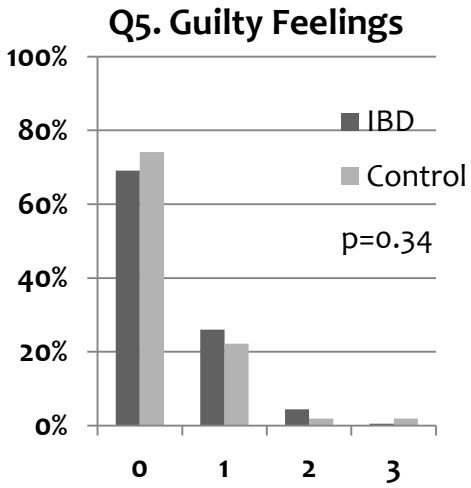
The majority of differences are found in the somatic-type symptoms and a minority in the cognitive symptoms, demonstrating an emphasis in somatic symptoms in using the BDI-II to identify depression in IBD patients.

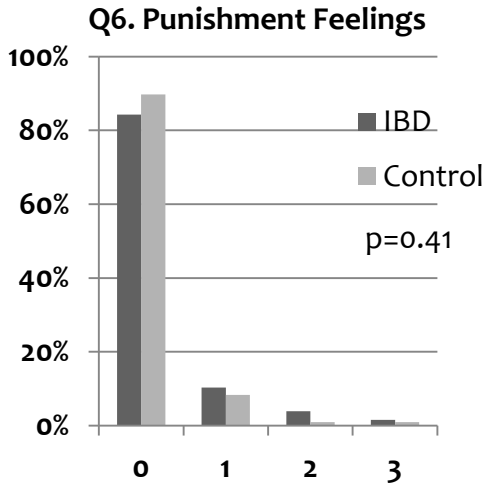

Q1. Sadness
100%
80%
60%
40%
20%
0%
0
1
2
3
IBD
Control
p=0.05

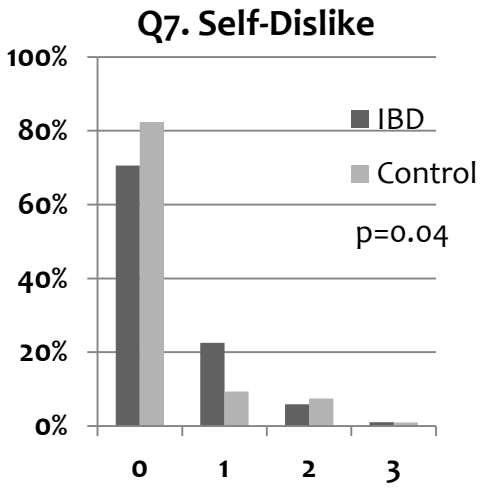

Q2. Pessimism
100%
80%
60%
40%
20%
0%
0
1
2
3
IBD
Control
p=0.65

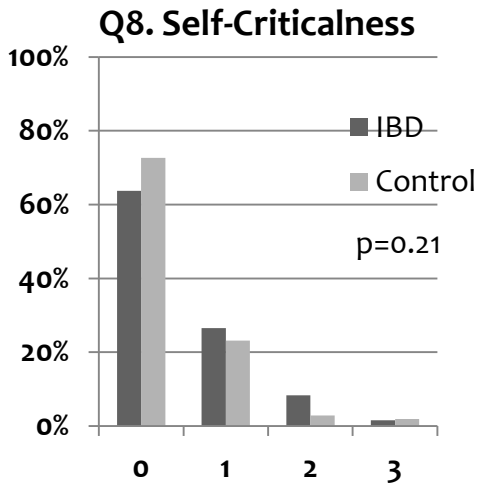

Q3. Past Failure
100%
80%
60%
40%
20%
0%
0
1
2
3
IBD
Control
p=0.38

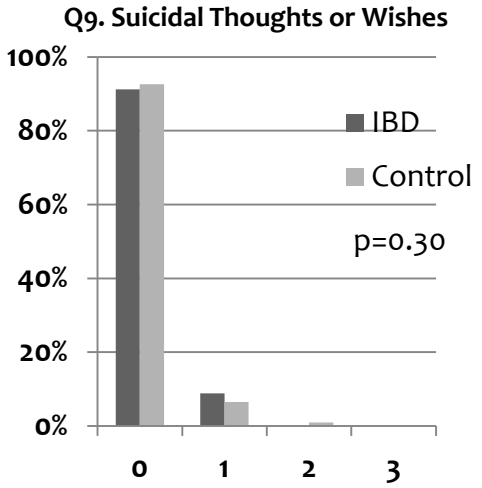

Q4. Loss of Pleasure
100%
80%
60%
40%
20%
0%
0
1
2
3
IBD
Control
p=0.08

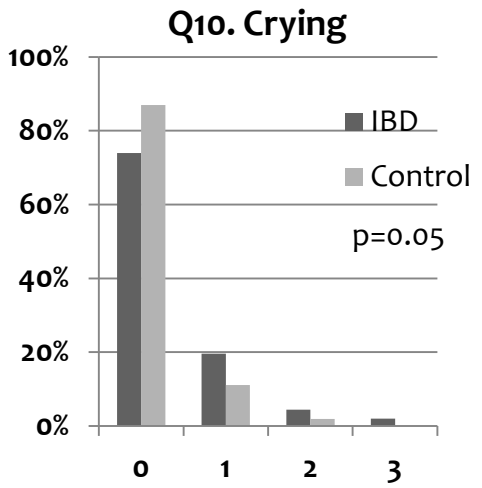

Q5. Guilty Feelings
100%
80%
60%
40%
20%
0%
0
1
2
3
IBD
Control
p=0.34

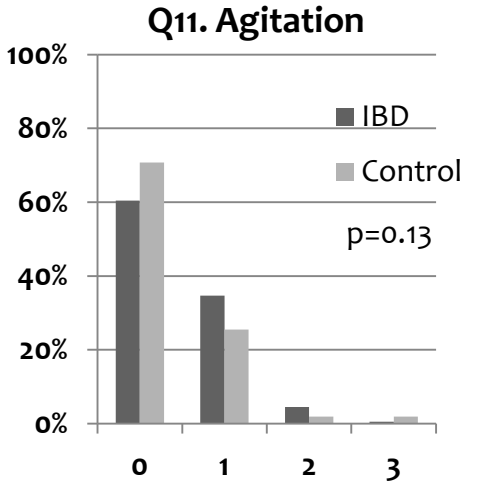

Q6. Punishment Feelings
100%
80%
60%
40%
20%
0%
0
1
2
3
IBD
Control
p=0.41

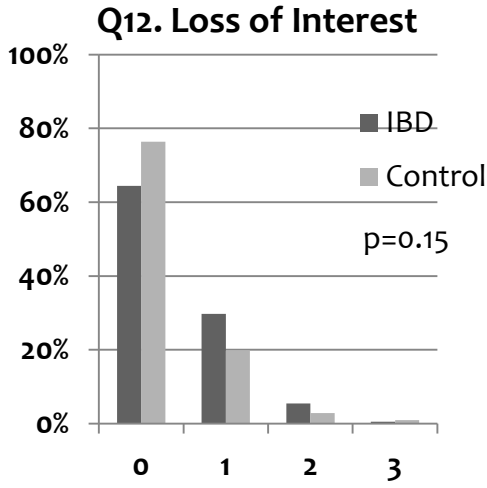

Q7. Self-Dislike
100%
80%
60%
40%
20%
0%
0
1
2
3
IBD
Control
p=0.04

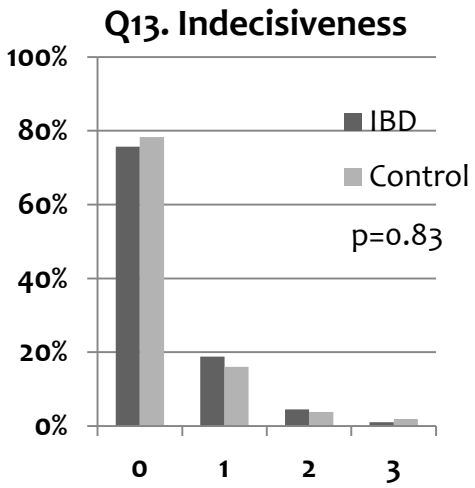

Q8. Self-Criticalness
100%
80%
60%
40%
20%
0%
0
1
2
3
IBD
Control
p=0.21

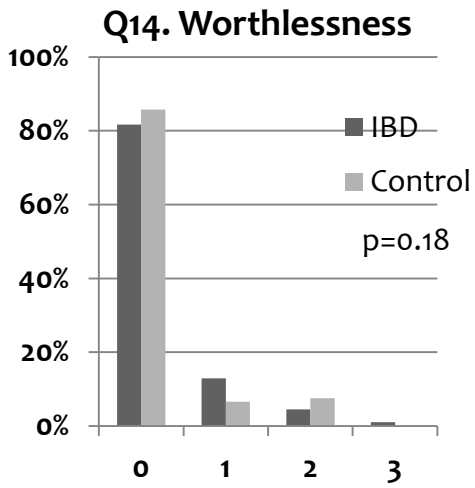

Q9. Suicidal Thoughts or Wishes
100%
80%
60%
40%
20%
0%
0
1
2
3
IBD
Control
p=0.30

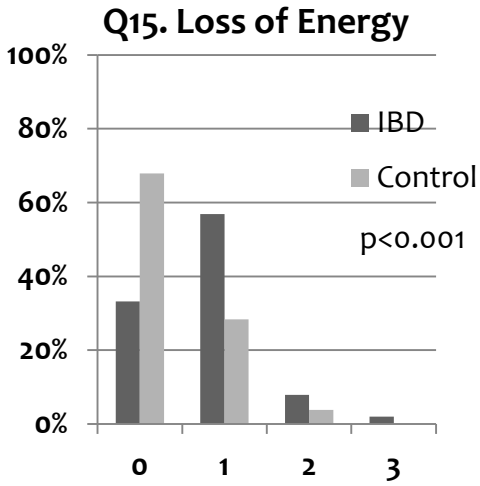

Q10. Crying
100%
80%
60%
40%
20%
0%
0
1
2
3
IBD
Control
p=0.05

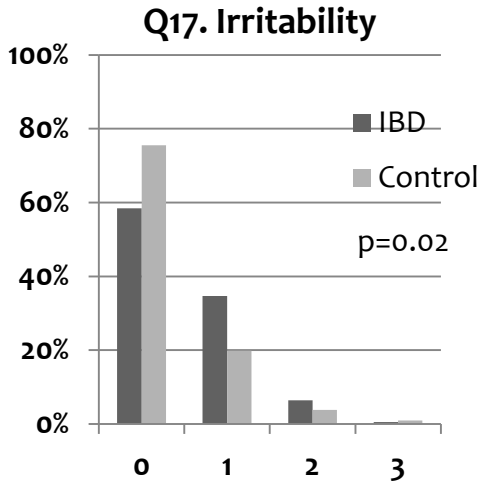

Q11. Agitation
100%
80%
60%
40%
20%
0%
0
1
2
3
IBD
Control
p=0.13

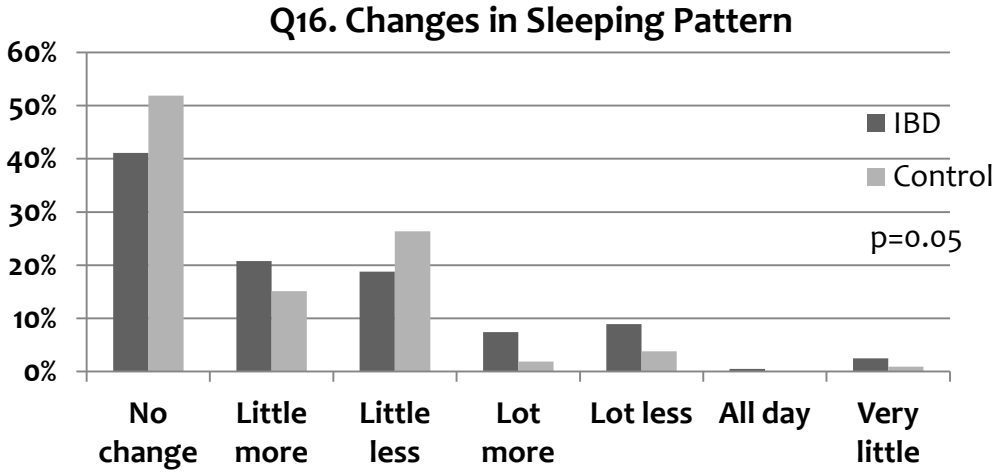

Q12. Loss of Interest
100%
80%
60%
40%
20%
0%
0
1
2
3
IBD
Control
p=0.15

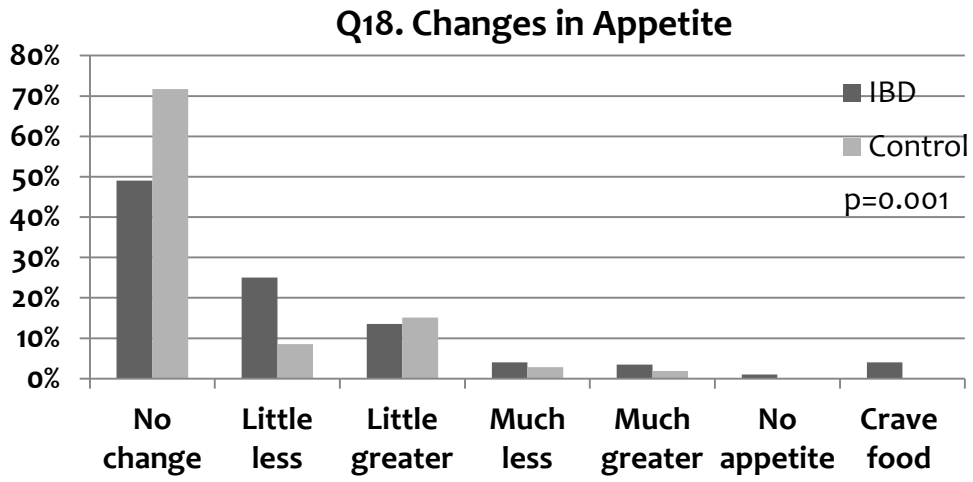

Q13. Indecisiveness
100%
80%
60%
40%
20%
0%
0
1
2
3
IBD
Control
p=0.83

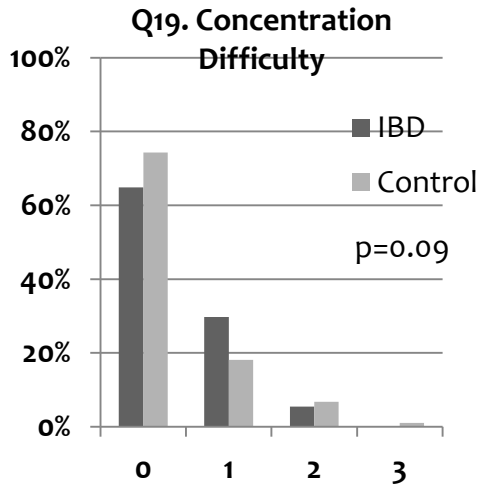

Q14. Worthlessness
100%
80%
60%
40%
20%
0%
0
1
2
3
IBD
Control
p=0.18

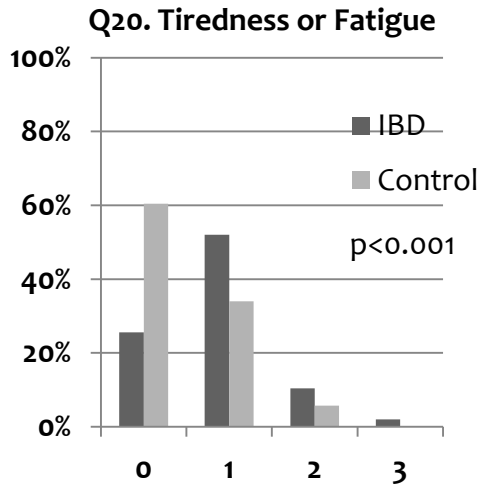

Q15. Loss of Energy
100%
80%
60%
40%
20%
0%
0
1
2
3
IBD
Control
p<0.001


Q17. Irritability
100%
80%
60%
40%
20%
0%
0
1
2
3
IBD
Control
p=0.02


Q16. Changes in Sleeping Pattern
60%
50%
40%
30%
20%
10%
0%
No change
Little more
Little less
Lot more
Lot less
All day
Very little
IBD
Control
p=0.05


Q18. Changes in Appetite
80%
70%
60%
50%
40%
30%
20%
10%
0%
IBD
Control
p=0.001
No change
Little less
Little greater
Much less
Much greater
No appetite
Crave food


Q19. Concentration Difficulty
100%
80%
60%
40%
20%
0%
IBD
Control
p=0.09
0
1
2
3


Q20. Tiredness or Fatigue
100%
80%
60%
40%
20%
0%
IBD
Control
p<0.001
0
1
2
3

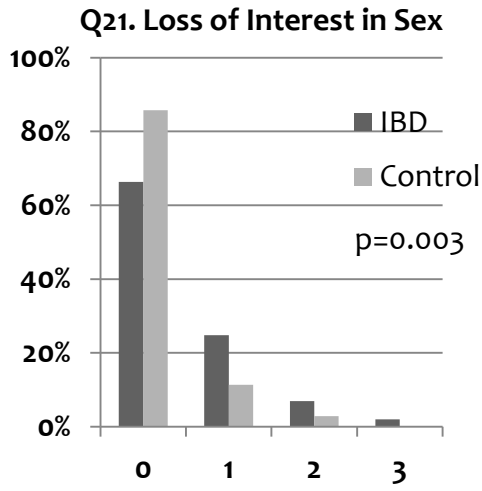

Q21. Loss of Interest in Sex
100%
80%
60%
40%
20%
0%
IBD
Control
p=0.003
0
1
2
3

Figure 4.2. Responses to individual BDI-II questions for IBD patients and healthy controls

4.4. Discussion

4.4.1. Overall Depression Scores

This study shows that IBD patients, aged 18-30 years have increased levels and rates of depression compared to healthy controls when assessed by the self-administered Beck Depression Inventory-II. While both cognitive/affective and somatic sub-scores are higher in IBD patients, there is a greater difference in mean in the somatic symptoms. Previous studies have shown that in patients with Crohn's disease, active disease is associated with fatigue, depression, and sleep disturbance.[16] In this study of IBD patients with both active and inactive disease, only 25.6% of IBD patients reported no tiredness or fatigue compared to 60.4% of healthy controls. A change in sleeping pattern was reported by nearly 60% of IBD patients. Current corticosteroid use was seen in only 5.4% of IBD patients; therefore the higher depression scores were not driven by corticosteroids use.

In studies of adolescents with IBD, a later diagnosis of IBD has been shown to be associated with higher rates of depression.[8] We found no difference in depression in early adulthood between those diagnosed before and after age 18. This does study did not assess depression in the period following diagnosis, and patients diagnosed earlier may have experienced more depression at that time.

No differences were seen in depression between patients with Crohn's disease and ulcerative colitis. This finding is in keeping with what has previously been reported in the literature.[3,17] Gender differences in depression have previously been described. In adolescents with IBD, girls had more emotional, anxious/depressed symptoms, and somatic complaints compared

to boys.[17] In our study, depression scores were not different between male and female IBD patients, however the value of the female scores were higher.

4.4.2. Individual Beck Depression Inventory-II Questions

In the cognitive/affective portion of the BDI-II, IBD patients are quite similar to healthy controls for the majority of the questions. However, IBD patients report more sadness, self-dislike, and crying than healthy controls. There is also a trend toward IBD patients reporting a lack of enjoyment in things they used to enjoy.

The somatic portion of the BDI-II contains 7 questions. In virtually all of the somatic symptoms, IBD patients had more depressive symptoms than healthy controls. This includes a loss in energy, irritability, tiredness or fatigue, changes in sleeping patterns and appetite, concentration difficulty, and loss of interest in sex. Symptoms like loss in energy and fatigue may be explained by anemia associated with IBD or an inflammatory state. A change in appetite may also be seen in patients with IBD depending on their disease location or severity. Irritability and concentration difficulty are not easily explained by IBD symptoms.

4.4.3. Summary

In summary, this study demonstrates that with the Beck Depression Inventory-II as a tool to measure depression, IBD patients have more depression than healthy controls. The majority of the differences between IBD patients and healthy controls are due to somatic symptoms. However, differences between the groups in terms of cognitive-type depressive symptoms were also seen, suggesting that the differences in depression are not only due to somatic symptoms and disease-associated changes. The differences between IBD and control groups were not significant in married participants, but the trend toward higher scores in married IBD patients was

still seen. No differences were seen in depression in early adulthood in IBD patients based upon type of IBD or age of diagnosis. Higher BDI-II scores are associated with lower SIBDQ scores in IBD patients, indicating that depression is associated with poorer HRQOL in patients with IBD.

4.5. References

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5. Workplace Performance in Young Adults with Inflammatory Bowel Disease

5.1. Background

Workplace performance is an important component of health care outcomes and has an enormous impact on society as a whole. The consequence of illness leading to absences and poor performance in the work place has a huge economic impact and needs to taken into account as an important factor in the treatment of illness. It has been reported that depression in the United States cost an estimated $51.5 billion in workplace costs alone in the year 2000; workplace costs represent 59% of the overall costs attributed to depression.[1] In the US, pediatric inpatient IBD care costs an estimated $152.4 million in medical costs alone.[2] Using a labor force participation model, the estimated annual costs of IBD associated with work loss were $3.6 billion in the US in 1998.[3]

In the Manitoba IBD Cohort study, patients with IBD were just as likely to be employed as the non-IBD cohort but 3x more participants reported reduced activity compared to the community sample.[4] In a study of Finnish adult IBD patients, 27% of employed IBD patients indicated that they had missed work in the last year due to their IBD, with women missing more work than men.[5] No differences were seen between Crohn's disease and UC patients in absenteeism.[5] The majority of patients that missed work, missed between 1 and 5 days, however 2.2% missed >30 days in the last year.[5]

Loss in productivity and costs to society are incurred by both absences (absenteeism) and due to persons not working effectively (presenteeism). In a cost-analysis study of the direct and indirect costs of IBD on employer-sponsored health insurance, UC patients but not Crohn's disease patients had higher costs associated with absenteeism when compared to matched

controls .[6] Both CD and UC patients had higher short-term disability costs compared to matched controls; those diagnosed with IBD were 2.5X more likely to receive short-term disability in the 1st year after diagnosis.[6]

Disease remission for both Crohn's disease and ulcerative colitis leads to improvements in employment and workplace productivity. In unemployed patients who entered the ACCENT I trial, a maintenance study of infliximab in patients with Crohn's disease, 31% of the patients who were in clinical remission at week 54 were employed compared to just 16% of those not in clinical remission.[7] However, unemployment rate of patients entering this study was a staggering 38.4%, providing evidence of the negative impact of moderate to severe Crohn's disease on quality of life and ability to function in society.[7] In a meta-analysis of studies of patients with Crohn's disease, employed patients treated with adalimumab had improvements in absenteeism, presenteeism, and workplace productivity, with improvements seen as early as 4 weeks.[8] Employment and disability status has been examined in adults with ulcerative colitis with infliximab-induced remission; in this study remission was associated with increase in productivity, higher employment rates and less disability compensation.[9]

The impact of IBD on young people and school attendance and adjustment has been the focus of a few studies. In a study comparing adolescents (age 12 – 25) with IBD to other chronic gastrointestinal illnesses (celiac, chronic liver disease, food allergy and congenital disorders), IBD patients had the most absences due to illness, and along with adolescents with liver disease were less likely to have a paid job.[10] In a recent study of adolescents with IBD, IBD patients had significantly more full-day absences than healthy adolescents and poorer school functioning than healthy adolescents.[11] In a pilot study of college students with IBD, there was an inverse relationship between disease activity and adjustment to college, while overall the IBD patients were similar

to healthy controls.[12] The impact of having a pediatric diagnosis of IBD on the workplace functioning in early adulthood is not well understood.

5.2. Methods

The World Health Organization Health and Work Performance Questionnaire (HPQ) was chosen to measure workplace performance.[13] This is a self-report tool that measures the impact of health problems on job performance, absence due to sickness and work-related accidents.[14] It is reliable and valid tool.[15] To my knowledge, it has not been used previously in patients with inflammatory bowel disease. Absenteeism is reported over the past 4 weeks and time missed is reported in hours. Absolute absenteeism is calculated with the following formula:[16]

4X(hours expected to work per week) – hours worked over the past 28 days

Relative absenteeism is calculated with the following formula:

[4X(hours expected to work per week) – hours worked over the past 28 days] ÷ (4X(hours expected to work per week)

The HPQ measures work performance using a 0-10 rating scale. Participants are also asked to rate the usual performance of most workers in a similar job; this serves as an internal control and allows us to calculate a relative measure. Work performance is measured as "presenteeism" which is a measure of inadequate work performance.[15]

Absolute presenteeism is calculated by multiplying the score out of 10 for a person's overall performance by 10.

Relative presenteeims is merely a ratio their overall job performance on days that they worked divided by how they rate the overall performance of most workers in a job similar to theirs. To avoid extremes created by over- or under-estimating the performance of others, the range of values are limited

between 0.25 (meaning their performance is 25% of others) and 2.0 (meaning their job performance is 200% than of their co-workers).

5.3. Results

5.3.1. Reasons for Being Off Work

5.3.1.1. All participants

The WHO HPQ was completed and returned by 309 participants. Similar numbers of patients in the IBD patients (40/202; 19.9%) and healthy controls (18/107; 16.8%) indicated that they were not currently working (X^2[1, 309]=0.4, p=0.52). There were no differences in mean age (24.5 v. 24.4, difference in mean = 0.13, [-0.96, 1.24], p=0.81) or gender (63.8% and 61.8% were female; X^2[1, 309]=0.1, p=0.77) between those working and not working. The reasons for being off work are listed in Table 5.1. Of note, 4 IBD patients and 2 controls listed more than 1 reason for being off work; all reasons were counted. In the comments section, one patient with IBD, age 19 indicated that they were not unable to finish high school due to illness. The reasons were similar between groups with the largest differences being more controls unemployed and looking for work (15.9% v. 9.4%, X^2[1, 309]=2.9, p=0.09) and more IBD patients being on maternity leave (5.0% v. 0.9%, X^2[1, 309]=3.3, p=0.07). Two percent of IBD patients were temporarily laid off compared to no controls (X^2[1, 309]=2.1, p=0.14). The proportion of IBD and control patients that were on short-term (3.5% v. 0.9%, X^2[1, 309]=1.8, p=0.18) or extended sick leave (2.0% v. 0.9%, X^2[1, 309]=0.5, p=0.49) was similar.

Table 5.1. Proportion of participants with various reasons for currently not working

	IBD	Control	p-value
N	202	107	

Unemployed & looking for work	19 (9.4%)	17 (15.9%)	0.09
Temporarily laid off	4 (2.0%)	0 (0%)	0.14
Maternity leave	10 (5.0%)	1 (0.9%)	0.07
Short term sick leave	7 (3.5%)	1 (0.9%)	0.18
Extended sick leave or disability	4 (2.0%)	1 (0.9%)	0.49

5.3.1.2. IBD Patients by type of IBD

Within the IBD group, rates of not working similar in Crohn's and UC patients (22.5% v. 15.1%, (X^2[1, 202]=1.6, p=0.20). The average ages of the CD and UC patients were similar (24.6 v. 24.8 years, difference in mean = 0.17, [-0.99, 1.34], p=0.77). There were no differences in gender (61.2% CD patients and 60.3% UC patients were female; (X^2[1. 202]=0.02, p=0.89). Reason for IBD patients being off work are listed in Table 5.2. Similar proportions of CD and UC patients were unemployed and looking for work (10.9% v. 6.8%, X^2[1, 202]=0.9, p=0.35), temporarily laid off (0.8% v. 4.1%, X^2[1, 202]=2.7, p=0.10), or on maternity leave (4.7% v. 5.5%, X^2[1, 202]=0.1, p=0.79). In regards to sick leave or disability, more CD patients than UC patients were on short-term disability (5.4% v. 0%, X^2[1, 202]=4.1, p=0.04) and similar proportions were on long-term disability (2.3% v. 1.4%, X^2[1, 202]=0.2, p=0.64)

Table 5.2. Reasons for being off work, by IBD Diagnosis

	CD	**UC**	**p-value**
N	115	68	
Unemployed & looking for work	14 (10.9%)	5 (6.8%)	0.35
Temporarily laid off	1 (0.8%)	3 (4.1%)	0.10

Maternity leave	6 (4.7%)	4 (5.5%)	0.79
Short term sick leave	7 (5.4%)	0 (0%)	0.04
Extended sick leave or disability	3 (2.3%)	1 (1.4%)	0.64

5.3.1.3. IBD patients by age of diagnosis

IBD patients diagnosed under age 18 tended to be slightly more likely to indicate that they were not currently working compared to those diagnosed in adulthood (25.3% v 15.0%, $X^2[1, 202]=3.4$, p=0.07). Patients diagnosed under 18 were significantly younger than those diagnosed in adulthood (22.5 v. 26.7 years, difference in means = 4.2, [3.26, 5.18], $p=1.27x10^{-15}$) and less likely to be female (52.6% v. 68.2%, $X^2[1, 202]=5.1$, p=0.02). Reasons for IBD patients being off work by age of diagnosis are listed in Table 5.3. More IBD participants diagnosed under 18 years indicated that they were unemployed and looking for work (14.7% v. 4.7%, $X^2[1, 202]=6.0$, p=0.01) and tended to be less likely to be on maternity leave (2.1% v. 7.5%, $X^2[1, 202]=3.1$, p=0.08). Similar proportions of IBD patients diagnosed under 18 years or 18 years and older were temporarily laid off (2.1% v. 1.9%, $X^2[1, 202]=0.01$, p=0.90), on short-term sick leave (5.3% v. 1.9%, $X^2[1, 202]=1.7$, p=0.19), or on long-term disability (3.2% v. 0.9%, $X^2[1, 202]=1.3$, p=0.26).

Table 5.3. Reasons for being off work by age of diagnosis

	Dx < 18	**Dx 18+**	**p-value**
N	81	102	
Unemployed & looking for work	14 (14.7%)	5 (4.7%)	0.01
Temporarily laid off	2 (2.1%)	2 (1.9%)	0.90
Maternity leave	2 (2.1%)	8 (7.5%)	0.08

Short term sick leave	5 (5.3%)	2 (1.9%)	0.19
Extended sick leave or disability	3 (3.2%)	1 (0.9%)	0.26

5.3.2. *Types of Work Engaged In*

5.3.2.1. All participants

The proportion of IBD patients and healthy controls who indicated that they were involved in specific types of work is depicted in Table 5.4. Participants who indicated that they were currently off work (in the section above) were excluded from this analysis. More IBD patients than controls indicated that they were caregivers for their children (14.4% v. 4.5%, X^2[1, 248]=5.7, p=0.02), working full-time paying job (65.0% v. 52.3%, X^2[1, 248]=3.8, p=0.05). Whereas, more healthy controls indicated they are full-time students (52.4% v. 25.0%, X^2[1, 248]=20.1, p=7.27 x 10^{-6}) and involved in volunteer work (28.4% v. 13.8%, X^2[1, 248]=7.9, p=0.005) than IBD patients. Similar proportions of IBD and controls patients indicated they were working a part-time paying job (25.6% v. 33.0%, X^2[1, 248]=1.5, p=0.22), were self-employed (6.3% v. 5.7%, X^2[1, 248]=0.03, p=0.86), were a part-time student (5.6% v. 4.5%, X^2[1, 248]=-/1. P=0.72) or engaged in housework or home maintenance (63.8% v. 59.1%, X^2[1, 248]=0.5, p=0.47). The mean age of IBD patients included in this analysis was slightly higher than the controls (24.8 v. 23.9, difference in means = 0.89, [-0.07, 1.87], p=0.07). The proportion of females was similar in each group (61.3% IBD v. 64.8% controls, X^2[1, 248]=0.3, p=0.58).

Table 5.4. Proportion of participants indicating that they do various types work

	IBD	**Control**	**p-value**
N	160	88	

Caregiver for their children	23 (14.4%)	4 (4.5%)	0.02
Working full-time paying job	104 (65.0%)	46 (52.3%)	0.05
Working part-time paying job	41 (25.6%)	29 (33.0%)	0.22
Self-employed	10 (6.3%)	5 (5.7%)	0.86
Volunteer work	22 (13.8%)	25 (28.4%)	0.005
Full-time student	40 (25.0%)	47 (52.4%)	7.27×10^{-6}
Part-time student	9 (5.6%)	4 (4.5%)	0.72
Housework/home maintenance	102 (63.8%)	52 (59.1%)	0.47

5.3.2.2. IBD patients by type of IBD

The types of work engaged in by Crohn's and UC patients is shown in Table 5.5. The ages of these groups were similar (24.9 CD v. 24.7 UC, difference in means = 0.21, [-1.03, 1.46], p=0.74) as were the proportion of female participants (60.6% CD v. 62.3% UC, X^2[p=0.83). Approximately 15% of CD and UC patients were caregivers for their children (14.1% v. 14.8%, X^2[1, 160]=0.01, p=0.92). The majority of CD and UC patients indicated they were working a full-time paying job (62.6% v. 68.9%, X^2[1, 160]=0.64, p=0.42). Twenty-seven percent of CD patients and 23% of UC patients indicated that they were working a part-time job (X^2[1, 160]=0.4, p=0.54). Similar proportion of CD and UC patients, indicated that they were self-employed (5.1% v. 8.2%, X^2[1, 160]=0.6, p=0.43) or doing volunteer work (16.2% v. 9.8%, X^2[1, 160]=1.3, p=0.26). In regards to being a student, 25.3% of CD patients and 24.6% of UC patients were full-time students (X^2[1, 160]=0.01, p=0.93) and 4.0% CD patients and 8.2% of UC patients were part-time students (X^2[1, 160]=1.2, p=0.27). Slightly more CD patients than UC patients indicated that they were involved in housework or home maintenance (68.7% v. 55.7%, X^2[1, 160]=2.7, p=0.10).

Table 5.5. Types of work of IBD patients, by type of IBD

	CD	UC	p-value
N	99	61	
Caregiver for their children	14 (14.1%)	9 (14.8%)	0.92
Working full-time paying job	62 (62.6%)	42 (68.9%)	0.42
Working part-time paying job	27 (27.3%)	14 (23.0%)	0.54
Self-employed	5 (5.1%)	5 (8.2%)	0.43
Volunteer work	16 (16.2%)	6 (9.8%)	0.26
Full-time student	25 (25.3%)	15 (24.6%)	0.93
Part-time student	4 (4.0%)	5 (8.2%)	0.27
Housework/home maintenance	68 (68.7%)	34 (55.7%)	0.10

5.3.2.3. IBD patients by age of diagnosis

The types of work engaged in by IBD patients are shown in Table 5.6, organized by age of diagnosis. IBD patiently diagnosed under age 18 are less likely to be a caregiver for their children (4.3% v. 22.2%, X^2[1, 160]=10.3, p=0.001), less likely to have a full-time paying job (54.3% v. 73.3%, X^2[1, 160]=6.3, p=0.01), and more likely to be a full-time student (40.0% v. 13.3%, X^2[1, 160]=14.9, p=0.0001). IBD patients diagnosed under and over 18 were similar with respect to the proportions having a part-time paying job (70.0% v. 77.8%, X^2[1, 160]=1.3, p=0.26), being self-employed (7.1% v. 5.6%, X^2[1, 160]=0.2, p=0.68), having volunteer work (11.4% v. 15.6%, X^2[1, 160]=0.6, p=0.45), being a part-time student (91.4% v. 96.7%, X^2[1, 160]=2.0, p=0.15), and engaging in housework of home maintenance (60.0% v. 66.7%, X^2[1, 160]=0.8, p=0.38). Those diagnosed in childhood were significantly younger 22.6 v. 26.5, difference in means = 3.9, [2.84, 4.96], p=1.47x10^{-11}) but with no difference in gender (45.7% male v. 54.3%, X^2[1, 160]=2.5, p=0.11).

Table 5.6. Types of work of IBD patients, by age of diagnosis

	<18	18+	p-value
N	70	90	
Caregiver for their children	3 (4.3%)	20 (22.2%)	0.001
Working full-time paying job	38 (54.3%)	66 (73.3%)	0.01
Working part-time paying job	21 (30.0%)	20 (22.2%)	0.26
Self-employed	5 (7.1%)	5 (5.6%)	0.68
Volunteer work	8 (11.4%)	14 (15.6%)	0.45
Full-time student	28 (40.0%)	12 (13.3%)	0.0001
Part-time student	6 (8.6%)	3 (3.3%)	0.15
Housework/home maintenance	42 (60.0%)	60 (66.7%)	0.38

5.3.3. Work Category and Supervision of Others

5.3.3.1. All participants

The distribution of work category of IBD patients and controls is depicted in Figure 5.1. There were significant differences in the work category between IBD patients and controls (X^2[7, 201]=15.4, p=0.03). The most common job category for both groups was professional, with 34.8% controls and 27.0% IBD patients selecting this. Almost twice as many IBD patients indicated that their main job category was sales as controls (19.9% v. 10.1%) with less than half as many IBD patients describing their main job category as technical support (8.5% v. 17.4%). IBD patients were more likely to list "precision production and crafts worker" (7.8% v. 0%). Similar proportion of IBD and control participants indicated their main job was clerical (19.9% v. 18.8%), executive, administrator, or senior manager (2.8% v. 4.3%), operator/laborer (5.7% v. 1.4%), or service (8.5% v. 13.0%).

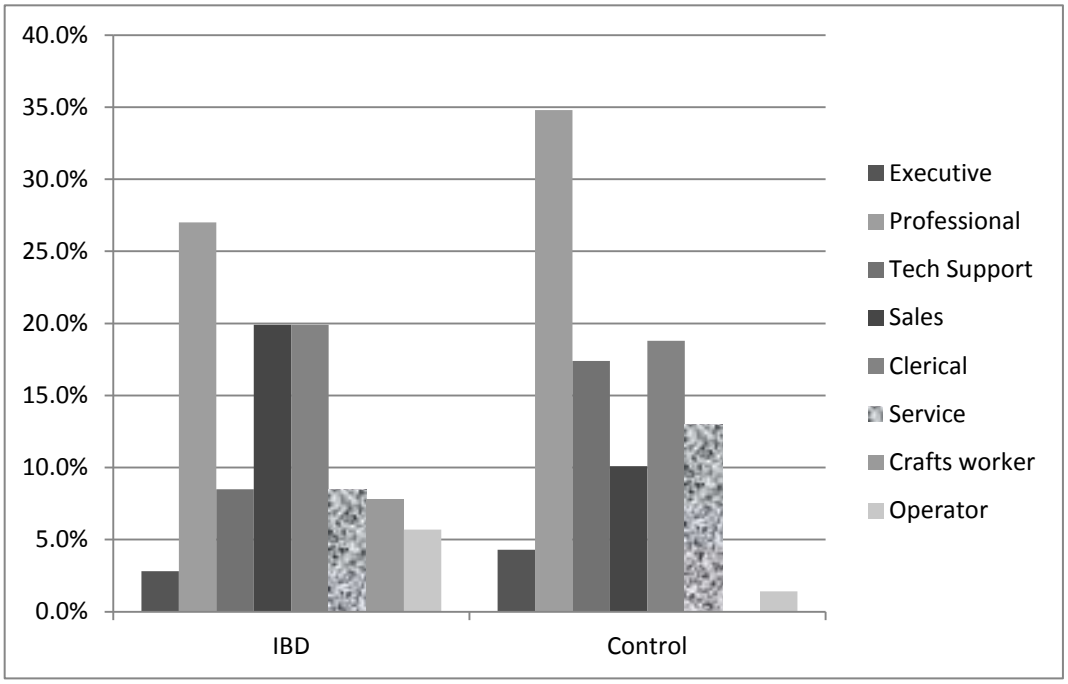

Figure 5.1. Distribution of work category differed between IBD patients and controls

Participants with IBD were more likely to supervise others compared to controls (34.0% v. 18.8%, X^2[1, 210]=5.2, p=0.02). Gender was not different between those that supervised others and those that did not (60.7% female v. 62.4%, X^2[1, 210]=0.1, p=0.81). Those that supervised were on average 1.5 years older than those that didn't (26.0 v. 24.4, difference in means = 1.6, [0.53, 2.72], p=0.004). The average number of people supervised was similar between IBD and control groups (8.7 v. 6.5, difference in means = 2.2, [-5.38, 9.76], p=0.57).

5.3.3.2. IBD patients by type of IBD

The distribution of work category differed between IBD patients with Crohn's disease and UC (Table 5.2; X^2[7, 141,]=15.5, p=0.03). No UC patients described their main job in the category of executive, administrator, or senior manager compared to 4.7% of Crohn's patients. Professional was the most common job category for both CD and UC patients (28.2% v. 25.0%). Technical support was

the main job of 17.9% of UC patients and only 2.4% of Crohn's patients. The proportions of CD and UC patients indicating that their main job was sales was similar (17.6% v. 23.2%). More CD patients indicated that their main job was clerical (23.5% v. 14.3%). Twice as many CD patients indicated their main job was service as UC patients (10.6% v. 5.4%). Similar proportions of CD and UC patients indicated that their main job was crafts worker (7.1% v. 8.9%) or operator (5.9% v. 5.4%).

The average age of these 2 groups was the same (25.0±0.42 v. 25.0±0.51, difference in means =0.1, [-1.25, 1.38], p=0.93) as was the proportion of females (58.8% v. 60.7%, X^2[1, 141]=0.1, p=0.82). There was no difference the proportion of participants with CD and UC that supervised others (35.3% v. 32.1%, X^2[1, 141]=0.1, p=0.70).

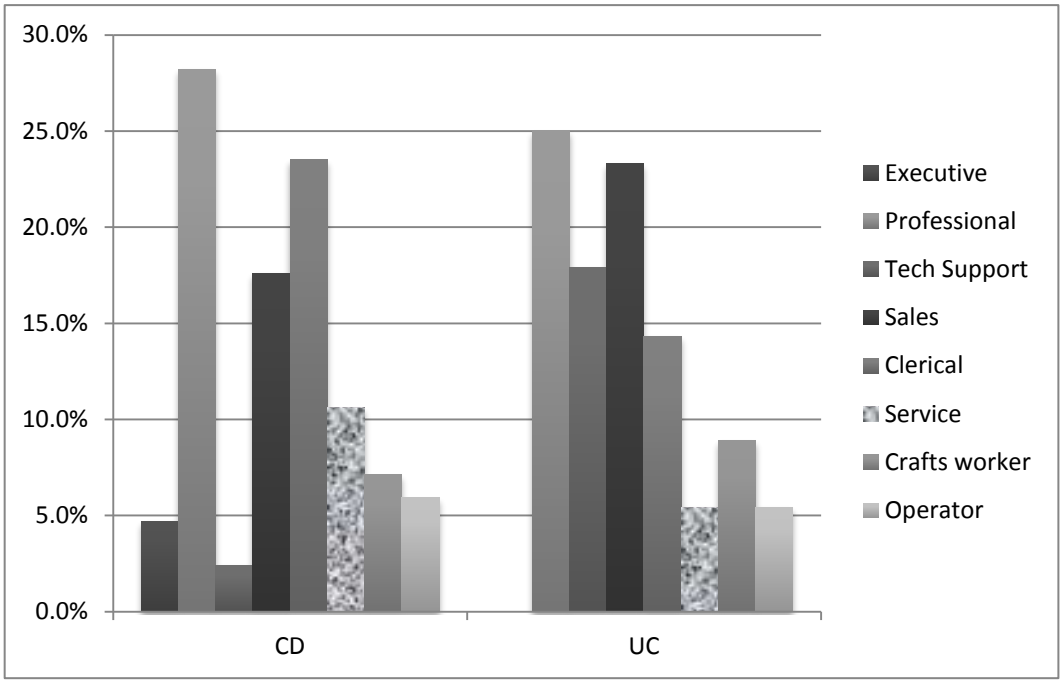

Figure 5.2. Distribution of work category by type of IBD

5.3.3.3. IBD patients by age of diagnosis

The distribution of main job category was similar in IBD patients by age of diagnosis (X^2[7, 141]=11.5, p=0.12, Figure 5.3). The most common job category of patients diagnosed under age 18 was sales at 27.1%, followed by professional at 20.3%, and then clerical at 18.6%. In patients diagnosed at 18 years or older, the most common job category was professional at 31.7%, followed by clerical at 20.7%, and sales at 14.6%. None of the IBD patients diagnosed under age 18 indicated their main job to be executive, compared to 4.9% of those diagnosed in adulthood. Those diagnosed under 18 were younger at the time of the survey (22.8 years v. 26.5, difference in means = 3.64, [2.49, 4.80]. p=5.10×10^{-9}) with no difference in gender (X^2[1, 141]=2.1, p=0.15). Approximately one-third of each group indicated that they supervised others (32.9% v. 35.6%, X^2[1, 141]=0.1, p=0.74).

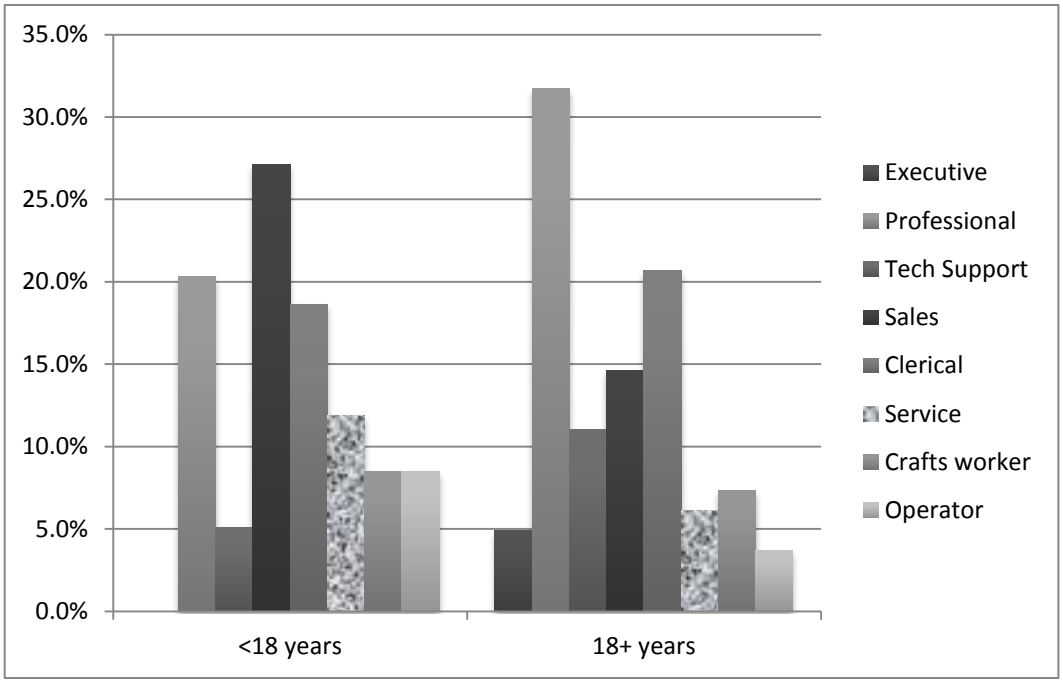

Figure 5.3 Distribution of main job category of IBD patients was not different by age of diagnosis

5.3.4. *Absenteeism*

Absenteeism can be measured as an absolute value in terms of number of hours or days missed. Since, many people may be required to work a variable number of hours per week, relative absenteeism is ratio of number of hours missed divided by the number of hours expected to work. The WHO-HPQ measures absenteeism over the last 28 days.

5.3.4.1. All participants

Absolute absenteeism (absolute hours lost per month) was higher for IBD patients than controls (15.7 v. 4.3 hours, difference in means = 11.4, [0.92, 21.9], p=0.03). There was also a trend toward IBD patients having a higher relative absenteeism (ratio of hours lost divided by hours expected) as compared to controls (0.08 v. -0.04, difference in means = 0.12, [-0.01, 0.25], p=0.07).

5.3.4.2. IBD patients by type of IBD

Absolute absenteeism (14.1 v. 18.0 hours, difference in means = 3.9, [-9.57, 17.31], p=0.57) and relative absenteeism (0.07 v. 0.10, difference in means = 0.03, [-0.10, 0.16], p=0.65) was similar between Crohn's disease and ulcerative colitis groups

5.3.4.3. IBD patients by age of diagnosis

Patients diagnosed under age 18 years old had lower rates of absolute absenteeism than those diagnosed in adulthood (5.5 v. 22.9 hours, difference in means = 17.4, [4.33, 30.42], p=0.009). Relative absenteeism was also lower in those diagnosed under age 18 than those diagnosed in adulthood (-0.01 v. 0.15, difference in means = 0.16, [0.03, 0.30], p=0.01).

5.3.5. *Presenteeism*

Presenteesism is a concept of patients being at work, but not working effectively. This also contributes to the indirect costs of IBD to employers and society. The participant comparing their performance to that of their peers makes up the value of presenteeism in the HPQ.

5.3.5.1. All participants

Absolute presenteeism (81.3 v. 78.7, difference in means = 2.6, [-0.97, 6.21] p=0.15) and relative presenteeism (1.03 v. 1.02, difference in means = 0.01, [-0.02, 0.05], p=0.51) was similar between IBD and control groups.

5.3.5.2. IBD patients by type of IBD

CD and UC patients had similar levels of absolute presenteeism (81.7 v. 80.7, difference in means = 0.9, [-3.50, 5.38], p=0.68). Relative presenteeism was also similar between CD and UC patients (1.03 v. 1.03, difference in means = 0.002, [-0.04, 0.04], p=0.94).

5.3.5.3. IBD patients by age of diagnosis

IBD patients diagnosed in under age 18 and 18 years and older had similar levels of absolute (82.3 v. 80.6, difference in means = 1.7, [-2.74, 6.08], p=0.46) and relative presenteeism (1.01 v. 1.04, difference in means = 0.03, [-0.02, 0.07], p=0.22).

5.3.6. *Workplace Performance*

5.3.6.1. All participants

Participants were asked to categorize their work performance over the last four weeks. IBD patients' responses differed from controls in their responses regarding having higher and lower performance than co-workers as well as in

their response to the frequency by which health problems limit their workplace performance.

5.3.6.1.1. Performance higher

In regards to frequency of their workplace performance being higher than most workers in their job, the distribution of responses was different between IBD and control groups (X^2[4, 206]=11.1, p=0.025; Figure 5.4). Control patients were more likely to indicate that their performance is better than their peers some of the time (51.5% v. 30.4%). IBD patients indicate that their performance is better than their peers all of the time (10.1% v. 2.9%), most of the time (39.9% v. 35.3%), a little of the time (9.4% v. 4.4%) or none of the time (10.1% v. 5.9%) as compared to control patients indicating each of these responses.

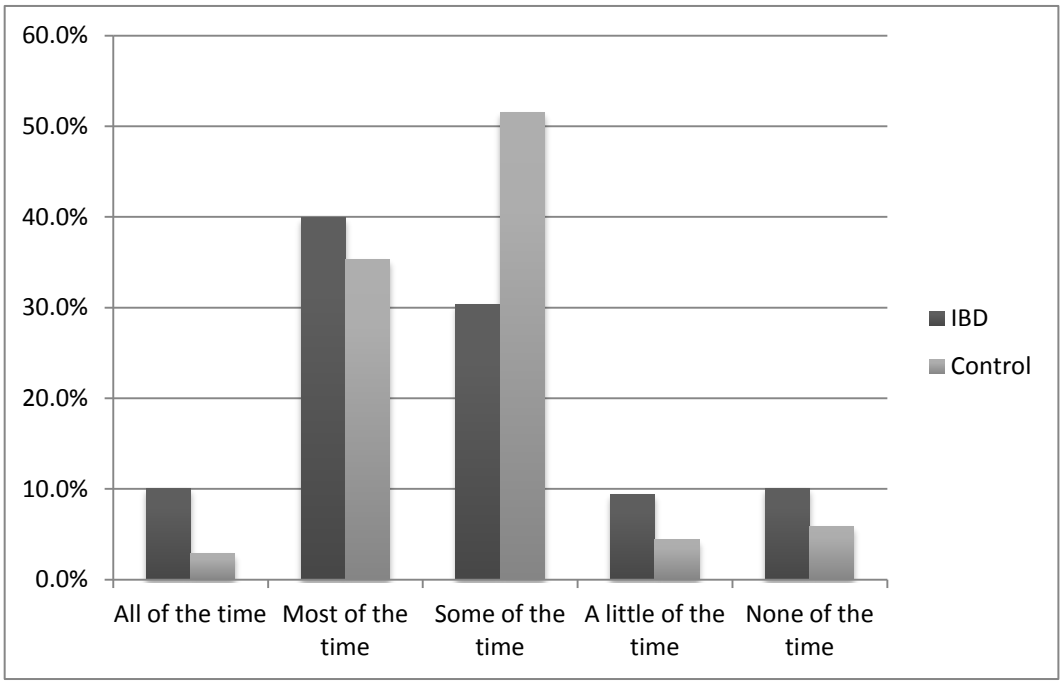

Figure 5.4. Performance higher for IBD patients and controls

5.3.6.1.2. Performance lower

The distribution of responses to how often their performance is lower than their peers is different between IBD and controls patients (X^2[4, 206]=12.4, p=0.01; Figure 5.5). IBD patients were more likely to indicate their

performance was lower "none of the time" (42.8% v. 27.9%) and less likely to indicate some of the time (10.9% v. 29.4%) compared to healthy controls.

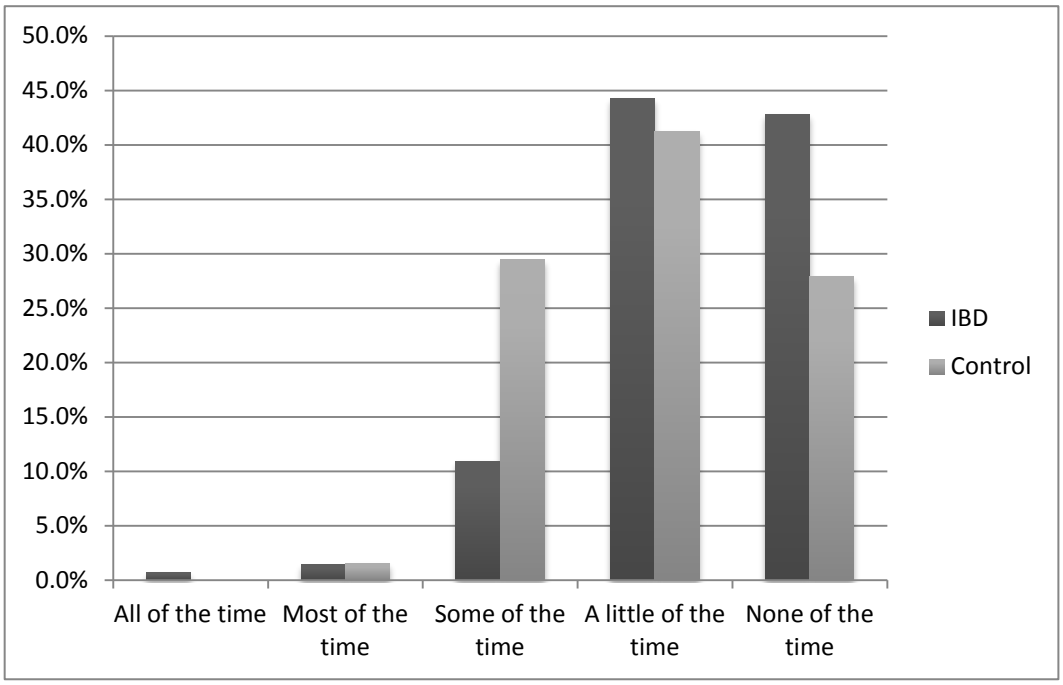

Figure 5.5. Performance Lower for IBD patients and controls

5.3.6.1.3. How often did you do no work when you were supposed to?

The responses to this question were similar for IBD and control patients (X^2[3, 205]=2.7, p=0.45; Figure 5.6). No patients from either group indicated that they were not working all of the time, and a few from each group saying this was true most of the time (0.7% v. 1.5%). The majority of IBD and controls indicated that they were not working a little (48.2% v. 45.6%) or none of the time (40.9% v. 35.3%).

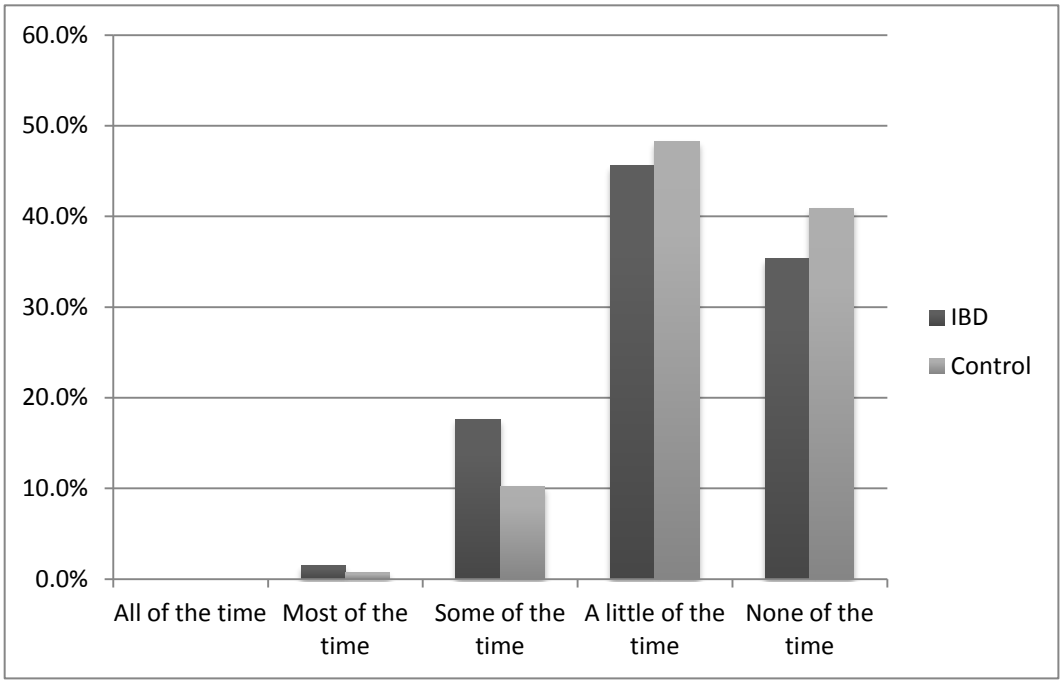

Figure 5.6. How often did you do no work at times when you were supposed to?

5.3.6.1.4. How often did you find yourself not working as carefully as you should?

The responses to this question were similar for IBD and control patients (X^2[4, 206]=0.68; Figure 5.7). The majority of IBD and healthy controls indicated that they were not working carefully a little (37.0% v. 44.1%) or none of the time (44.9% v. 36.8%). Only a few IBD patients and healthy controls said that they were not working carefully all of the time (0.7% v. 0%) or most of the time (5.8% v. 4.4%).

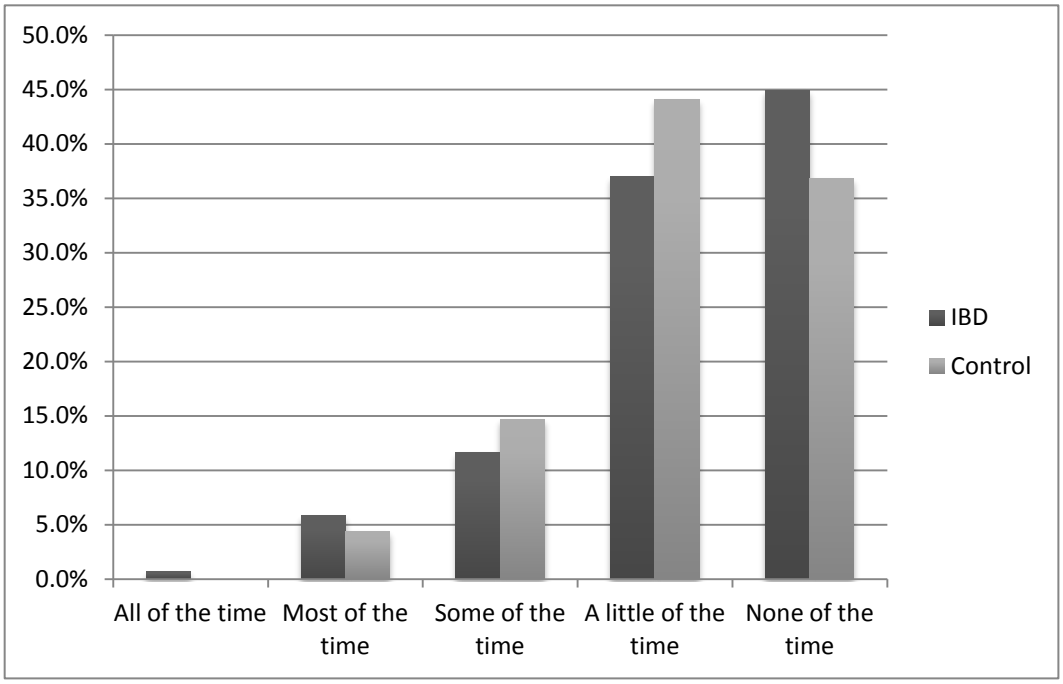

Figure 5.7. How often did find yourself not working as carefully as you should?

5.3.6.1.5. How often was the quality of your work lower than it should have been?

The responses to this question were similar for IBD and control patients (X^2[3, 206]=2.4, p=0.50; Figure 5.8). The majority of IBD and healthy controls indicated that the quality of their work was lower a little (41.3% v. 51.5%) or none of the time (51.4% v. 44.1%).

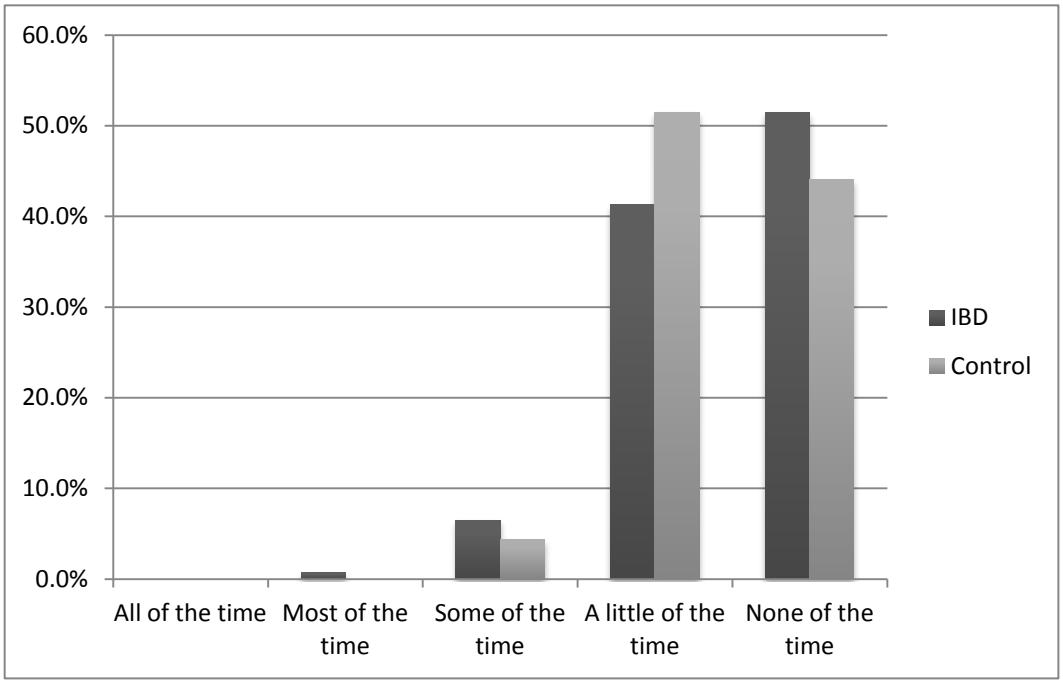

Figure 5.8. How often was the quality of your work lower than in should have been?

5.3.6.1.6. How often did you not concentrate on your work?

The responses to this question were similar for IBD and control patients (X^2[3, 206]=0.2, p=0.98; Figure 5.9). The proportion of IBD and controls with each response was nearly identical (most of the time: 5.8% v. 4.4%; some of the time: 10.9% v. 11.8%; a little of the time: 51.4% v. 51.5%; none of the time: 31.9% v. 32.4%).

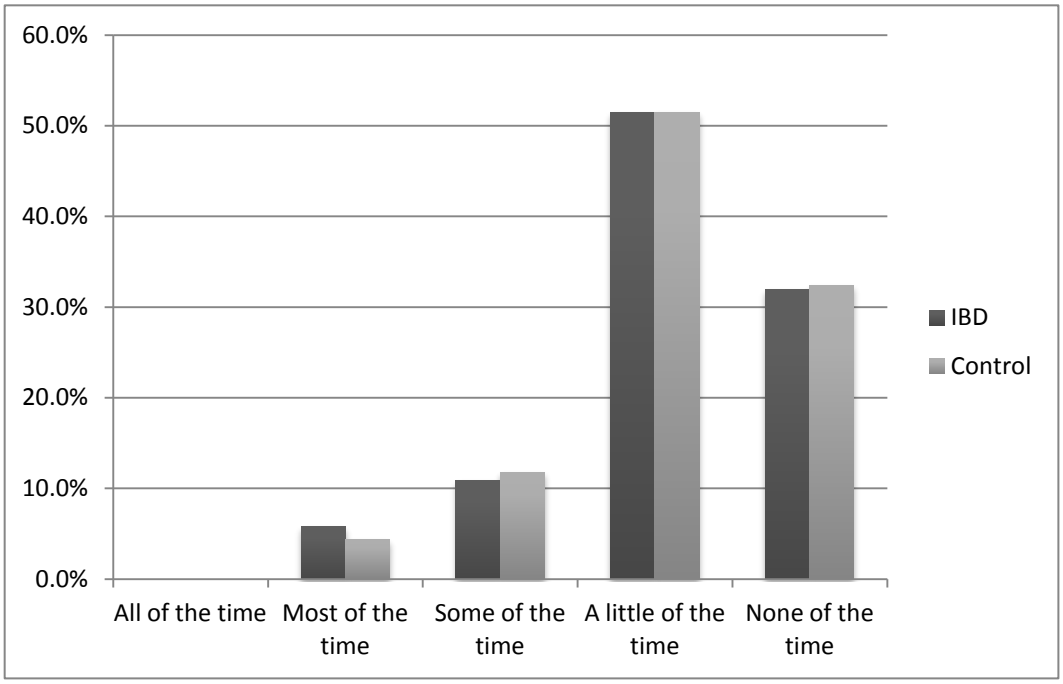

Figure 5.9. How often did you not concentrate on your work?

5.3.6.1.7. How often did your health problems limit the kind or amount of work that you could do?

The most prominent difference between IBD and control groups was seen in response to the question about their health problems limiting the kind or amount of work they could do ($X^2[4, 206]=23.6$, p=0.00009; Figure 5.10). While 80.9% of healthy controls indicated that their health limited their work none of the time, only 46.4% of IBD patients chose this response. Only a few IBD patients said their health limited their work all (0.7%) or most of their time (2.2%), while no healthy controls chose these options. IBD patients were more likely than controls to say their health limited their work some (21.0% v. 4.4%) or a little of the time (29.7% v. 14.7%) in the last 4 weeks.

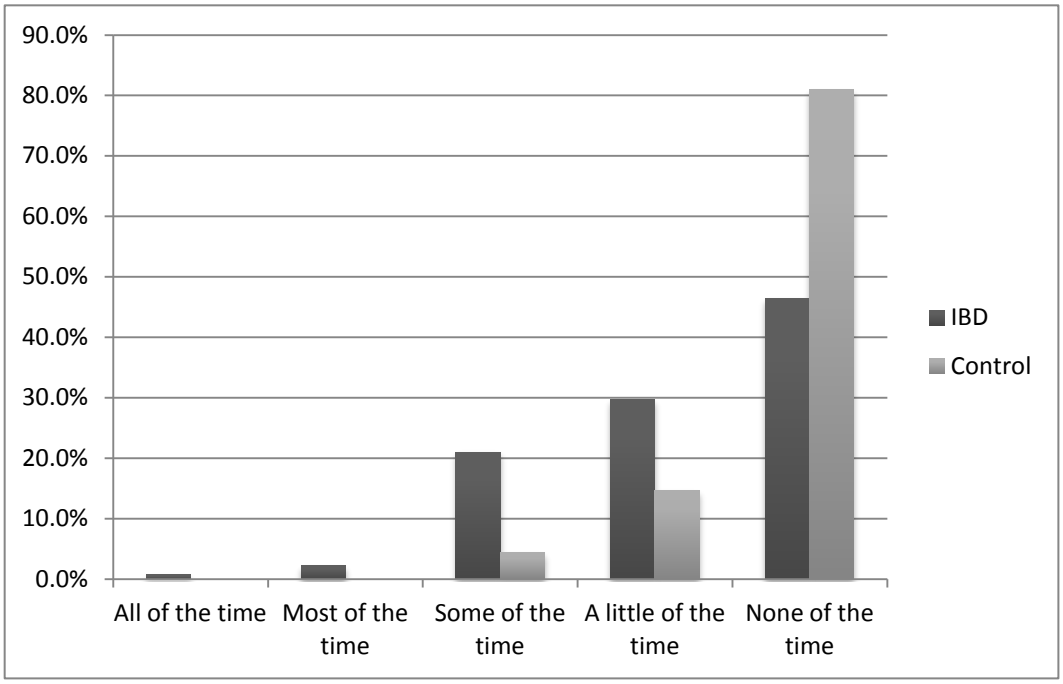

Figure 5.10. How often did your health problems limit the kind or amount of work you could do?

5.3.6.2. IBD patients by type of IBD

Responses to work performance questions were similar between patients with Crohn's disease and ulcerative colitis in regards to rating their performance higher (X^2[4, 138]=4.1, p=0.40), performance lower (X^2[4, 138]=4.6, p=0.33), not working carefully (X^2[4, 138]=1.7, p=0.78), lower work quality (X^2[3, 138]=2.1, p=0.56), not concentrating (X^2[3, 138]=2.0, p=0.57), or their health limiting the amount of quality of work (X^2[4, 138]=2.8, p=0.58).

The distribution of responses was different for CD and UC patients for the question about doing no work when they were supposed to X^2[4, 137]=10.7, p=0.01). Crohn's disease patients were more likely than UC patients to indicate that they were not working when they were supposed to some of the time (15.5% v. 1.9%). UC patients were more likely than CD patients to say they were not working a little of the time (60.4% v. 40.5%). Similar proportions of CD and

UC patients that there was none of the time when they were not working when they were supposed to (44.0% v. 35.8%).

5.3.6.3. IBD Patients by Age of Diagnosis

Responses to work performance questions were similar between patients with diagnosed under age 18 and 18 years and older in regards to rating their performance higher (X^2[4, 138]=2.5, p=0.64), performance lower (X^2[4, 138]=3.9, p=0.43), not working when they were supposed to (X^2[3, 137)=1.4, p=0.72), not working carefully (X^2[4, 138]=1.7, p=0.78), lower work quality (X^2[3, 138]=1.4, p=0.70), not concentrating (X^2[3, 138]=2.6, p=0.46), or health limiting the amount of quality of work (X^2[4, 138]=3.2, p=0.53).

5.4. Discussion

5.4.1. Employment

In our population of IBD patients and controls, 19.9% of IBD patients and 16.8% of controls indicating that they were not working. This is similar to the data found by Longobardi *et al* in which 14.8% of non-IBD were not in the labour force along with 18.5% of IBD patients without symptoms.[3] They further went onto show that 31.5% of IBD patients aged 20-64 years with symptoms were not in the labour force.[3] In our study, we found that Crohn's patients were more likely to be off work due to short-term disability than UC patients, however when the IBD groups combined were compared to controls there was no differences. This is in contrast to the data from a cost-analysis study were both UC and CD were more likely to be on short-term disability.[6]

Patients diagnosed in childhood were more likely to not be working and to characterize themselves as unemployed and looking for work than those diagnosed in adulthood, however they age group of the pediatric diagnosed patients was significantly younger which may also explain this difference.

When IBD patients and healthy controls were asked to categorize their main job, professional was the most common category, however approximately 1/3 of controls indicated this compared to just 25% of IBD patients. In this study, IBD patients were more likely to categorize their main job as sales and less as technical support, compared to healthy controls. Of IBD patients, Crohn's patients were more likely to have indicated their main job was in sales or service and less likely to be technical support than UC patients. The distribution of job category by age of diagnosis of IBD patients was similar. Interpretation of job category in young adults age 18-30 is somewhat difficult to interpret, as their current job category may or may not represent a permanent position.

5.4.2. Absenteeism and Presenteeism

Absolute and relative absenteeism, but not presenteeism was higher in IBD patients as compared to healthy controls. Absenteeism was similar for Crohn's disease and UC patients in our study. Nurmi *et al* also found that absenteeism was similar between Finnish CD and UC patients.[5] However, Gibson *et al* found that absenteeism costs are higher in UC but not CD patients when compared to matched controls. IBD patients who were diagnosed in childhood had lower absolute absenteeism in early adulthood than those diagnosed at age 18 or older. Presenteeism was similar for IBD patients, by both type of IBD and age of diagnosis.

5.4.3. Workplace Performance

The most striking difference we found between IBD and healthy controls in regards to workplace performance is that only 46% of IBD patients indicated that their health did not limit the amount or quality of work they could do, compared to 81% of healthy controls. However, IBD patients were less likely than healthy controls to say that their job performance was lower some of the time and more likely to say it was lower, none of the time. These results are

somewhat contradictory, raising the question if this self-report questionnaire of workplace performance is accurate to assess this. For IBD patients, workplace performance was similar by both type of IBD and age of diagnosis.

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6. General Discussion and Conclusions

6.1. Inflammatory Bowel Disease and Well Being

Inflammatory bowel disease is a chronic disease that is known to have a significant impact on the physical functioning of patients. Patients with Crohn's disease have many symptoms including diarrhea, abdominal pain, weight loss, growth failure, anemia, poor energy and may have complications including bowel obstructions, fistulas, and abscesses. Patients with ulcerative colitis have bloody diarrhea, urgency, tenesmus, fecal incontinence, abdominal cramping and may have complications including toxic megacolon, fulminant colitis, or colon cancer. Currently, there is no cure for IBD and the goals of treatment are induction and maintenance of remission. IBD is treated through a combination of medical and surgical therapies. While we have good therapies for IBD, no treatment is perfect and patients remain at risk for disease relapses or "flares".

The impact of inflammatory bowel disease extends beyond the physical. The top concerns of IBD patients are the uncertain nature of the disease, the effects of treatments, including having an ostomy bag or medication effects, and the risk of malignancy.[1,2] IBD impacts the emotional functioning of individuals; anxiety and depression are more common in patients with IBD.[3,4] Patients also indicate significant concern about being a burden on others and their ability to obtain their potential.[1] Employment and financial independence can also be a challenge for patients with IBD; poor energy, absenteeism and need to be on short-term disability may decrease their ability to complete their work and limit their opportunities for promotion.

We know that disease remission lead to improved health-related quality of life with less depression and better overall functioning.[4] In a recent Spanish study, IBD patients in 80% of patients in clinical and endoscopic remission had normal

HRQOL.[5] Furthermore, induction of remission with biologics leads to improved employment rates and less absenteeism and improved workplace productivity.

Traditionally, pediatric medical care of IBD patients is multi-disciplinary and takes a holistic approach with consideration given to the developmental and psychosocial aspects in the care of patients.[6] Adult IBD care is disease-centered with little to no consideration given to the psychosocial aspects of care. IBD diagnosed in childhood may interfere with the sexual and psychosocial development.[7] In Canada, timing transition from pediatrics to adult practice is chronologically based without consideration to their maturity or psychological readiness. Patients are transitioned from pediatrics prior to their 18th birthday. While there is a significant body of pediatric literature focused on the psychosocial adjustment of IBD patients during childhood and adolescence, there is less known about the long-term impact of having a childhood diagnosis of IBD on the psychosocial functioning.

We hypothesized that young adults with IBD have impaired psychosocial functioning in early adulthood compared to healthy controls.

6.2. What is Psychosocial Functioning?

Psychosocial functioning refers to an individual's thoughts and behaviors in the context of a social environment than enables them to function or take a meaningful role in society. It encompasses many facets and is therefore a difficult concept to both define and measure. To assess psychosocial functioning in adolescents with IBD, Mackner and Crandall assessed social competence, self-esteem, coping strategies, behavioral/emotional functioning, and social support.[8] Ross *et al* looked at 5 outcomes in a meta-analysis assessing psychosocial functioning in pediatric IBD: self-esteem HRQOL, anxiety and depression, social competences and behavioral

functioning.[9] Psychosocial functioning and health related quality of life (HRQOL) are often measured through questionnaires or structured interviews.[9] Psychosocial functioning is related to the concept of success in life. In children and adolescents, social, physical, and academic skills are required to set them us for success and independence as adults.[10] Maslow and colleagues have included vocation as an outcome, along education and social outcomes as measures of success.[11]

In children and adolescents, achievement of developmental milestones is a way to measure success. In adulthood, success is often measured in educational, vocational, and social milestones. However, it is difficult to assess the timing of when these adult milestones should be met. Over time, demographic changes, including delay in marriage and having children, have led to a proposal of a new developmental period called emerging adulthood.[12] This refers to 18-25 year olds, in which they are not adolescents and not yet adults; they are no longer dependant like in adolescence and yet have not entered the enduring responsibilities of adulthood.

To assess psychosocial functioning of IBD patients age 18-30, we used the Course of Life Questionnaire to assess the attainment of developmental milestones, the Beck Depression Inventory-II to assess depression, the World Health Organization Health and Workplace Performance Questionnaire to assess workplace functioning.

6.3. Do Patients with Inflammatory Bowel Disease Have Impaired Psychosocial Functioning Compared to Healthy Controls?

6.3.1. Milestone Development and Functioning in Society

Unlike other chronic childhood illnesses we found that IBD patients do not have impaired attainment of developmental milestones as compared to healthy controls.[13] Female IBD patients had better autonomy (8.2 v. 7.6) and

psychosexual development scores (7.0 v. 5.9) than healthy females but similar social development scores. Male IBD patients were similar to healthy males in regards to attainment of developmental milestones. Part of the difference in females for autonomy development may be due to less female IBD patients living with their parents (20% v. 33%). We know from our HPQ analysis that more healthy controls are full-time students (52% v. 25%); this difference may help explain this as students may chose to live at home while pursuing a post-secondary education. However, more male controls also live with their parents compared to male IBD patients (51% v. 25%), and yet the overall autonomy score of male participants is similar between groups. Therefore it seems unlikely that full-time student status is enough to drive the difference in female participants.

The psychosexual development scores of female IBD patients were also higher than in female controls. Early sexual debut has been described in females with chronic illness.[14] While the Course of Life Questionnaire does not specifically measure early sexual debut, we did find that more female IBD patients experienced their first sexual intimacy (88% v. 55%) and sexual intercourse (72% v. 36%) at age 18 or earlier than healthy females.

The relatively low autonomy and psychosexual development scores of the healthy controls in this study raises the question of a confounding variable affecting our healthy control group. However, the only available comparison data is from Dutch patients and so these differences may also represent cultural differences. The psychosexual development score of female IBD patients is similar to that of Dutch female survivors of childhood cancer and lower than the female controls.[15] In contrast, male IBD patients had lower a psychosexual development score (6.3) than with Dutch male survivors of childhood cancer (6.5) and Dutch male controls (7.1). This raises the possibility that it is the male IBD patients that have delayed psychosexual development.

Nevertheless, compared to the age-matched, Canadian controls female IBD patients had advanced psychosexual development, and the psychosexual development of male IBD patients is similar to healthy male controls. Male and female IBD patients were similar to healthy controls in regards to high risk behavior.

When IBD patients are compared by type of IBD, Crohn's disease patients have lower psychosexual (6.6 v. 7.0) and social development scores (20.5 v. 21.2) compared to those with ulcerative colitis. Crohn's and UC patients are similar with respect to autonomy development and high risk behavior.

6.3.2. Depression as a Measure of Psychological Functioning

Beck Depression Inventory-II scores were higher in the IBD group than in healthy controls (9.2 v. 6.0). Very few IBD patients were currently on corticosteroids, therefore increased depression scores in IBD patients was not simply to corticosteroid side effects. A difficulty in measuring depression in patients with chronic illness is that depressive symptoms include physical or somatic symptoms that may be due to physical illness, rather than a manifestation of a psychiatric illness. In order to elucidate if these higher scores are only due to physical symptoms, the Beck Depression Inventory-II was divided into 2 parts: somatic and cognitive or affective symptoms. While there was the biggest difference between IBD and controls in regards to somatic symptoms (4.4 v. 2.5), there was also a difference in the cognitive score (4.8 v. 3.5). Therefore, we know that the depressive symptoms seen in IBD patients are not only due to the physical symptoms of IBD.

We found an inverse relationship between HRQOL, as measured by the SIBDQ, and depression. A similar relationship has recently been published in the literature. In a study of 80 IBD patients, HRQOL was inversely associated with depressive and anxiety symptoms, as measured by the Hospital Anxiety and Depression Scale.[16] In the small subset of Spanish IBD patients that had

impaired HRQOL in the setting of clinical and endoscopic remission, they were more likely to report impairment in depression and anxiety, as measured by HRQOL questionnaires.[5] Together these results show importance of assessing for co-morbid depression in IBD patients in order to improve their HRQOL. The SIBDQ is a simple 10-item questionnaire that is easy to administer; use of this questionnaire in patients that are in clinical or endoscopic remission may allow physicians to screen for poor quality of life and possible underlying anxiety or depression.

The overall BDI-II depression scores were similar for patients with Crohn's disease and UC patients. Previous studies looking for risk factors for depression in IBD found similar rates of depression in CD and UC patients using the Hospital Anxiety and Depression Scale.[4,17] The Hospital Anxiety and Depression Scale does not allow for the distinction between the cognitive and somatic symptoms of depression. In our study, we found that the somatic and cognitive sub-scores were similar for patients with Crohn's disease and ulcerative colitis.

6.3.3. Workplace functioning

In this study, less than 20% of IBD patients and healthy controls age 18-30 years old were currently not working. Interestingly, in this population healthy controls were more likely to be unemployed and looking for work. In regards to the types of work engaged in, IBD patients were more likely to have a full-time job (65% 52%), but less likely to be a full-time student (25% v. 52%), or engage in volunteer work (14% v 28%). Absenteeism (16 v. 4 hours per month), but not presenteeism (81% v. 79%), was higher in IBD patients than in healthy controls. IBD patients were much more likely to have indicated that their health limited the amount or quality of work that they could do (64% v. 19%), but were less likely to indicated that their performance was lower than their colleagues (57% v. 72%). This could mean that IBD patients work harder to

compensate for the limitations they experience as a result of their health, or alternatively that they overestimate their workplace performance.

While the percentage of CD and UC patients that were currently off work were similar, more CD patients than UC patients 5% were off work due to short-term disability (5% v. 0%). The type of work engaged in was similar for CD and UC patients, with approximately 2/3 having a full-time job and ¼ being full-time students. The top job category for both CD and UC patients was professional. However, more CD patients had service (11% v. 5%) or clerical jobs (24% v. 14%), which more UC patients had technical support jobs (18% v. 2%). Absenteeism and presenteeism were similar for both CD and UC patients.

6.4. Does a Childhood Diagnosis of Inflammatory Bowel Disease Impact the Psychosocial Functioning?

Autonomy development is poorer or delayed in patients with a younger age of diagnosis. This is in contrast to previous a previous study using a different questionnaire to measure autonomy development, they found that in patients with IBD only adolescents, but not children have problems with autonomy.[18] In that study, autonomy is measured patients that are currently in childhood or adolescence, while in our study we are looking at the development of autonomy up until the age of 18.[18] Patients diagnosed in childhood tend to have lower autonomy development scores than those diagnosed in adolescence (7.4 v. 7.9), which are in turn lower than the scores of those diagnosed in adulthood (8.4). The younger they are diagnosed, the more likely they are to still live at home (childhood: 38% v. adolescence: 32% v. adulthood: 12%).

Interestingly, while they are just as likely to have jobs outside the home as those diagnosed later, patients diagnosed younger are less likely to have regular chores or tasks at home. It is not clear why patients diagnosed

younger are less likely to have chores at home, but we can hypothesize that is due to differences in parenting, as parents are the ones who would delegate these tasks. Parents may choose to prioritize activities outside of the home in an effort to promote the social development of their children. It is possible that with the physical demands of an illness like IBD that young patients do not have the energy to both participate in activities outside the home and complete chores or tasks at home.

Further support of the theory that parents prioritize outside activities over tasks or chores at home is that the overall the social development score was similar regardless of the age of diagnosis of IBD. Patients diagnosed in childhood and adolescence were more likely to participate in competitive sports in elementary school. In a study of parenting style and bonding, Crohn's disease patients perceived their fathers as being overprotective, demonstrating excessive control and intrusive parenting; no differences were seen in the overprotective score of mothers of CD patients compared to controls.[19]

Despite the similarities in overall social development of IBD patients and controls, there are some subtle signs that pediatric diagnosed IBD patients may struggle in junior or senior high. Patients diagnosed under age 18 tend to be less likely to have at least 4 friends (82% v. 91%), belong to a group of friends (82% v. 92%), or to spend the majority of their leisure time with friends (81% v. 90%). Interestingly, it is only patients diagnosed in adolescence that were less likely to belong to a group of friends in junior or senior high but not those diagnosed in childhood (79 v. 91%), as compared to patients diagnosed at age 18 or older (92%). Furthermore, patients with a pediatric diagnosis of IBD tend to be more likely to be suspended or expelled for misbehavior in junior or senior high.

While overall, the substance use and gambling scores were similar between those diagnosed before and after 18 were similar, pediatric diagnosis of IBD may be protective for alcohol use and smoking in junior or senior high. Patients diagnosed under 18 tended to be less likely to smoke (19% v. 33%) or drink alcohol (16% v. 26%) in junior or senior high.

When IBD patients diagnosed under 18 were compared to those diagnosed in adulthood, there was a trend toward delayed psychosexual development (6.5% v. 6.9%). The main difference was in the proportion of patients who had their first sexual intercourse by age 18 or earlier (55% v 70%). While the IBD groups by age of diagnosis are too small to be further divided, it is important to remember that the proportion of males is slightly higher in the diagnosed under 18 group (48% v. 32%) and female IBD patients have higher psychosexual development scores than males (7.0 v. 6.3).

Average depression scores and distribution of patients by level of depression were similar by age of diagnosis. In a previous study of adolescents with IBD, age of diagnosis was positively correlated with more depressive symptoms.[20] The BDI-II used in our study to assess depression asks about symptoms over the last 2 weeks. We were unable to determine if patients diagnosed in childhood or adolescence had more or less depression in adolescence.

Patients diagnosed with IBD under age 18 were less likely to have graduated from high school (91% v. 98%) and tended to be more likely to not currently be working (25% v. 15%). They were more likely to report being unemployed and looking for work (15% v. 5%). In regards to type of work, those diagnosed under age 18 were more likely to be a full-time student (40% v. 13%), less likely to be a caregiver for their children (4% v. 22%), and less likely to have a full-time job (54% v. 73%). Absenteeism was lower in those diagnosed under age 18 (5 v. 23 hours per month). This raises the possibility that those diagnosed in childhood may be able to cope better with their symptoms and not miss work.

6.5. Summary

Overall, unlike other childhood illness the milestone development of IBD patients is not hampered compared to healthy controls. The higher levels of depression in IBD patients are not only due to somatic or physical symptoms, but also due to increased cognitive or affective symptoms. While approximately 80% of IBD patients in this population are working, they do have 4x more hours of absenteeism than healthy controls. Over half of IBD patients indicated that their health limited the amount or quality of work that they could do, compared to just 19% of healthy controls.

Crohn's and UC patients were similar to one another in their psychosocial development, with the exception of delayed psychosexual and social development. CD and UC patients have similar levels of depression. CD patients are more likely to off work due to short-term disability, but have similar amounts of absenteeism.

A younger age of diagnosis is associated with poorer autonomy development; this may be due to parental expectations as fewer IBD patients report having regular chores or tasks at home in both elementary and junior/high school. Furthermore, a younger age of diagnosis is associated with an increased likely of living with their parents as a young adult. Depression scores in early adulthood was not associated with age of diagnosis. Patients diagnosed under age 18 were more likely to not have graduated from high school and were more likely to be employed; these differences may be in part due to a younger mean age of the pediatric diagnosed group. However, those with a pediatric diagnosis of IBD had less absenteeism than those diagnosed later.

6.6. Future Directions

Further exploration of the cause of delayed or impaired autonomy development in patients with a pediatric diagnosis of IBD would help us to

direct interventions to improve autonomy in young people with IBD. It is important for us to understand if it is the result of differences in parenting or if children and adolescents are unable to meet all the demands that they face. It would also be important to further study the impact of a diagnosis of IBD and the psychosexual functioning in young adults.

In regards to workplace functioning, it would be important to understand whether the increased absenteeism and lower rate of post-secondary training impacts long-term career success.

Application of this work to clinical practice would be to assess the HRQOL using the SIBDQ to screen for possible co-morbid depression in patients with IBD.

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7. Appendices

APPENDIX 1. Course of Life Questionnaire

Course of life Questionnaire for Young Adults

Instructions
This questionnaire is divided into four sets of questions. Three sets of questions relate to a certain period of your life. The first one is about your elementary school years. The second one is about your junior and high school years. The third one is about the years after high school which includes your years at college, trade school, etc. The last series of questions does not relate to a specific period.

Before each set of questions, there is information about which time period the questions are referring to. For each question, please mark the answer that best represents you.

If multiple answers are allowed, the question will tell you to mark all the answers that apply.

Please answer all questions. Do not leave any blank.
Thank you.

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November 2009

Part 1 Your Elementary School Years

The following questions refer to the years you were in elementary school, from kindergarten through the end of 6th grade.

1.	What type of school did you attend? (more than one answer possible)	❑ Regular Elementary (public) ❑ Special Education ❑ Private School ❑ Home Schooled (grades _____) ❑ Other, Explain_____
2.	Did you repeat a grade?	❑ No ❑ Yes, 1 year ❑ Yes, 2 years ❑ Yes, more than 2 years
3.	How old were you when you left 6th grade?	❑ 10 ❑ 11 ❑ 12 ❑ 13 ❑ 14
4.	Did you participate for at least one year in any competitive sports during elementary school?	❑ Yes ❑ No
5.	Did you participate for at least one year in any other activity (for example, scouts, music, dance)?	❑ Yes ❑ No
6.	a. How many friends did you have during your early elementary school years (kindergarten through third grade)?	❑ None ❑ 1 ❑ 2 or 3 ❑ 4 or more
	b. How many friends did you have during your later elementary school years (fourth through sixth grade)?	❑ None ❑ 1 ❑ 2 or 3 ❑ 4 or more
7.	Did you have a best friend during elementary school?	❑ Yes ❑ No
8.	During elementary school, did you get in trouble with the police or other law enforcement officials? (more than one answer possible)	❑ No ❑ Yes, for theft ❑ Yes, for destruction of property ❑ Yes for violence towards others ❑ Yes, for other offenses: Explain____
9.	Have you ever been suspended or expelled for misbehavior during elementary school?	❑ Yes ❑ No
10.	Did you have any regular chores/tasks at home during elementary school such as washing dishes, running errands, vacuuming, setting the table, etc.?	❑ Yes ❑ No
11.	Who did you spend most of your time playing with during elementary school? (choose only one answer)	❑ With friends ❑ With brothers/sisters ❑ With parents ❑ Alone
12.	Did you have any type of job outside of your home to earn money, such as washing cars, mowing lawns, baby sitting, during elementary school?	❑ Yes ❑ No

Part 2 Your Junior and/or High School Years

The following questions refer to the years you were in junior and high school, from 7th through 12th grade.

13. What type of school did you attend after elementary school and did you get a diploma? (more than one answer possible)

	Attended	Diploma Yes	Diploma No
Regular High School	❒	❒	❒
Vocational School	❒	❒	❒
Other _____	❒	❒	❒

13a. Did you participate in any honours program?

❑ Yes
❑ No

13b. Did you participate in any extra-curricular activities?

❑ Yes
❑ No

14. If you did not get a diploma, which class and in which school was the highest one completed?

_____

15. Did you repeat a year in junior and/or high school?

❑ No
❑ Yes, 1 year
❑ Yes, 2 years
❑ Yes more than 2 years

16. How old were you when you left high school?

❑ 14
❑ 15
❑ 16
❑ 17
❑ 18
❑ 19
❑ 20 or older

17. Did you participate in any competitive sports for at least one year during junior and/or high school?

❑ Yes
❑ No

18. Did you participate in any other activity (for example, scouts, music, dance) for at least one year during junior and/or high school?

❑ Yes
❑ No

19. How many friends (male and female) did you have during your junior and/or high school years?

❑ None
❑ 1
❑ 2 or 3
❑ 4 or more

20. Did you have a best friend during junior and/or high school?

❑ Yes
❑ No

21. Did you feel that you belong to a group of friends during junior and/or high school?

❑ Yes
❑ No

22. Who did you spend most of your leisure time with during junior and/or high school? (choose only one answer)

❑ With friends
❑ With brothers/sisters
❑ With parents
❑ Alone

23. Did you have any regular chores/tasks at home during junior and/or high school such as washing dishes, running errands, vacuuming, setting the table, etc.?

❑ Yes
❑ No

24.	Did you have a paid job during junior and/or high school?	❑ Yes ❑ No (*skip to question 25*)
	If Yes: How old were you when you had your first paid job outside the home?	❑ Younger than 12 ❑ 12-14 ❑ 15-18 ❑ 19 or older
25.	Did you drink alcohol during junior and/or high school?	❑ Never ❑ Occasionally ❑ Often ❑ Very often
26.	Did you take "calming" drugs such as valium or other sedatives during junior and/or high school?	❑ Never ❑ Occasionally ❑ Often ❑ Very often
27.	Did you use soft drugs such as marijuana or hashish during junior and/or high school?	❑ Never ❑ Occasionally ❑ Often ❑ Very often
28.	Did you take psychedelic drugs such as LSD or XTC during junior and/or high school?	❑ Never ❑ Occasionally ❑ Often ❑ Very often
29.	Did you take hard drugs such as cocaine or heroine during junior and/or high school?	❑ Never ❑ Occasionally ❑ Often ❑ Very often
30.	Did you smoke cigarettes during junior and/or high school?	❑ No ❑ Yes, 1-10 cigarettes per day ❑ Yes, 11-20 cigarettes per day ❑ Yes, more than 20 cigarettes per day
31.	Did you gamble for money (for example play in a casino or at a slot machine) during junior and/or high school?	❑ Never ❑ Occasionally ❑ Often ❑ Very often
32.	During junior or high school, did you get in trouble with the police or other law enforcement officials? (more than one answer possible)	❑ No ❑ Yes, for theft ❑ Yes, for destruction of property ❑ Yes for violence towards others ❑ Yes, traffic offense ❑ Yes, for other offenses: Explain____
33.	Have you ever been suspended or expelled for misbehavior during junior and/or high school?	❑ Yes ❑ No
34.	Have you ever been asked to leave a class by the teacher because of your behavior during junior and/or high school?	❑ Yes ❑ No
35.	How often did you go to a bar or dance club during junior and/or high school?	❑ Often ❑ Occasionally ❑ Never

Part 3 The Years After High School

The following questions refer to the years after high school

36.	Did you continue your education **after** high school?	❑ Yes ❑ No, (*skip to question 37*)

What type of school did you attend following high school? (more than one answer possible)	Still Attending	Diploma Not Completed	Diploma Completed
❑ Technical School, such as ITT, Trade school	❑	❑	❑
❑ Apprenticeship (eg. plumber, electrician)	❑	❑	❑
❑ College	❑	❑	❑
❑ University	❑	❑	❑
❑ Graduate school	❑	❑	❑
❑ Other _____			

37.	Did you find a paying job after completion of high school?	❑ Yes ❑ No
38.	Did you participate for at least one year in competitive sports (for example, soccer, judo, tennis, etc) after completion of high school ?	❑ Yes ❑ No
39.	Did you participate for at least one year in any other activity (for example, scouts, music, dance) after completion of high school?	❑ Yes ❑ No
40.	Did you drink alcohol after completion of high school?	❑ Never ❑ Occasionally ❑ Often ❑ Very often
41.	Did you take "calming" drugs such as valium or other sedatives after completion of high school?	❑ Never ❑ Occasionally ❑ Often ❑ Very often
42.	Did you use soft drugs such as marijuana or hashish after completion of high school?	❑ Never ❑ Occasionally ❑ Often ❑ Very often
43.	Did you take psychedelic drugs such as LSD or XTC after completion of high school?	❑ Never ❑ Occasionally ❑ Often ❑ Very often
44.	Did you take hard drugs such as cocaine or heroine after completion of high school?	❑ Never ❑ Occasionally ❑ Often ❑ Very often
45.	Did you smoke cigarettes after completion of high school?	❑ No ❑ Yes, 1-10 cigarettes per day ❑ Yes, 11-20 cigarettes per day ❑ Yes, more than 20 cigarettes per day
46.	Did you gamble for money (for example play in a casino or at a slot machine) after completion of high school	❑ Never ❑ Occasionally ❑ Often ❑ Very often

Part 4 The following questions do not relate to a specific age/school period

47.	At what age did you have your first girl/boyfriend?	❑ I haven't had one yet ❑ Younger than 12 ❑ 12-14 ❑ 15-17 ❑ 18 or older
48.	At what age did you take your first vacation without adults?	❑ I haven't yet ❑ Younger than 12 ❑ 12-14 ❑ 15-17 ❑ 18-20 ❑ 21 or older
49.	At what age did you fall in love for the first time?	❑ I haven't yet ❑ Younger than 13 ❑ 13-18 ❑ 19 or older
50.	At what age did you experience sexual intimacy (not intercourse) for the first time?	❑ I haven't yet ❑ Younger than 13 ❑ 13-18 ❑ 19 or older
51.	At what age did you experience sexual intercourse for the first time?	❑ I haven't yet ❑ Younger than 13 ❑ 13-18 ❑ 19 or older
52.	At what age did you leave your parents home to live somewhere else?	❑ I haven't yet, I still live at home ❑ Younger than 11 ❑ 11-15 ❑ 16 – 20 ❑ 21 or older
52a.	What was the reason for leaving the parental home?	❑ Problems with parents ❑ Illness or physical disability ❑ Study ❑ Living with partner ❑ Other_____

53.	Have you ever experienced any of the following events, and, if so, in which period of your life—before elementary school, during elementary school, during junior/high school or after high school. *If you didn't experience such an event, leave that line blank.*	Before elementary school	During elementary school	During junior or high school	After high school
	Had a serious illness yourself, if so, which one _____	❑	❑	❑	❑
	Had a serious accident yourself	❑	❑	❑	❑
	Your parents got a divorce.	❑	❑	❑	❑
	Death of a family member.	❑	❑	❑	❑
	Severe illness of a family member.	❑	❑	❑	❑
	Moving	❑	❑	❑	❑
	Sexual harassment	❑	❑	❑	❑
	Imprisonment of a family member	❑	❑	❑	❑
	Death of a close friend	❑	❑	❑	❑
	Parent losing his/her job	❑	❑	❑	❑
	Parent admitted to a psychiatric hospital.	❑	❑	❑	❑

Now some general questions:

54.	What year were you born in?	_____
55.	What date did you complete this questionnaire?	_____ _____ , 20_____ month day year
56.	Are you ❒ male or ❒ female?	
57.	What is your living situation?	❑ Parents' home/foster home ❑ On my own (renting or buying a home) ❑ Living with partner/spouse with or without children ❑ In a school dorm/apartment ❑ With roommates ❑ In a group home ❑ Other_____
58.	What is your marital status?	❑ Married/living together ❑ Divorced ❑ Single ❑ Widowed
59.	Do you have any children?	❑ No ❑ Yes, _____(number)
The next 4 questions (a-d) are for females only.		
a.	Are you currently pregnant?	❑ Yes ❑ No
b.	How many pregnancies did you carry full-term?	❑ 0 ❑ 1 ❑ 2 ❑ More than 2
c.	Have you ever had a miscarriage?	❑ Yes ❑ No
d.	Have you ever had an abortion?	❑ Yes ❑ No
60.	What is your religious affiliation?	❑ None (*skip to question 62*) ❑ Roman Catholic ❑ Protestant ❑ Muslim ❑ Hindu ❑ Jewish ❑ Other_____
61.	How active are you in your religious affiliation?	❑ Active ❑ Inactive

62.	Put a check in the column to indicate which type of family setting you **mainly** live/lived in before elementary school, during elementary school and during junior/high school. (choose one answer for each time period/column)	Before elementary school	During elementary school	During junior or high school
	Living with your father and mother	❑	❑	❑
	Living with just your mother	❑	❑	❑
	Living with just your father	❑	❑	❑
	Living with your mother and her partner	❑	❑	❑
	Living with your father and his partner	❑	❑	❑
	Living with an adoptive/foster family	❑	❑	❑
	Living in a children's home	❑	❑	❑
	Other _____	❑	❑	❑

63.	How many children are (were) there in the family where you grew up, including yourself?	❑ 1 ❑ 2-3 ❑ 4 or more
64.	What is your position in the family?	❑ Only child ❑ Oldest child ❑ One of the middle children ❑ Youngest child
65.	What is your mother's highest level of education?	❑ Less than high school ❑ Graduated high school/GED ❑ Some college/ vocational school ❑ Graduated college/vocational school ❑ Some professional/ graduate school ❑ Graduated professional/graduate school
66.	What is your father's highest level of education?	❑ Less than high school ❑ Graduated high school/GED ❑ Some college/ vocational school ❑ Graduated college/vocational school ❑ Some professional/ graduate school ❑ Graduated professional/graduate school

67. What type of job did your father have most of his life (including househusband)?

_____

68. What type of job did your mother have most of her life (including housewife)?

_____

Thank you for completing this Course of life questionnaire!

APPENDIX 2. Beck Depression Inventory – II

BDI-II

Date:

Name: _____ Marital Status: _____ Age: _____ Sex: _____

Occupation: _____ Education: _____

Instructions: This questionnaire consists of 21 groups of statements. Please read each group of statements carefully, and then pick out the **one statement** in each group that best describes the way you have been feeling during the **past two weeks, including today.** Circle the number beside the statement you have picked. If several statements in the group seem to apply equally well, circle the highest number for that group. Be sure that you do not choose more than one statement for any group, including Item 16 (Changes in Sleeping Pattern) or Item 18 (Changes in Appetite).

1. Sadness
- 0 I do not feel sad.
- 1 I feel sad much of the time.
- 2 I am sad all the time.
- 3 I am so sad or unhappy that I can't stand it.

2. Pessimism
- 0 I am not discouraged about my future.
- 1 I feel more discouraged about my future than I used to be.
- 2 I do not expect things to work out for me.
- 3 I feel my future is hopeless and will only get worse.

3. Past Failure
- 0 I do not feel like a failure.
- 1 I have failed more than I should have.
- 2 As I look back, I see a lot of failures.
- 3 I feel I am a total failure as a person.

4. Loss of Pleasure
- 0 I get as much pleasure as I ever did from the things I enjoy.
- 1 I don't enjoy things as much as I used to.
- 2 I get very little pleasure from the things I used to enjoy.
- 3 I can't get any pleasure from the things I used to enjoy.

5. Guilty Feelings
- 0 I don't feel particularly guilty.
- 1 I feel guilty over many things I have done or should have done.
- 2 I feel quite guilty most of the time.
- 3 I feel guilty all of the time.

6. Punishment Feelings
- 0 I don't feel I am being punished.
- 1 I feel I may be punished.
- 2 I expect to be punished.
- 3 I feel I am being punished.

7. Self-Dislike
- 0 I feel the same about myself as ever.
- 1 I have lost confidence in myself.
- 2 I am disappointed in myself.
- 3 I dislike myself.

8. Self-Criticalness
- 0 I don't criticize or blame myself more than usual.
- 1 I am more critical of myself than I used to be.
- 2 I criticize myself for all of my faults.
- 3 I blame myself for everything bad that happens.

9. Suicidal Thoughts or Wishes
- 0 I don't have any thoughts of killing myself.
- 1 I have thoughts of killing myself, but I would not carry them out.
- 2 I would like to kill myself.
- 3 I would kill myself if I had the chance.

10. Crying
- 0 I don't cry any more than I used to.
- 1 I cry more than I used to.
- 2 I cry over every little thing.
- 3 I feel like crying, but I can't.

_____ Subtotal Page 1 Continued on Back

11. Agitation

0 I am no more restless or wound up than usual.
1 I feel more restless or wound up than usual.
2 I am so restless or agitated that it's hard to stay still.
3 I am so restless or agitated that I have to keep moving or doing something.

12. Loss of Interest

0 I have not lost interest in other people or activities.
1 I am less interested in other people or things than before.
2 I have lost most of my interest in other people or things.
3 It's hard to get interested in anything.

13. Indecisiveness

0 I make decisions about as well as ever.
1 I find it more difficult to make decisions than usual.
2 I have much greater difficulty in making decisions than I used to.
3 I have trouble making any decisions.

14. Worthlessness

0 I do not feel I am worthless.
1 I don't consider myself as worthwhile and useful as I used to.
2 I feel more worthless as compared to other people.
3 I feel utterly worthless.

15. Loss of Energy

0 I have as much energy as ever.
1 I have less energy than I used to have.
2 I don't have enough energy to do very much.
3 I don't have enough energy to do anything.

16. Changes in Sleeping Pattern

0 I have not experienced any change in my sleeping pattern.

1a I sleep somewhat more than usual.
1b I sleep somewhat less than usual.

2a I sleep a lot more than usual.
2b I sleep a lot less than usual.

3a I sleep most of the day.
3b I wake up 1–2 hours early and can't get back to sleep.

17. Irritability

0 I am no more irritable than usual.
1 I am more irritable than usual.
2 I am much more irritable than usual.
3 I am irritable all the time.

18. Changes in Appetite

0 I have not experienced any change in my appetite.

1a My appetite is somewhat less than usual.
1b My appetite is somewhat greater than usual.

2a My appetite is much less than before.
2b My appetite is much greater than usual.

3a I have no appetite at all.
3b I crave food all the time.

19. Concentration Difficulty

0 I can concentrate as well as ever.
1 I can't concentrate as well as usual.
2 It's hard to keep my mind on anything for very long.
3 I find I can't concentrate on anything.

20. Tiredness or Fatigue

0 I am no more tired or fatigued than usual.
1 I get more tired or fatigued more easily than usual.
2 I am too tired or fatigued to do a lot of the things I used to do.
3 I am too tired or fatigued to do most of the things I used to do.

21. Loss of Interest in Sex

0 I have not noticed any recent change in my interest in sex.
1 I am less interested in sex than I used to be.
2 I am much less interested in sex now.
3 I have lost interest in sex completely.

_____ Subtotal Page 2
_____ Subtotal Page 1
_____ Total Score

APPENDIX 3. Short Quality of Life in Inflammatory Bowel Disease Questionnaire

Short Quality of Life in Inflammatory Bowel Disease Questionnaire

This questionnaire is designed to find out how you have been feeling during the last 2 weeks. You will be asked about symptoms you have been having as a result of your inflammatory bowel disease, the way you have been feeling in general, and how your mood has been.

1. How often has the feeling of fatigue or of being tired and worn out been a problem for you during the last 2 weeks? (Choose one option)

   - ☐ All of the time
   - ☐ Most of the time
   - ☐ A good bit of the time
   - ☐ Some of the time
   - ☐ A little of the time
   - ☐ Hardly any of the time
   - ☐ None of the time

2. How often during the last 2 weeks have you had to delay or cancel a social engagement because of your bowel problem? (Choose one option)

   - ☐ All of the time
   - ☐ Most of the time
   - ☐ A good bit of the time
   - ☐ Some of the time
   - ☐ A little of the time
   - ☐ Hardly any of the time
   - ☐ None of the time

3. How much difficulty have you had, as a result of your bowel problems, doing leisure or sports activities you would have liked to have done during the last 2 weeks? (Choose one option)

   - ☐ A great deal of difficulty, activities made impossible
   - ☐ A lot of difficulty
   - ☐ A fair bit of difficulty
   - ☐ Some difficulty
   - ☐ A little difficulty
   - ☐ Hardly any difficulty
   - ☐ No difficulty; the bowel problems did not limit sports or leisure activities

4. How often during the last 2 weeks have you been troubled by pain in the abdomen? (Choose one option)

   - ☐ All of the time
   - ☐ Most of the time
   - ☐ A good bit of the time
   - ☐ Some of the time
   - ☐ A little of the time
   - ☐ Hardly any of the time
   - ☐ None of the time

5. How often during the last 2 weeks have you felt depressed or discouraged? (Choose one option)

   - ☐ All of the time
   - ☐ Most of the time
   - ☐ A good bit of the time
   - ☐ Some of the time
   - ☐ A little of the time
   - ☐ Hardly any of the time
   - ☐ None of the time

6. Overall, in the last 2 weeks, how much of a problem have you had with passing large amounts of gas? (Choose one option)

   - ☐ A major problem
   - ☐ A big problem
   - ☐ A significant problem
   - ☐ Some trouble
   - ☐ A little trouble
   - ☐ Hardly any trouble
   - ☐ No trouble

7. Overall, in the last 2 weeks, how much of a problem have you had maintaining or getting to the weight you would like to be? (Choose one option)

   - ☐ A major problem
   - ☐ A big problem
   - ☐ A significant problem
   - ☐ Some trouble
   - ☐ A little trouble
   - ☐ Hardly any trouble
   - ☐ No trouble

8. How often during the last 2 weeks have you felt relaxed and free of tension? (Choose one option)

   - ☐ None of the time
   - ☐ A little of the time
   - ☐ Some of the time
   - ☐ A good bit of the time
   - ☐ Most of the time
   - ☐ Almost all of the time
   - ☐ All of the time

9. How much of the time during the last 2 weeks have you been troubled by a feeling of having to go to the bathroom even though your bowels were empty? (Choose one option)

   - ☐ All of the time
   - ☐ Most of the time
   - ☐ A good bit of the time
   - ☐ Some of the time
   - ☐ A little of the time
   - ☐ Hardly any of the time
   - ☐ None of the time

10. How much of the time during the last 2 weeks have you felt angry as a result of your bowel problem? (Choose one option)

    - ☐ All of the time
    - ☐ Most of the time
    - ☐ A good bit of the time
    - ☐ Some of the time
    - ☐ A little of the time
    - ☐ Hardly any of the time
    - ☐ None of the time

(Appendix from American Journal of Gastroenterology, 1996, 91(8):1571-3).

APPENDIX 4. World Health Organization Health and Performance Questionnaire

World Health Organization Health and Performance Questionnaire (HPQ): Clinical Trials Baseline Version

TRACKING NUMBER

INSTRUCTIONS

Most of the following questions have numbered response options. Respond by CIRCLING THE NUMBER for your preferred answer. For example, if you consider your health "Fair," respond as follows:

A1. In general, how would you rate <u>your overall health</u> now?

1. Excellent
2. Very Good
3. Good
4. Fair
5. Poor

If none of the categories fits you exactly, please respond with the closest category to your experience.

If you want to change your response, put an "X" through the incorrect response and circle the correct response. For example, if you want to change your response from "Fair" to "Good," make the correction as follows:

A1. In general, how would you rate <u>your overall health</u> now?

1. Excellent
2. Very Good
3. Good
4. Fair
5. Poor

A few questions in the booklet require you to fill in numbers or to provide brief written descriptions. Please fill these out legibly.

C1. How old are you?

46 YEARS OLD

There are no right or wrong answers. Your responses are completely confidential. Please answer as honestly and accurately as you can.

A. YOUR WORK

A1. Are you currently in any of the following work situations? For each "Yes" response, record how long you have been in this situation (for example, 3 weeks or 5 months or 7 years).

	Yes	No	How long have you been in this situation? *Enter Number*	*(Circle only one)* Weeks	Months	Years
a. Unemployed and looking for work?..	1	2	_____	1	2	3
b. Temporarily laid off?.....	1	2	_____	1	2	3
c. Maternity leave?.....	1	2	_____	1	2	3
d. Short-term sick leave?.....	1	2	_____	1	2	3
e. Extended sick leave or disability?.....	1	2	_____	1	2	3
f. Retired?.....	1	2	_____	1	2	3

A2. Do you do any of the following kinds of work? For each "Yes" response, estimate the number of hours you typically spend doing this kind of work each week. If it varies, estimate the average.

	Yes	No	Average Number of Hours each Week
a. Caregiver for your child(ren)?.....	1	2	_____
b. Working a full-time paying job?.....	1	2	_____
c. Working a part-time paying job?.....	1	2	_____
d. Self-employed?.....	1	2	_____
e. Volunteer work?.....	1	2	_____
f. Full-time student?.....	1	2	_____
g. Part-time student?.....	1	2	_____
h. Housework/home maintenance?.....	1	2	_____

A3. **If you currently work for pay or profit or are on sick leave, please choose the category that best describes your <u>main</u> job. If none of the categories fits you exactly, please respond with the closest category. If you are currently not working and not on sick leave, skip to question B1.** ***(Circle only <u>one</u> number.)***

1. Executive, administrator, or senior manager
   (e.g., CEO, sales VP, plant manager)

2. Professional
   (e.g., engineer, accountant, systems analyst)

3. Technical support
   (e.g., lab technician, legal assistant, computer programmer)

4. Sales
   (e.g., sales representative, stockbroker, retail sales)

5. Clerical and administrative support
   (e.g., secretary, billing clerk, office supervisor)

6. Service occupation
   (e.g., security officer, food service worker, janitor)

7. Precision production and crafts worker
   (e.g., mechanic, carpenter, machinist)

8. Operator or laborer
   (e.g., assembly line worker, truck driver, construction worker)

A4. **How many people do you <u>personally</u> supervise on your main job?**

_____ NUMBER OF PEOPLE

A5. **How many hours does your employer expect you to work in a typical 7-day week? If it varies, estimate the average. If you are self-employed, estimate the number of hours you would consider a full work week. If you have more than one job, combine total number of hours for all jobs.**

_____ NUMBER OF HOURS

A6. **Now please think of your work experiences over the past 4 weeks (28 days). In the spaces provided below, write the number of days you spent in each of the following work situations.**

In the past 28 days, how many days did you…	NUMBER OF DAYS
a. ...miss an **entire** work day because of problems with your physical or mental health?	_____
b. ...miss an **entire** work day for any other reason (including vacation)?	_____
c. ...miss **part** of a work day because of problems with your physical or mental health?	_____
d. ...miss **part** of a work day for any other reason (including vacation)?	_____
e. ...come in early, go home late, or work on your day off?	_____

A7. **About how many hours altogether did you work in the past 4 weeks (28 days)? (See examples below.) If you have more than one job, report the combined total number of hours for all jobs. If you did not work at all in the past 28 days, enter "0" and skip to question B1.**

_____ NUMBER OF HOURS

Examples for Calculating Hours Worked in the Past 4 Weeks
40 hours per week for 4 weeks = 160 hours
35 hours per week for 4 weeks = 140 hours
40 hours per week for 4 weeks with 2 8-hour days missed = 144 hours
40 hours per week for 4 weeks with 3 4-hour partial days missed = 148 hours
35 hours per week for 4 weeks with 2 8-hour days missed and 3 4-hour partial days missed = 112 hours

A8. Did you have any of the following experiences at work in the past 4 weeks?

	Yes	No
a. Any special work success or achievement?.....	1	2
b. Any special work failure?.....	1	2
c. An accident that caused either damage, work delay, a near miss, or a safety risk?....	1	2

d. If you answered "Yes" to any of the questions A8a, A8b, or A8c, please describe what happened.

_____

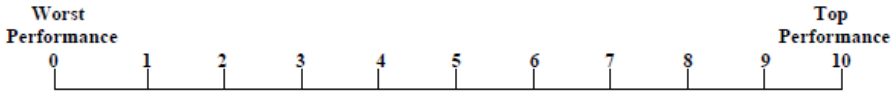
_____

_____

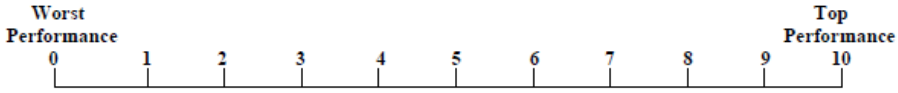
A9. The next questions are about the time you spent during your hours at work in the past 4 weeks. Circle the one number from each question that comes closest to your experience.

	All of the time	Most of the time	Some of the time	A little of the time	None of the time
a. How often was your performance **higher** than most workers on your job?.....	1	2	3	4	5
b. How often was your performance **lower** than most workers on your job?.....	1	2	3	4	5
c. How often did you do no work at times when you were supposed to be working?..	1	2	3	4	5
d. How often did you find yourself not working as **carefully** as you should?.....	1	2	3	4	5
e. How often was the **quality** of your work lower than it should have been?.....	1	2	3	4	5
f. How often did you not concentrate enough on your work?.....	1	2	3	4	5
g. How often did health problems limit the kind or amount of work you could do?.....	1	2	3	4	5

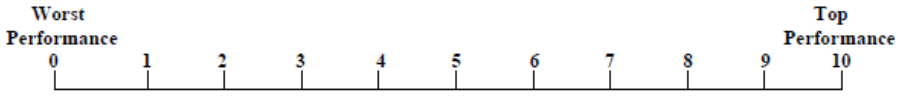
A10. **On a scale from 0 to 10 where 0 is the worst job performance anyone could have at your job and 10 is the performance of a top worker, how would you rate the usual performance of most workers in a job similar to yours?** *(Circle the number)*



A11. **Using the same 0-to-10 scale, how would you rate your usual job performance over the past year or two?** *(Circle the number)*



A12. **Using the same 0-to-10 scale, how would you rate your overall performance on the days you worked during the past 4 weeks?** *(Circle the number)*



A13. How would you compare your overall job performance on the days you worked during the past 4 weeks with the performance of most other workers who have a similar type of job? *(Circle the number)*

1. You were **a lot better** than other workers
2. You were **somewhat better** than other workers
3. You were **a little better** than other workers
4. You were about **average**
5. You were **a little worse** than other workers
6. You were **somewhat worse** than other workers
7. You were **a lot worse** than other workers

APPENDIX 5. Recruitment Letter for IBD Patients

UNIVERSITY OF ALBERTA

Division of Gastroenterology
Department of Medicine

Richard N. Fedorak, MD, FRCPC
Professor of Medicine

Zeidler Family Gastrointestinal Health & Research Institute
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Edmonton, Alberta, Canada T6G 2X8
www.medicine.med.ualberta.ca/divisions/gast

Tel: 780-492-6941
Clinic Line 492-8120
Fax: 780-492-8121

Date: _____

Name/Address_____
_____
_____

Dear _____,

You are being invited to participate in an exciting research project entitled, ***The Impact of Childhood Inflammatory Bowel Disease and the General Well Being and Societal Functioning in Early Adulthood***. We are contacting all our patients, aged 18-30, with a diagnosis of inflammatory bowel disease in case they would like to participate.

As you know the Division of Gastroenterology at the University of Alberta is Canada's leading gastrointestinal research centre. Your participation in this project will help us in finding better ways to treat IBD patients.

What Is The Research Project?
The purpose of this project is to develop a better understanding of how a diagnosis of Crohn's disease or ulcerative colitis, early in life, impacts the social interactions and functioning later in life.

What Will Be Required Of Me If I Agree To Participate?
Participants will be required to complete 4 simple questionnaires and a medical history sheet. The total time to complete the questionnaires is 45-60 minutes.

What is in it for me?
There may be no direct benefit to you but you will help researchers understand whether a diagnosis of inflammatory bowel disease early in life has an impact on patients' general well being and ability to function in society. To help compensate you for your time, we are please to provide you with a $20 gift certificate for completion of the questionnaires.

Please contact Dr. Karen Kroeker (IBD Fellow) at kkroeker@ualberta.ca or 780-248-1032 if you would like to learn more about the study. You will be given a more detailed description of the study if you are interested in participating. Participation in this study is voluntary. Whether you participate or not will have no effect on the medical care you will receive here at the University of Alberta.

If we have not heard back from you, we may contact you by phone to see if you want to hear more about this study.

With warm regards,
Sincerely,

KAREN KROEKER, MD, FRCPC
IBD Fellow

RICHARD N FEDORAK, MD, FRCPC, FRCP (London)
Professor of Medicine

Dec 2, 2009

APPENDIX 6. Patient Demographic Sheet

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Fax: 780-492-8121

DEMOGRAPHICS SHEET – IBD Patients

Do you have inflammatory bowel disease? ☐ Crohn's ☐ Ulcerative Colitis ☐ Not sure

When were you diagnosed? _____ (Year)

Have you ever had surgery for your inflammatory bowel disease? ☐ No ☐ Yes
If yes, please list the surgery and the date:

Surgery:	Date (Year):
_____	_____
_____	_____
_____	_____

Was there any event related to your inflammatory bowel disease that you would say was particularly significant? This may have been the diagnosis, a surgery, or hospitalization, etc.
☐ No ☐ Yes
If yes, what was the event? _____
How old were you? _____

What medications do you OR have you taken for your inflammatory bowel disease?
☐ Sulfasalazine (Salazopyrine)
☐ Mesalamine (Pentasa, Asacol, Salofalk, Mezavant)
☐ Budesonide
☐ Prednisone (steroids)
☐ Methotrexate (MTX)
☐ Imuran (azathioprine)/ 6-MP (6-mercaptopurine, Purinethol)
☐ anti-TNF/Biologics (Infliximab/Remicade, Adalimumab/Humira, Certolizumab/Cimzia)
☐ Other, please list: _____

<u>CURRENT</u> MEDICAL HISTORY:

Are you currently on any medications prescribed by a physician? ☐ No ☐ Yes
If yes, please list:

_____	_____
_____	_____
_____	_____

Do you have any other medical conditions (eg. Asthma, arthritis, heart, kidney or liver problems)? ☐ No ☐ Yes
If yes, please list:

_____	_____
_____	_____
_____	_____

Have you ever had any other surgery (not related to your inflammatory bowel disease)?
☐ No ☐ Yes
If yes, please list the surgery and the date:

Surgery:	Date (Year):
_____	_____
_____	_____
_____	_____

APPENDIX 7. Newspaper Advertisement for Healthy Controls

WANTED HEALTHY ADULTS

Research Study Comparing the General Well Being and Societal Functioning of Healthy Persons to Patients with Chronic Illness

PARTICIPANTS NEEDED

What is the goal of the study?

The goal of the study is to compare the development, workplace performance, and mood of healthy persons to patients with inflammatory bowel disease.

Who can enter the study?

Healthy adults aged 18 – 30. Fluency in written English is required.

What are the participants asked to do?

Participants will need to complete ~20 page survey about their childhood & adolescence, workplace performance and mood.

Are participants compensated?

Participants will be compensated with a $20 gift certificate for returning the completed surveys.

Who can I contact for more information?

You may call 780-248-1032 or email survey@ualberta.ca to learn more about this study.

UNIVERSITY OF ALBERTA

The Impact of Childhood Inflammatory Bowel Disease and the General Well Being and Societal Functioning in Early Adulthood

APPENDIX 8. Healthy Control Demographics Sheet

UNIVERSITY OF ALBERTA
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richard.fedorak@ualberta.ca
www.medicine.medsask.ualberta.ca/divisions/gastro/
Tel: 780-492-6941
Clinic Line: 492-8120
Fax: 780-492-8121

DEMOGRAPHICS SHEET – Healthy Volunteers

CURRENT MEDICAL HISTORY:

Are you currently on any medications prescribed by a physician? ☐ No ☐ Yes
If yes, please list:

_____ _____
_____ _____
_____ _____

Do you have any chronic medical conditions (eg. Asthma, arthritis, kidney or liver problems, or inflammatory bowel disease)? ☐ No ☐ Yes
If yes, please list:

_____ _____
_____ _____
_____ _____

PAST MEDICAL HISTORY:

Have you ever had surgery? ☐ No ☐ Yes
If yes, please list the surgery and the date:
Surgery: Date (Year):

_____ _____
_____ _____
_____ _____

Have you ever been admitted to hospital? ☐ No ☐ Yes
If yes, please list the reason and the date:
Reason for hospitalization: Date (Year):

_____ _____
_____ _____
_____ _____

Have you ever been diagnosed with a medical condition (eg. Asthma, arthritis, heart, kidney or liver problems, or inflammatory bowel disease)? ☐ No ☐ Yes
If yes, please list:

_____ _____
_____ _____
_____ _____

APPENDIX 9. Healthy Control Consent Form

UNIVERSITY OF ALBERTA
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APPENDIX 8. Healthy Control Demographics Sheet

INFORMATION SHEET – IBD Patients

Title of Research Study: **The Impact of Childhood Inflammatory Bowel Disease and the General Well Being and Societal Functioning in Early Adulthood**

Principal Investigator(s): Dr. Richard Fedorak

Sub-Investigator(s): Dr. Karen Kroeker

Background: *Children and teenagers with chronic illness, like inflammatory bowel disease, sometimes have more difficulty in being successful in life during their teenage years compared to their peers who are healthy. We want to know if these difficulties persist into early adulthood (ages 18-30).*

You are being asked to participate because:

a) you have Crohn's disease or ulcerative colitis AND
b) you are between the ages of 18 and 30

Purpose: *You are being asked to participate in a research study in order to determine the impact of being diagnosed with inflammatory bowel disease (Crohn's disease or ulcerative colitis) before the age of 18. We are interested in finding out if young adults with a childhood diagnosis of Crohn's or ulcerative colitis are similar or different to their peers in areas of societal functioning (development, depression, work and education).*

Procedures: *Participating in this study will involve:*

a) *Completion of 4 questionnaires and a demographic information sheet. This will take approximately 45-60 minutes.*
b) *Your medical records (office charts and Alberta Netcare) will be accessed to obtain your medical history (regarding diagnosis, treatment, extent of disease, etc.)*

Possible Benefits: *There may be no direct benefit to you but you will help researchers understand whether a diagnosis early in life has an impact on patients' general well being and ability to function in society.*

Possible Risks: *None anticipated. However, if evidence of significant depression is identified in your surveys, your family physician will be notified and you may require follow-up at the University of Alberta outpatient psychiatry department.*

Confidentiality: *Personal health records relating to this study will be kept confidential. Any research data collected about you during this study will not identify you by name, only by your initials and a coded number. Your name will not be disclosed outside the research clinic. Any report published as a result of this study will not identify you by name.*

For this study, the study doctor may need to access your personal health records for health information such as past medical history and test results. He/she may also need to contact your family physician and your other health care providers to obtain additional medical information. The health information collected as part of this study will be kept confidential unless release is required by law, and will be used only for the purpose of the research study. By signing the consent form you give permission to the study staff to access any personally identifiable health information which is under the custody of other health care professionals as deemed necessary for the conduct of the research.

Study data will be stored for a minimum of 5 years on the secured intranet at Division of Gastroenterology at the University of Alberta.

Voluntary Participation: *You are free to withdraw from the research study at any time, and your continuing medical care will not be affected in any way. You are free to leave questions blank if you so choose. If the study is not undertaken or if it is discontinued at any time, the quality of your medical care will not be affected. If any knowledge gained from this or any other study becomes available which could influence your decision to continue in the study, you will be promptly informed.*

Reimbursement of Expenses: *You will be reimbursed $20 in the form of a bookstore gift certificate for your time. This will be mailed to you after the survey has been returned.*

Contact Names and Telephone Numbers:
If you have concerns about your rights as a study participant, you may contact the Patient Relations Office of Alberta Health Services, at (780)342-8080. This office has no affiliation with the study investigators.

Please contact any of the individuals identified below if you have any questions or concerns:

Dr. Karen Kroeker, IBD Fellow kkroeker@ualberta.ca; Phone 780-248-1032

**This information sheet is yours to keep.

UNIVERSITY OF ALBERTA
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Edmonton, Alberta, Canada T6G 2X8
Tel: 780-492-6901
Clinic Line 492-8120
Fax: 780-492-8121

Part 1 (to be completed by the Principal Investigator):

Title of Project: The Impact of Childhood Inflammatory Bowel Disease and the General Well Being and Societal Functioning in Early Adulthood

Principal Investigator(s): Dr. Richard Fedorak Phone Number(s): 780-492-8120

Co-Investigator(s): Dr. Karen Kroeker Phone Number(s): 780-248-1032

Part 2 (to be completed by the research subject):

	Yes	No
Do you understand that you have been asked to be in a research study?	☐	☐
Have you read and received a copy of the attached Information Sheet?	☐	☐
Do you understand the benefits and risks involved in taking part in this research study?	☐	☐
Have you had an opportunity to ask questions and discuss this study?	☐	☐
Do you understand that you are free to withdraw from the study at any time, without having to give a reason and without affecting your future medical care?	☐	☐
Has the issue of confidentiality been explained to you?	☐	☐
Do you understand who will have access to your records, including personally identifiable health information?	☐	☐

Who explained this study to you? _____

I agree to take part in this study: YES ☐ NO ☐

Signature of Research Subject _____

(Printed Name) _____

Date:_____

Signature of Witness _____

I believe that the person signing this form understands what is involved in the study and voluntarily agrees to participate.

Signature of Investigator or Designee _____ Date _____

**Please sign and return one (1) copy of this page and keep one (1) for your records.

APPENDIX 10. IBD Patient Consent Form

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www.medicine.medicine.ualberta.ca/divisions/gastro
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Fax: 780-492-8121

APPENDIX 8. Healthy Control Demographics Sheet

INFORMATION SHEET – IBD Patients

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Principal Investigator(s): Dr. Richard Fedorak

Sub-Investigator(s): Dr. Karen Kroeker

Background: *Children and teenagers with chronic illness, like inflammatory bowel disease, sometimes have more difficulty in being successful in life during their teenage years compared to their peers who are healthy. We want to know if these difficulties persist into early adulthood (ages 18-30).*

You are being asked to participate because:

a) you have Crohn's disease or ulcerative colitis AND
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Possible Benefits: *There may be no direct benefit to you but you will help researchers understand whether a diagnosis early in life has an impact on patients' general well being and ability to function in society.*

Possible Risks: *None anticipated. However, if evidence of significant depression is identified in your surveys, your family physician will be notified and you may require follow-up at the University of Alberta outpatient psychiatry department.*

Confidentiality: *Personal health records relating to this study will be kept confidential. Any research data collected about you during this study will not identify you by name, only by your initials and a coded number. Your name will not be disclosed outside the research clinic. Any report published as a result of this study will not identify you by name.*

For this study, the study doctor may need to access your personal health records for health information such as past medical history and test results. He/she may also need to contact your family physician and your other health care providers to obtain additional medical information. The health information collected as part of this study will be kept confidential unless release is required by law, and will be used only for the purpose of the research study. By signing the consent form you give permission to the study staff to access any personally identifiable health information which is under the custody of other health care professionals as deemed necessary for the conduct of the research.

Study data will be stored for a minimum of 5 years on the secured intranet at Division of Gastroenterology at the University of Alberta.

Voluntary Participation: *You are free to withdraw from the research study at any time, and your continuing medical care will not be affected in any way. You are free to leave questions blank if you so choose. If the study is not undertaken or if it is discontinued at any time, the quality of your medical care will not be affected. If any knowledge gained from this or any other study becomes available which could influence your decision to continue in the study, you will be promptly informed.*

Reimbursement of Expenses: *You will be reimbursed $20 in the form of a bookstore gift certificate for your time. This will be mailed to you after the survey has been returned.*

Contact Names and Telephone Numbers:
If you have concerns about your rights as a study participant, you may contact the Patient Relations Office of Alberta Health Services, at (780)342-8080. This office has no affiliation with the study investigators.

Please contact any of the individuals identified below if you have any questions or concerns:

Dr. Karen Kroeker, IBD Fellow kkroeker@ualberta.ca; Phone 780-248-1032

**This information sheet is yours to keep.

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Tel: 780-492-6961
Clinic Line 492-8120
Fax: 780-492-8121

Part 1 (to be completed by the Principal Investigator):

Title of Project: The Impact of Childhood Inflammatory Bowel Disease and the General Well Being and Societal Functioning in Early Adulthood

Principal Investigator(s): Dr. Richard Fedorak Phone Number(s): 780-492-8120

Co-Investigator(s): Dr. Karen Kroeker Phone Number(s): 780-248-1032

Part 2 (to be completed by the research subject):

	Yes	No
Do you understand that you have been asked to be in a research study?	☐	☐
Have you read and received a copy of the attached Information Sheet?	☐	☐
Do you understand the benefits and risks involved in taking part in this research study?	☐	☐
Have you had an opportunity to ask questions and discuss this study?	☐	☐
Do you understand that you are free to withdraw from the study at any time, without having to give a reason and without affecting your future medical care?	☐	☐
Has the issue of confidentiality been explained to you?	☐	☐
Do you understand who will have access to your records, including personally identifiable health information?	☐	☐

Who explained this study to you? _____

I agree to take part in this study: YES ☐ NO ☐

Signature of Research Subject _____

(Printed Name) _____

Date: _____

Signature of Witness _____

I believe that the person signing this form understands what is involved in the study and voluntarily agrees to participate.

Signature of Investigator or Designee _____ Date _____

****Please sign and return one (1) copy of this page and keep one (1) for your records.**