Journal of the Canadian Association of Gastroenterology, 2022, 5(2), 59–67
https://doi.org/10.1093/jcag/gwab022
Original Article
Advance Access publication 21 July 2021

Original Article

Factors Associated With Social Participation in Persons Living With Inflammatory Bowel Disease

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ABSTRACT

Background: Inflammatory bowel disease (IBD) including Crohn's disease (CD) and ulcerative colitis (UC) imposes a significant burden on health-related quality of life, particularly in social domains. We sought to investigate the factors that limit social participation in patients with IBD.

Methods: We assessed a cohort of 239 Manitobans with IBD. We collected sociodemographic information, medical comorbidities, disease phenotype, symptom activity and psychiatric comorbidity (using the Structured Clinical Interview for DSM-IV). Participants completed the eight-item Ability to Participate in Social Roles and Activities (APSRA) questionnaire, which assesses participation restriction, including problems experienced in social interaction, employment, transportation, community, social and civic life.

Results: Poorer social participation scores were associated with earning less than $50,000 CAD income annually ($P < 0.001$), actively smoking ($P = 0.006$), higher symptom scores ($P < 0.001$ for CD, $P = 0.004$ for UC), and having an increasing number of chronic medical conditions ($R = -0.30$). History of depression ($P < 0.001$) and anxiety ($P = 0.001$) and having active depression ($P < 0.001$) and anxiety ($P = 0.001$) all predicted poor social participation scores. IBD phenotype or disease duration was not predictive. Based on multivariable linear regression analysis, significant predictors of variability in social participation were medical comorbidity, psychiatric comorbidity, psychiatric symptoms and IBD-related symptoms.

Conclusions: The factors that predict social participation by IBD patients include income, smoking, medical comorbidities, IBD symptom burden, and psychiatric comorbidities. Multivariable linear regression suggests that the most relevant factors are medical comorbidity, psychiatric comorbidity, psychiatric symptoms and IBD symptoms.

Keywords: *Quality of life; Social participation; Socio-economical and psychological end points*

Introduction

Social participation, also referred to as social engagement or social involvement, has been proposed as an indicator of health, well-being and positive social behaviours (1). Core components of social participation are inclusion in a community, having social contacts and being involved in societal activities (2). Physical and mental health are both factors that may influence social participation (3).

Received: March 3, 2021; Accepted: June 29, 2021.

Inflammatory bowel disease (IBD), including Crohn's disease (CD) and ulcerative colitis (UC), causes many debilitating physical symptoms such as abdominal pain, diarrhea, fatigue and rectal bleeding (4). These symptoms can be burdensome and have the potential to limit social participation. In qualitative studies, people with IBD have reported that many disease-related concerns impair self-perception of body image, lead to fear of stigmatization and cause social isolation (5). For example, fear of poor hygiene and incontinence contributed to feelings of vulnerability, insecurity and limit perceived attractiveness (5). The unpredictability of symptoms negatively affected intimacy, autonomy and the sense of being able to provide for family. In addition, necessary adjustments to diet and lifestyle led participants to give up on engaging in social activities, leading to social isolation. Immunosuppressed persons endorsed avoidant behaviour in social contexts due to a fear of acquiring infections (5).

Furthermore, people with IBD also have a higher incidence and prevalence of psychiatric disorders than people without IBD (6). Depressive symptoms include low energy and anhedonia, while anxiety is characterized by fatiguability and excessive worsening (7). Both psychiatric diseases have the potential to cause clinically significant distress or impairment in social, occupational or other important areas of functioning (7).

The associations between IBD disease activity, comorbid psychiatric disorders and social participation are, however, poorly understood (8). Prior studies are limited in that they do not comprehensively and specifically assess social participation, and the factors that may influence it (4,9–14). In older adults without IBD, predictors of social participation include socioeconomic status, marital status, presence of children, ethnicity, chronic medical conditions and gender (3,15,16). We aimed to assess the association between IBD disease activity and psychiatric comorbidity with social participation in persons with IBD. We hypothesized that participants with active IBD would have lower social participation than participants with inactive IBD. Further, we expected social participation to be lower in participants with depression or anxiety.

METHODS

Participants

As described previously, from November 2014 to July 2016, we enrolled persons with IBD, including Crohn's disease and ulcerative colitis, in a cohort study examining psychiatric comorbidity in immune-mediated inflammatory disease (17). All study participants were aged ≥18 years old, able to provide written informed consent and had an adequate knowledge of the English language to complete questionnaires. Diagnoses of IBD were confirmed by review of medical records and by querying treating physicians directly if needed. Ethics approval was gained from the University of Manitoba Health Research Ethics Board. Study data were managed using REDCap electronic data capture tools hosted at the University of Manitoba (18).

Measures

Based on the input of the study's Patient Advisory Committee, a measure of social participation was collected at the second study visit (first follow-up, 1 year post-enrollment). Therefore, the study cohort for the present analysis included participants with IBD who completed that visit. We used information regarding patient sociodemographic characteristics, comorbidity, IBD phenotype, mental health and social participation for this study.

Sociodemographic Characteristics

Participants reported gender, age, race/ethnicity, highest level of education attained, annual household income, marital status and number of children. Race/ethnicity was reported as white and non-white, as most of the cohort was white. Education was dichotomized as less than high school or high school level education and beyond. Annual household income was dichotomized as <$50,000 versus ≥$50,000. Marital status was categorized as single (never married, widowed, divorced) or married (married, co-habiting). Current smoking status was also recorded as yes versus no.

Medical Comorbidities

Using a validated questionnaire (19), participants reported whether a doctor has ever diagnosed them with any of the following conditions: high cholesterol, high blood pressure, heart trouble, disease of arteries in the legs, lung trouble, diabetes mellitus, cancer of the breast, cancer of the colon or rectum, cancer of the lung, skin cancer, other cancers, migraine, thyroid disease, lupus, osteoarthritis, osteoporosis, fibromyalgia, kidney disease, peptic ulcer disease, liver problems, irritable bowel syndrome and epilepsy (seizure disorder). We summarized these as a count of physical comorbidities.

Psychiatric Morbidity

We identified lifetime and current diagnoses of depression and anxiety disorders using the Structured Clinical Interviews for DSM-IV Axis I Disorders (SCID) (20), the gold-standard method for eliciting psychiatric history (21). As DSM-IV rather than DSM-V was in use at the time of the study inception, post-traumatic stress disorder and obsessive-compulsive disorder were included as anxiety disorders, in keeping with the DSM-IV classification scheme. Current depressive symptoms were measured using the Patient Health Questionnaire-9 (PHQ-9), a self-administered questionnaire with total scores

ranging from 0 to 27(22). Higher scores indicate more severe depressive symptoms. It has been validated in the IBD population and has a sensitivity of 95% and specificity of 83% at a score of ≥10 (23). The internal consistency (95% confidence interval [CI]) is 0.89 (0.92 to 0.95) and test–retest reliability (95% CI) is 0.85 (0.80 to 0.89) (23). Anxiety symptoms were measured using the Generalized Anxiety Disorder-7 (GAD-7), a seven-item anxiety scale with scores ranging from 0 to 21 (24), with higher scores indicating worse anxiety symptoms. In the IBD population, it has a sensitivity of 64% and specificity of 88% for detecting anxiety at a score of ≥10 (23). The internal consistency (95% CI) is 0.91 (0.84 to 0.99) and test–retest reliability (95% CI) is 0.76 (0.68 to 0.82) (23).

IBD Characteristics

We characterized disease phenotype and progression in IBD using the Montreal Classification System (25). Symptomatic disease activity was measured using the Harvey Bradshaw Index (HBI) (26) for Crohn's disease (CD), and the Powell-Tuck Index (PTI) (27) for ulcerative colitis (UC) as administered by trained research staff. A score of ≥5 is considered active disease on the HBI and on the PTI (26–28). The HBI has a 93% correlation to the widely-used Crohn's Disease Activity index (26), with the advantage of being simpler to use due to its sole reliance on easily attainable clinical factors. The PTI has a test–retest reliability (95% CI) of 0.80 (0.56 to 0.91) (28). IBD duration was calculated by subtracting self-reported age at diagnosis from current age. Participants taking any immunomodulatory therapy were considered treated pharmacologically for their IBD; all others were considered pharmacologically untreated.

Nonspecific Symptom Burden

To characterize nonspecific symptoms in the population, we assessed pain using the modified Pain Effects Scale (29); scores range from 6 to 30, with higher scores indicating greater pain impact. For fatigue, we used the Daily Fatigue Impact Scale (DFIS) (30), which is a validated tool that includes eight items ranked 0 to 4, with higher scores indicating high daily fatigue burden.

Social Participation

Social participation was assessed using a validated questionnaire from the Patient-Reported Outcomes Measurement Information System (PROMIS) assessment center, specifically the eight-item Ability to Participate in Social Roles and Activities (APSRA, PROMIS Item Bank V2.0, 8a). This questionnaire assesses participation restriction, including problems experienced in social interaction, employment, transportation, community, social and civic life (31). Internal consistency, test–retest reliability, construct validity and responsiveness have been demonstrated in other populations (32). For example, studies in patients with systemic lupus erythematosis have demonstrated an interclass correlation coefficient (SEM) of 0.85 (3.50), where >0.7 generally indicates acceptable test–retest reliability (32). Each of the 8 items is worded in terms of perceived limitations, but the responses are reverse-coded so that higher scores indicate better participation or abilities. Responses for each item are never (5), rarely (4), sometimes (3), usually (2) and always (1). Responses are summed across all items, thus raw scores range from 8 to 40. Raw scores are converted into T-scores with a mean of 50 and standard deviation (SD) of 10; 50 is considered average for the U.S. general population.

Analysis

Categorical variables were summarized as frequency (%), and continuous variables were summarized as mean (SD). We compared groups using Student's *t*-tests, chi-square tests, Kruskal–Wallis tests and Pearson correlations as appropriate; correlations are reported with 95% CI.

To assess the association of participant characteristics with social participation, we conducted multivariable linear regression analysis using a hierarchical approach. Characteristics included sociodemographics as defined above, IBD characteristics (type, duration, active status and treatment status), and psychiatric characteristics (history of psychiatric disorders and elevated psychiatric symptoms). Depression and anxiety were combined in this analysis to avoid collinearity, given the well-established degree of comorbidity of these disorders (33). Similarly, pain and fatigue scores are accounted for in IBD symptom scores and were omitted from this analysis due to collinearity. We entered the sociodemographic variables, followed by IBD characteristics, followed by psychiatric variables. Adjusted R^2 was used to assess proportion of variation explained by the variables studied. For context, an R^2 of 1 indicates that the variables in the regression explain 100% of the variability in the data, whereas an R^2 of 0 suggests that there is no relationship between the variables and the variability in the data. An R^2 >25% is considered a large effect. We assessed collinearity using variance inflation factors (VIF), where a VIF >2 was considered collinear. Assumptions for linear regression were verified including normality of residuals and distribution of errors, and homoscedasticity.

In a similar manner, subgroup analysis was performed by gender and IBD type.

Statistical analysis was performed with SPSS (IBM SPSS Statistics for Windows, Version 26.0. Armonk, NY: IBM Corp).

RESULTS

Of 247 participants enrolled in the primary study, 239 completed the first follow-up (year 2) study visit and were

included in the analysis. Most were white women of mean (SD) age of 48.6 (14.9) years (Table 1). Only 22 participants (<10%) of participants self-identified as belonging to an indigenous population. Over two-thirds of participants had some postsecondary education, and two-thirds were married. Nearly two-thirds of participants had CD. The most common self-reported medical comorbidities were IBS (21.8%), hypertension (20.1%), migraines (16.3%), high cholesterol (14.2%), osteoarthritis (14.2%) and lung disease (14.2%).

The mean (SD) APSRA score in this sample was 51.3 (8.9) and did not differ from the general U.S. population (P = 0.12). As compared to annual household incomes of <$50,000, higher incomes were associated with higher ASPRA scores (mean difference [95% CI] of 5.30 [2.72, 7.87]). Other demographic factors were not associated with ASPRA scores.

ASPRA scores did not differ by IBD type, but having more medical comorbidities was associated with lower APSRA scores (r = −0.30; 95% CI: −2.05, −0.85, P < 0.001; Figure 1). In particular, comorbid IBS was associated with poor social participation with mean difference (95% CI) of −3.85 (−1.15, −6.54), P = 0.005. Patients with osteoarthritis also had lower social participation with mean difference (95% CI) of −5.40 (−2.20, −8.61), P = 0.001. Those with hypertension, migraines, high cholesterol and lung disease did not have significant differences in social participation (P = 0.07, 0.07, 0.21, 0.38, respectively). Smokers had worse social participation than nonsmokers with a mean difference (95% CI) of −4.42 (−1.31, −7.54), P = 0.006.

Psychiatric Morbidity

Two-thirds of participants had a lifetime history of depression, while 1 in 10 had a lifetime history of an anxiety disorder. On

Table 1. Baseline characteristics of study population and association with social participation as measured by Ability to Participate in Social Roles and Activities (APSRA) T-scores

Patient characteristics	N = 239 (%)	APSRA T-score (Mean [SD], or Pearson R for continuous variables)	P-value
Inflammatory bowel disease type			
Crohn's disease	147 (61.5)	50.9 (8.6)	0.30
Ulcerative colitis	92 (38.5)	52.1 (9.2)	
Gender			
Male	89 (37.2)	51.9 (8.8)	0.43
Female	150 (62.8)	51.0 (8.9)	
Age (mean [SD])	48.6 (14.9)	R = −0.10*	0.12
Race			
White	202 (84.9)	51.5 (8.8)	0.46
Non-white	36 (15.1)	50.3 (9.0)	
Education			
High school or less	74 (31.0)	50.5 (9.0)	0.34
Postsecondary education	165 (69.0)	51.7 (8.8)	
Income			
<$50,000 (CAD)	58 (24.3)	47.6 (7.8)	**<0.001**
≥ $50,000 (CAD)	158 (66.1)	52.9 (8.8)	
No response	23 (9.6)	49.9 (9.4)	
Marital Status			
Single/Divorced/Widowed	86 (36.0)	49 (8.6)	0.09
Married/Co-habiting	153 (64.0)	52.0 (8.8)	
Children			
No	89 (37.2)	50.4 (9.1)	0.20
Yes	150 (62.8)	52.0 (8.8)	
Number of chronic medical comorbidities (mean [SD])	1.8 (1.8)	R = −0.30*	**<0.001**
Smoking status			
No	203 (84.9)	52.0 (8.8)	**0.006**
Yes	36 (15.1)	47.6 (8.5)	

Bold reflects statistically significant P values.

*Signifies Pearson correlation coefficient for continuous variables.

average, participants with a lifetime history of depression had lower APSRA scores as compared to those without such a history with mean difference of −4.21 (95% CI: −1.87, −6.54; $P < 0.001$; Table 2). Participants with elevated depressive symptoms had substantially lower scores than participants who did not have evaluated symptoms (mean difference: −12.4; 95% CI: −8.86, −16.2, $P < 0.001$). Findings were similar for a history of anxiety disorder (mean difference in APSRA scores of −6.19 (95% CI: −2.51, −9.87, $P = 0.001$) and elevated symptoms of anxiety (mean difference −7.98; 95% CI: −3.27, −12.7, $P = 0.001$; Figure 2).

IBD-Related Factors and Nonspecific Symptoms

For CD and UC, greater disease activity was associated with lower APRSA scores (Figure 3 and Table 3). Higher fatigue scores (DFIS) were associated with lower APSRA scores ($r = 0.71$; 95% CI: −1.01, −0.78, $P < 0.001$) as were higher modified Pain Effects Scale scores ($r = 0.72$; 95% CI: −1.37, −1.07, $P < 0.001$). IBD phenotype and treatment status were not associated with social participation (Supplementary Table 1).

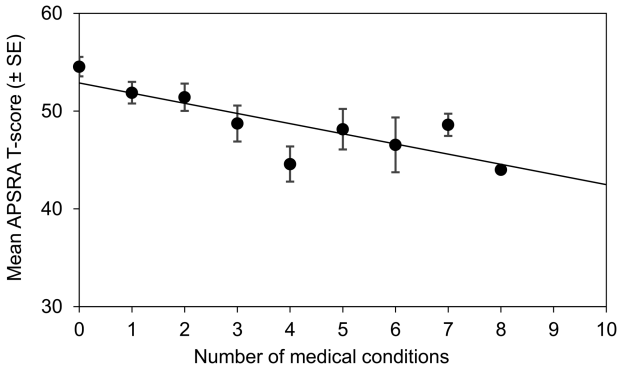

Figure 1. Relationship between number of medical comorbidities and social participation as measured by Ability to Participate in Social Roles and Activities (APSRA) T-scores.

Multivariable Linear Regression

With multivariable linear regression analysis, having lower annual income, active IBD, a history of depression or anxiety disorder, and elevated symptoms of depression or anxiety were associated with lower APSRA scores (Table 4). Overall, 39.1% of the variance in APSRA scores was accounted for by the assessed variables. 17.0% of the variance in APSRA scores was accounted for by the sociodemographic variables. An additional 5.8% (22.8% total) of the variance in APSRA scores was accounted for by adding the IBD characteristics. Adding psychiatric variables accounted for an additional 16.0% of variance, which resulted in the full model accounting for 39.1% of the variance (Table 4). Standardized residuals and error of APSRA scores in the study population were normally distributed, and the constant variance assumption was not violated. Collinearity was not observed as seen by VIF <2 for all variables.

Gender Subgroups

When we limited the analysis to males (37.2% of cohort), lifetime psychiatric history and elevated psychiatric symptoms remained associated with lower social participation scores ($P = 0.02$ and $P = 0.01$, respectively). However, active IBD symptoms ($P = 0.45$) and income ($P = 0.13$) were not significantly associated with a change in social participation, and having children was associated with higher APSRA scores ($P = 0.02$; Supplementary Table 2). Collectively, these variables explained 40.9% of the variance in APSRA scores.

When we limited the analysis to females (62.8% of cohort), lower annual income ($P = 0.01$), active IBD ($P = 0.01$), psychiatric history ($P = 0.05$) and active psychiatric symptoms

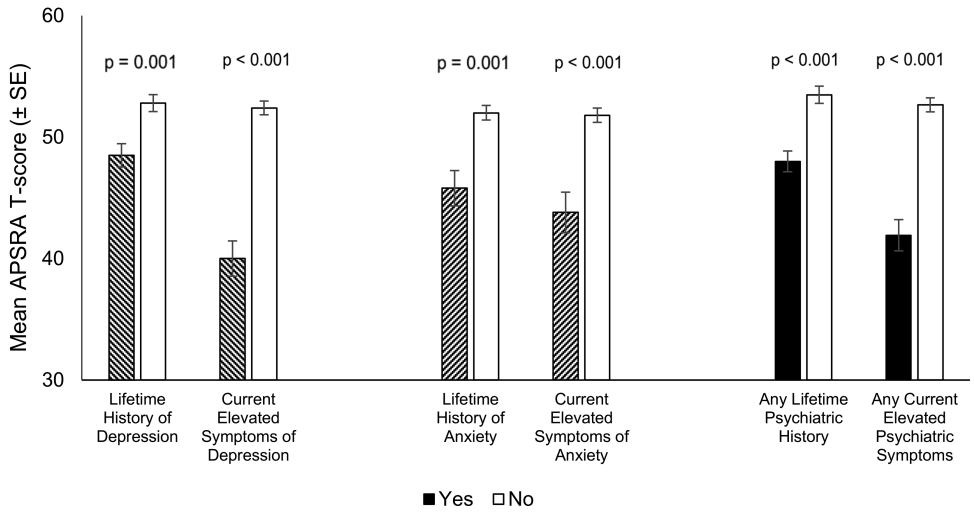

Figure 2. Association of psychiatric comorbidities and elevated psychiatric symptoms with social participation as measured by Ability to Participate in Social Roles and Activities (APSRA) T-scores.

Table 2. Association of psychiatric comorbidities and currently elevated psychiatric symptoms with association with social participation as measured by Ability to Participate in Social Roles and Activities (APSRA) T-scores

Psychiatric comorbidity	*N* = 238 (%)	APSRA T-Score (mean [SD])	*P*-value	% APSRA ≥ 1 SD below mean
Depression				
Lifetime history				
No history of depression	158 (66.1)	52.8 (8.7)	**<0.001**	3.5%
History of depression	80 (33.9)	48.5 (8.5)		4.2%
Current elevated depressive symptoms				
No	218 (91.6)	52.4 (8.3)	**<0.001**	4.2%
Yes	20 (20)	40 (6.5)		3.5%
Anxiety				
Lifetime history				
No history of anxiety	214 (90.0%)	52 (8.8)	**0.001**	5.6%
History of anxiety	24 (10.0%)	45.8 (7.1)		2.1%
Current elevated anxiety symptoms				
No	224 (94.1%)	51.8 (8.8)	**0.001**	5.6%
Yes	14 (5.9%)	43.8 (6.3)		2.1%

Lifetime history determined based on Structured Clinical Interview for DSM-IV Axis I Disorders (SCID); current symptom status based on the Patient Health Questionnaire-9 for depressive symptoms, and Generalized Anxiety Disorder-7 for anxiety symptoms. Bold reflects statistically significant *P* values.

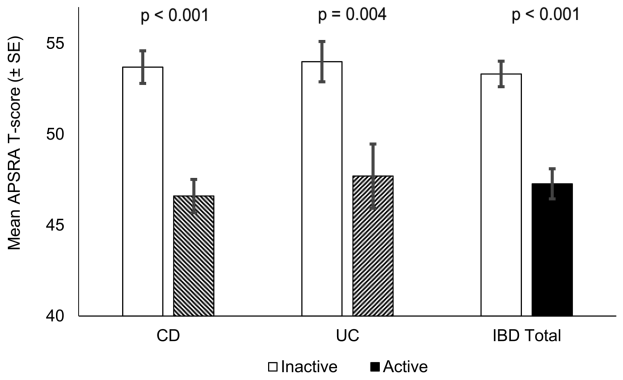

Figure 3. Association of active inflammatory bowel disease symptoms and social participation as measured by Ability to Participate in Social Roles and Activities (APSRA) T-scores.

(P < 0.001) were associated with lower APSRA scores (Supplementary Table 3), consistent with findings in the IBD population overall. These variables explained 39.2% of the variance in APSRA scores.

Disease Subgroups

In participants with CD (61.5% of the cohort), the factors associated with lower social participation were the same as those observed for the IBD population overall (Supplementary Table 4). In contrast, among the smaller subgroup of participants with UC (38.5% of the cohort), only elevated psychiatric symptoms were associated with lower social participation (Supplementary Table 5).

Discussion

In this well-characterized cohort of persons with IBD, we examined factors associated with social participation. We found that on average, social participation did not differ from expectations for the general population. However, participants with active CD or UC had lower social participation than those with inactive disease. Duration of disease did not correlate with any change in social participation. Psychiatric morbidity, comorbid medical conditions and smoking were also associated with lower social participation. Of the most common comorbid conditions, IBS and osteoarthritis were associated with lower social participation. This result is similar to non-IBD patients with IBS and osteoarthritis, who in previous studies, have also demonstrated limitations in social functioning (34–36). Other studies have also shown an association between smoking and lower social participation, suggesting that levels of social participation influence smoking behavior rather than the reverse (37). To our knowledge, the minimal clinically important difference for the APSRA has not been established in IBD populations. For other PROMIS instruments, minimal clinically important differences fall in the range of 2.3 to 5.5, that is one quarter to one-half an SD (38,39). In our regression analyses, psychiatric morbidity was associated with a reduction in APSRA scores by one third of a standard deviation, suggesting that this falls in a clinically meaningful range. Higher income was also associated with greater social participation. Other demographic factors were not associated with social participation, unlike in previously studied older populations (older than 55) (3,16).

Table 3. IBD symptom severity scores and association with social participation as measured by Ability to Participate in Social Roles and Activities (APSRA) T-scores

IBD type	*N* (%)	APSRA T-Score (mean [SD])	*P*-value*
Crohn's disease (Harvey-Bradshaw Index)			
Remission (≤5)	92 (67.1%)	53.7 (8.6)	**<0.001**
Active disease (>5)	45 (32.9)	46.6 (6.2)	
Mild (6–7)	17 (12.1%)	46.8 (8.1)	
Moderate to severe (>8)	29 (20.7%)	46.4 (4.8)	
Ulcerative colitis (Powell-Tuck Index)			
Remission (≤5)	63 (72.4%)	54.0 (8.7)	**0.004**
Active Disease (>5)	24 (27.5)	47.7 (9.1)	
Mild (5–10)	21 (24.1%)	49.1 (8.4)	
Moderate (11–14)	3 (3.4%)	37.9 (8.7)	
Severe (>15)	0 (0%)	-	

IBD, inflammatory bowel disease. Bold reflects statistically significant *P* values.

*Independent sample *T*-test comparing remission to active disease. One-way nonparametric ANOVA (Kruskal–Wallis test) comparing remission, mild and moderate to severe disease: $P < 0.001$ for CD and $P = 0.007$ for UC.

Table 4. Multivariable linear regression analysis for factors of social participation in IBD patients

Factor	Standardized coefficient (SD)		*P*-value	VIF	Adjusted partial R^2
Age	−0.12	(0.05)	0.12	1.51	0.014
Gender	−0.07	(1.16)	0.27	1.12	0.007
Race (white vs. non-white)	−0.03	(1.69)	0.65	1.15	0.001
Education level	0.02	(1.26)	0.73	1.13	0.001
Marital status	0.00	(1.52)	0.96	1.19	0.000
Children	0.11	(1.35)	0.08	1.11	0.018
Income	0.14	(1.30)	**0.04**	1.23	0.025
Smoking status	0.01	(1.63)	0.94	1.18	0.000
Number of medical comorbidities	−0.10	(0.35)	0.16	1.48	0.011
IBD type (Crohn's vs. UC)	0.03	(1.12)	0.60	1.06	0.002
Active IBD status	−0.18	(1.25)	**0.008**	1.21	0.041
Current IBD treatment	−0.10	(1.31)	0.12	1.08	0.014
Lifetime history of depression or anxiety disorder	−0.21	(1.17)	**0.001**	1.13	0.062
Elevated symptoms of depression or anxiety	−0.34	(1.76)	**<0.001**	1.11	0.146

IBD, inflammatory bowel disease. Bold reflects statistically significant *P* values.

This inconsistency may be due to demographic differences in our population as compared to the literature which emphasized older adults, the absence of adjustment for psychiatric morbidity in other studies, or other unmeasured factors.

Our findings are consistent with prior observations in the IBD population that, in general, higher disease activity, is associated with poorer HRQOL in social domains (4,40). Studies in the adolescent IBD population report a high rate of impairment in sports participation and in school performance which could adversely influence social functioning in adulthood (41). Surveys in adults indicate that IBD may alter decisions to pursue/maintain intimate relationships, pursue certain career paths and attend social events (14). Symptoms of diarrhea may contribute to fears of incontinence, poor hygiene, and social stigmatization, negatively influencing employment and interpersonal relationships (42). Even for persons who remain employed, taking recurrent sick leaves may creates difficulty in the social and financial domains (12).

People with IBD have a higher incidence and prevalence of psychiatric disorders (6). We found that psychiatric morbidity in the IBD population adversely affected social participation. Common symptoms of depression such as decreased energy, decreased concentration, anhedonia and sleep changes (7) may account for the poor social participation scores that we observed.

Similarly, anxiety is associated with fatigability, difficulty concentrating, excessive worrying and avoidant behaviours that may also adversely influence social participation (7). In prior studies, treatment for psychiatric conditions in those with IBD appeared effective in improving social activity as demonstrated by less social isolation (43). This highlights the importance of detecting and effectively treating psychiatric comorbidity in persons with IBD. In other studies, patients who had protective factors for psychological distress including social supports and coping methods had better reported social engagement, better symptom tolerance, less pain, less perceived stress and required fewer gastroenterologist visits (44). Nevertheless, the effect of mental health treatment on formal social participation outcomes in IBD has not been specifically studied.

Our findings should be interpreted in light of study limitations. Our study cohort had disproportionately more women than expected, thus our findings may not generalize as well to men with IBD. The number of participants self-identifying as non-white was relatively small, limiting inference to these groups. Given the greater likelihood of lower socioeconomic status and other disparities in these minority groups, further studies of social participation should be conducted in more ethnically diverse populations with consideration of a broad range of social factors, and whether their influences are differential across sociodemographic groups. Those under-represented include, but are not limited to, indigenous populations, immigrant populations and those from cultures in which discussing gastrointestinal symptoms may be stigmatized. Further studies should also explore patients with lower education and patients who work or live in crowded environments which may have limited access to bathrooms. Striving for greater representation of these groups in IBD and health care literature will allow for increased generalizability of these data to the Canadian population, and ensure that the health care needs of all members of the Canadian IBD population can be met.

Furthermore, we accounted for immunomodulatory therapies, but did not account for non-pharmacologic management such as surgery, nor therapies used to manage comorbid conditions. The number of studied medical comorbidities as factors of social participation was not exhaustive. Further studies should be conducted to comprehensively identify the influence of particular categories of comorbidity such as functional disorders, other immune-mediated inflammatory conditions and prognosis-limiting malignancy.

Moreover, the cross-sectional design limits causal inference. We also recognize that social participation likely reflects a combination of long-term disease experiences as well as current disease activity and symptoms. Future studies should examine factors that influence social participation over time. Our study was also limited to adult IBD patients but further research could also study younger patients, as gastrointestinal symptoms and increased bathroom requirements during development may impact current and future social participation.

Regarding the complex relationship between psychiatric symptoms, IBD and social participation, it is possible that elevated psychiatric symptoms occur in response to active IBD symptoms and are not truly independent of IBD status. However, we previously showed that in persons with IBD, worsening of symptoms of depression and anxiety increases the odds of subsequently developing active IBD as measured by HBI and PTI (45). While increased symptomatic disease activity was associated with decreased social participation, we only used symptom measures of disease activity and we did not assess inflammatory burden.

Overall, our study highlights several factors associated with social participation in persons living with IBD and suggests the need to adequately manage disease activity and psychiatric comorbidities with a holistic approach. Relevant strategies may include frequent enough visits to ensure that IBD symptoms are minimized or brought into remission and having readily accessible psychological support resources for patients with IBD. Lower social status is associated with worse IBD outcomes, (46) and herein we found that low income was associated with lower social participation. Hence, the social situation of persons with IBD impacts their outcomes and QOL and warrants attention, with the goal of improving the integration of people with IBD into the community.

SUPPLEMENTARY DATA

Supplementary data are available at *Journal of the Canadian Association of Gastroenterology* online.

Funding

This study was funded by the Canadian Institutes of Health Research (THC-135234), Crohn's and Colitis Canada and the Waugh Family Chair in Multiple Sclerosis (to R.A.M.). C.N.B. is supported in part by the Bingham Chair in Gastroenterology.

CONFLICT OF INTEREST

R.A.M. receives research funding from: CIHR, Research Manitoba, Multiple Sclerosis Society of Canada, Multiple Sclerosis Scientific Foundation, Crohn's and Colitis Canada, National Multiple Sclerosis Society, CMSC, the US Department of Defense. She is supported by the Waugh Family Chair in Multiple Sclerosis. C.N.B. has consulted to Abbvie Canada, Amgen Canada, Bristol Myers Squibb Canada, Janssen Canada, Pfizer Canada, Roche Canada, Sandoz Canada, Canada, Takeda Canada, Mylan Pharmaceuticals, and has received unrestricted educational grants from Abbvie Canada, Janssen Canada, Pfizer Canada and Takeda Canada. He has been on speaker's bureaus of Abbvie Canada and Takeda Canada, Medtronic Canada and JanssenCanada.

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