ORIGINAL ARTICLE

Gastroenterology: Inflammatory Bowel Disease

Impact of age at diagnosis on college adjustment in students with inflammatory bowel disease

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Abstract

Objectives: Little is known about the experience of college students with inflammatory bowel disease (IBD) and the factors associated with transition readiness, academic adjustment, and alternatively, those associated with academic hardship and attrition.

Methods: Survey-based cross-sectional studies, including those addressing disease-specific quality of life (Short Inflammatory Bowel Disease Questionnaire), IBD disease activity (Harvey–Bradshaw Index and Patient Simple Clinical Colitis Activity Index), college adjustment (Student Adjustment to College Questionnaire), transition readiness (Transition Readiness Assessment Questionnaire [TRAQ]), and self-efficacy (inflammatory bowel disease self-efficacy scale).

Results: The surveys were completed by 135 participants (59 IBD patients [37 Crohn's disease and 22 ulcerative colitis]; 76 controls). Participants with IBD were matched with respect to age, gender, academic status, and involvement in extracurricular activities. Participants endorsed making important college decisions associated with their disease and were significantly more likely to live at home ($p < 0.001$), take fewer credits ($p < 0.02$), and more likely than controls to have their education interrupted ($p < 0.0005$). Participant age at diagnosis was an important factor associated with college adjustment, with older age at diagnosis having the most association with the ability to adjust to college life. As expected based on prior literature, TRAQ scores suggested better than expected transition readiness in college students with IBD ($p < 0.0006$) with subscores revealing that female students are better at managing health issues and daily activities.

Conclusion: IBD affects the college experience of students–patients significantly and can have life-long implications. Newly diagnosed students are at risk of poor college adjustment impacting academic performance and their future success. Male students are at greater risk than female students of poor transitioning to adult IBD care. Students with IBD should receive enhanced and age-specific modern IBD care.

KEYWORDS

college students, Crohn's, inflammatory bowel disease, transition readiness, ulcerative colitis

[Correction added on 11 April 2025, after the first online publication: Subcategory has been updated.]

1 | INTRODUCTION

College students face a range of challenges, including academic demands, new social and sexual situations, financial responsibilities, and newfound independence.[1] However, students with inflammatory bowel disease (IBD) face additional physical, psychological, and practical challenges related to their chronic illness.[2–4] Poor adjustment to college can have implications for graduation rates, future economic success, and access to quality health insurance.[1]

Transitioning to the adult healthcare setting is a significant challenge for college-aged patients with IBD.[5–8] Young adults often face difficulty with managing autonomy and self-management behaviors in adult care settings.[9,10] Moreover, due to family preference and availability of local resources, the transition of care can differ with some patients remaining under pediatric care while others advance to adult clinic. As a result, access to multidisciplinary services may vary greatly. The subsequent healthcare utilization among adolescents and young adults (AYAs) with IBD has been shown to be significantly different than both their pediatric and older adult counterparts, using more corticosteroids in the management of their disease.[11] Patients also have increased psychosocial needs as IBD is associated with significant comorbidity including anxiety, depression, and fatigue[12,13] —each of which increases the burden on AYA learning to navigate schooling, social life, and unexpected changes in health independently. Understanding the barriers to college adjustment and readiness for disease management in this population is crucial for their long-term health and well-being.[4]

Our study aimed to investigate the factors influencing college adjustment, transition readiness, and self-efficacy in college students with IBD.[1–3,5–10]

2 | METHODS

2.1 | Patient population

We performed a Research Electronic Data Capture (REDCap)-based, cross-sectional survey study that enrolled patients from 2016 to 2019. Students–patients aged 18–25 with a diagnosis of Crohn's disease (CD) or ulcerative colitis (UC) and actively enrolled in college were asked to participate. Only full-time college students (whether 4-year or community college) were eligible to participate. Enrollment was self-reported. For our control group, college students aged 18–25 without any past medical history of IBD or other chronic diseases were enrolled. Participants with IBD and controls were matched with respect to age, gender, academic status, and involvement in extracurricular activities to ensure comparability between groups. We recruited

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What is Known

- Transition to adult healthcare is challenging for college-aged patients with IBD, emphasizing autonomy and self-management.
- Existing research highlights unique difficulties in navigating healthcare settings for college students with IBD.

What is New

- Age at IBD diagnosis correlates with increased difficulties with college adjustment.
- Newly diagnosed college students with IBD are identified as a high-risk group for poor adjustment, impacting academics and future success.
- College students with IBD show enhanced transition readiness compared to healthy peers, highlighting their adapted skills in managing health-related challenges.
- Gender differences emerge, with male college students with IBD endorsing lower self-efficacy skills during transition to adult care.

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students who received their IBD care at the University of Florida clinics as well as other participants, including healthy controls, through pamphlets, fliers, emails, and college-based support groups. No social media platforms were used in the recruitment process. This decision was based on the targeted demographic and privacy considerations given the sensitive nature of the health information involved. Based on prior experience surveying college students and anticipated recruitment challenges, we aimed to enroll 200 participants, with the goal of having 100 complete the survey. Informed consent was obtained in writing from participants by one of our investigators. For those unable to provide consent in person, consent was obtained over the phone using an IRB-approved phone script read aloud to the participant. A waiver of documented consent was granted for phone-based consent. Once enrolled, participants received a secure link to complete the survey, with no compensation offered for their voluntary participation. This study was approved by the University of Florida Institutional Review Board (IRB201600191).

2.2 | Survey instruments

Our survey was created with REDCap,[14] a secure web platform for building and managing online surveys and databases. The surveys included both disease-independent and IBD disease-specific questionnaires. All participants completed a survey detailing their

demographics, and their academic and extracurricular information. The results obtained were self-reported. The disease-independent surveys, unrelated to IBD, were administered to all study participants and included the Student Adjustment to College Questionnaire (SACQ) and the Transition Readiness Assessment Questionnaire (TRAQ). The SACQ is a well-validated, self-reported, adjustment to college survey, using 67 questions on four different subscales: academic, social, emotional, and school attachment.[15] Questions address how well students perceive that they are adapting to the demands of college life. The TRAQ is a validated 20-item, 5-domain patient-reported assessment that assesses transition readiness before transfer to adult healthcare.[16] Scores on this tool were intended to facilitate discussion around the adult skills adolescents must acquire before a successful transition. Disease-specific surveys were administered to participants with IBD. A disease history survey asked questions relevant to medical and surgical history, including current medication use. We used the Short Inflammatory Bowel Disease Questionnaire (SIBDQ) to assess IBD-related quality of life.[17] This validated questionnaire has 10 questions measuring the impact of IBD on social and emotional domains and physical symptoms and is scored on a 7-point Likert scale from 1 to 7. The absolute score ranges from 10 (*poor HRQOL*) to 70 (*optimum HRQOL*). The modified Harvey–Bradshaw Index (HBI) is based on a widely used Crohn's Disease Activity Index consisting of symptom questions, that do not include lab or physical exam data. This modification allows for self-reporting by patients and has been validated in prior survey studies. Students with UC completed the Patient Simple Clinical Colitis Activity Index (PSCCAI), a validated 16-question survey to assess disease activity.[18] Questions on the PSCCAI refer to disease symptoms during the previous week and are composed of six domains: bowel frequency during the day, bowel frequency during the night, urgency of defecation, blood in stool, general well-being, and number of defined extra-intestinal features of UC. PSCCAI score of <5 indicates inactive disease and ≥5 indicates active disease.

2.3 | Statistical analysis

We calculated descriptive statistics for the demographic characteristics and outcome scores of our study participants using SAS (SAS Institute Inc.).[19] We built linear regression models to identify variables' effects on each outcome score. The frequency and percentages of our demographic variables were calculated using chi-square and Fisher test analysis. The mean and standard deviation of the outcome scores of both our student populations were calculated. *T* tests were conducted to create p values determining the statistical significance of the comparisons between students with CD, UC, and control students. We built multiple linear regression models to examine the group (CD, UC, and control) difference on TRAQ total *z*-score. The dependent variable is TRAQ total *z*-score, and the independent variables are group memberships. In the model, we controlled for students' age, gender, disease status, and year of college. Participants with IBD and controls were well-matched with respect to age (mean age in those with IBD vs. controls in years: 21.7 ± 0.3 vs. 22.4 ± 0.1, respectively), gender, academic status, and involvement in extracurricular activities (Table 1). We tested for collinearity; however, no interactions were measured due to the relatively small sample size of the study. Multivariate analysis was also used to control the IBD population's SACQ score and predict certain factors, such as whether the student required surgery or had to drop classes and/or a semester. Continuous variables were categorized for ease of the implementation of an online survey, however using eight categories for age allowed us to assess possible age trends similar to a continuous variable. All analyses were performed using SAS Version 9.4; statistical significance was defined as $p < 0.05$ throughout.

3 | RESULTS

The surveys were completed by 135 participants (59 participants with IBD [37 CD and 22 UC]; 76 controls). There were 81 female participants and 54 male participants. The survey completion rates for controls, CD, and UC were 100% (76 out of 76), 80.56% (29 out of 36), and 90.90% (20 out of 22), respectively. The average age of all participants was 20.43 years (22.1 years for CD and 21.65 for UC). Participants with IBD demonstrated a wide range of disease activity scores. The mean HBI was 4.1 ± 0.6. The data were collected using the modified HBI, which does not require lab or physical exam data, making it suitable for self-reporting in survey studies as previously validated. The mean PSCCAI was 7.4 ± 0.5. The mean SIBDQ was 48.7 ± 12.0, and there was no difference in SIBDQ between CD and UC participants. As expected, disease activity (HBI and PSCCAI) was inversely correlated with SIBDQ (Figure 1). Several differences were noted in the college experience for participants with IBD compared to controls. Students with IBD endorsed making important college decisions based on their disease, such as choice of college and choice of major. Participants with IBD were significantly more likely to live at home, take fewer credits, and were more likely than controls to have their education interrupted, meaning at least one semester or greater pause in education. Participants with IBD were also significantly more likely than controls to have attended community college and to have taken out student loans. They were

TABLE 1 Study participant demographics.

|		Control N = 76		Case N = 59		
		Freq	%	Freq	%	p
Gender	Female	49	0.64	32	0.54	0.3044
	Male	27	0.36	27	0.46	
School	None now	1	0.01	2	0.03	0.0090
	Other	9	0.12	17	0.29	
	Community college	5	0.07	8	0.14	
	4-Year college	61	0.80	32	0.54	
Number of college credits	<6	8	0.11	11	0.19	0.0206
	6–12 (part time)	24	0.32	28	0.47	
	>12 (full time)	44	0.58	20	0.34	
Education interrupted?	No	67	0.88	36	0.61	0.0005
	Yes	9	0.12	23	0.39	
Duration of interruption (if interrupted)	Between one semester and 1 year	1	0.13	3	0.14	0.7264
	>1 year	2	0.25	10	0.45	
	One semester	5	0.63	9	0.41	
Relocated for college?	No	6	0.08	21	0.36	0.0002
	Yes	70	0.92	38	0.64	
If relocated, was it out of state?	No	62	0.87	37	0.76	0.1528
	Yes	9	0.13	12	0.24	
Living situation	At home with family	4	0.05	14	0.24	0.0011
	Off campus	36	0.47	31	0.53	
	On campus (dorm)	36	0.47	14	0.24	
Roommate status	No	15	0.20	23	0.39	0.0230
	Yes	61	0.80	36	0.61	
Roommates: Same sex or coed	Coed	5	0.08	6	0.17	0.3198
	Same sex	56	0.92	30	0.83	
Source of college funding	Employment	6	0.08	7	0.12	0.0192
	Parental support	40	0.53	21	0.36	
	Scholarship	19	0.25	10	0.17	
	Student loans	11	0.14	21	0.36	
Transportation	Personal transport	41	0.54	45	0.76	0.0099
	Pick and drop by others	1	0.01	1	0.02	
	Public transport	34	0.45	13	0.22	
Athletics	No	56	0.74	52	0.88	0.0621
	Yes	20	0.26	7	0.12	
Type of athletics	Intramural	19	1.00	6	0.75	0.0798
	Scholarship	NA	0.00	2	0.25	
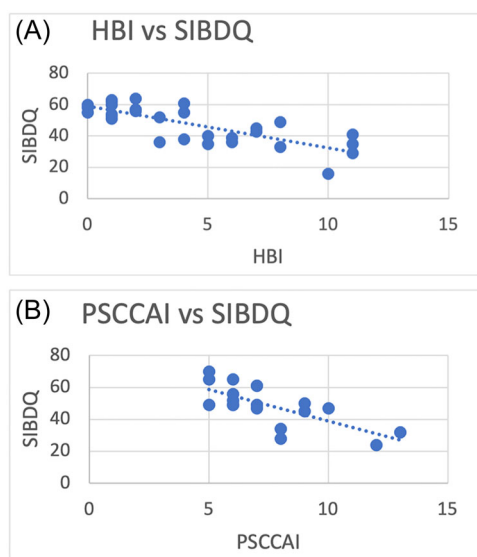
FIGURE 1 The relationship between students' disease severity (HBI and PSCCAI) and their SIBDQ survey results. (A) There was an inverse correlation between HBI and SIBDQ; R^2 value of 0.6214; $p \leq 0.0001$. (B). There was an inverse correlation between PSCCAI and SIBDQ; R^2 value of 0.513 with a p value of 0.0004. Greater disease activity is associated with poorer disease-specific quality of life. The relationship between SIBDQ and SACQ survey results of our IBD students–patients population. No significant relationship between SIBDQ and SACQ; R^2 value of 0.0171; $p = 0.356$. College adjustment versus disease activity. There was no correlation between SACQ and disease activity in either CD (HBI) or UC (PSSCAI). CD, Crohn's disease; HBI, Harvey–Bradshaw Index; IBD, inflammatory bowel disease; PSCCAI, Patient Simple Clinical Colitis Activity Index; SACQ, Student Adjustment to College Questionnaire; SIBDQ, Short Inflammatory Bowel Disease Questionnaire; UC, ulcerative colitis.

significantly less likely to use public transportation, have a roommate, and move out of town for college (Table 1). There was no difference in the mean age of patients who had their education interrupted versus participants with IBD with no education interruption (22.7 vs. 22.1, respectively). There was no correlation between HBI and the age at which education was interrupted.

In terms of disease demographics, 31% of participants with IBD previously had surgery for their disease. Immunomodulators were used by 22% of patients, biologics by 47%, and both immunomodulators and biologics were used by 14%. Most of the participants with IBD were cared for by an adult gastroenterologist (61%), 24% were cared for by a pediatric gastroenterologist, and 8.5% of patients were seeing both pediatric and adult providers. The remaining 6.8% of participants with IBD were unsure or had no gastroenterologist currently.

3.1 | College adjustment scores

Multivariable logistic regression was used to determine the predictors of poor college adjustment (low SACQ).

Somewhat surprisingly, active disease (as determined by the HBI and PSCCAI) and low IBDQ did not predict a low college adjustment score (Figure 2). Importantly, age at diagnosis predicted college adjustment score, with older age at diagnosis, that is, more recent diagnosis, having the most impact on the ability to adjust to college life. For every added year in age at diagnosis, the SACQ score decreased by 0.1 ($p \leq 0.02$). There was no significant relationship between disease activity (as determined by the HBI and PSCCAI) and college adjustment scores.

3.2 | Transition readiness and self-efficacy

Transition readiness scores revealed far better transition readiness in students with IBD versus controls (87.91 ± 9.47 vs. 81.41 ± 11.70; $p = 0.0006$). Students with IBD were better at managing their daily activities, medications, and appointment keeping than controls. Participants with IBD who received care from a pediatric gastroenterologist had lower TRAQ scores than those who saw adult gastroenterologists, though this was not statistically significant (84.86 vs. 90.41; $p = 0.06$). TRAQ score subgroup analysis and interaction between variables are shown in Table 2. Self-efficacy (inflammatory bowel disease self-efficacy scale) scores revealed scores indicating good self-efficacy (35.98 ± 3.48) in students. Additionally, we observed gender differences in self-efficacy skills among the participants. Male students reported lower levels of self-efficacy compared to their female counterparts, particularly in areas of managing health issues and daily activities. This observation aligns with the TRAQ scores, which indicated that female students were generally better at managing their health conditions and maintaining their health treatment regimens than male students.

4 | DISCUSSION

We conducted a comprehensive study on college adjustment and transition readiness in college students with IBD.[2,3] Our aim was to explore the college experience of these students and the relationship between transition readiness, disease activity, and college adjustment. It has been shown that fewer patients with IBD achieved postsecondary education compared to the general population.[20] Among those who do pursue higher education, unique challenges exist. Our findings indicate that IBD has significantly affected the college experience, with recently diagnosed students facing the greatest challenges in adjusting to college life.[2,3] Additionally, we observed that male students report lower levels of self-efficacy skills compared to their female counterparts.[2]
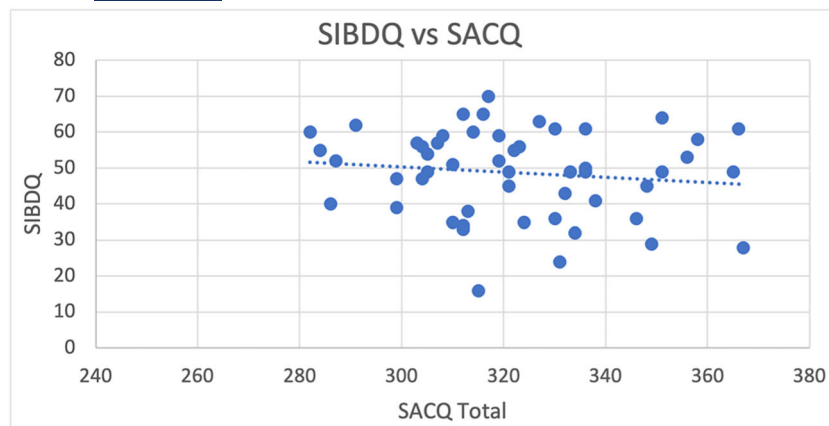
FIGURE 2 The relationship between SIBDQ and SACQ survey results of our IBD students–patients population. No significant relationship between SIBDQ and SACQ; R^2 value of 0.0171; $p = 0.356$. IBD, inflammatory bowel disease; SACQ, Student Adjustment to College Questionnaire; SIBDQ, Short Inflammatory Bowel Disease Questionnaire.

TABLE 2 SACQ average scores by subdomain for cases and controls.

SACQ subdomain	IBD	Control	p
Academic	35.82	35.67	0.43
Personal/ emotional	33.61	32.08	0.2
Attachment	14.89	14.16	0.2
Social environment	11.11	15.39	0.002

Abbreviations: IBD, inflammatory bowel disease; SACQ, Student Adjustment to College Questionnaire.

The factors affecting college students with IBD can have long-term implications, such as insurability and disease outcomes.[5] In addition, there is a profound psychological burden and increased risk of psychiatric comorbidity associated with IBD, including depression and anxiety disorders.[12,13] Despite these challenges, our study identified positive aspects, indicating that most students with IBD adapt well to college and have prospects for future economic success comparable to their peers.[2,3] Furthermore, participants with IBD demonstrated better knowledge of navigating the healthcare system and higher transition readiness compared to their healthy peers. These traits may stem from their prior experiences with the healthcare system due to their IBD diagnosis.[2]

Interestingly, disease severity (determined by HBI and PSSCAI) did not influence the ability to adjust to college life (SACQ) in our study based on logistic regression, which differs from previous research. The variations between studies could be attributed to differences in college environments or patient characteristics.[2,3,21]

Both our study and prior research highlight social aspects of college life that can have a greater impact on college adjustment than physical concerns.[1–3,12] The emotional and social domains examined in our study capture age-specific issues that may not be accounted for by disease activity indices or disease-specific quality-of-life questionnaires.[1] Our analysis revealed that students with IBD who scored lower in college adjustment lacked confidence in their ability to succeed.[1,6] This aligns with our group's previously published focus group findings, which emphasized the students' lack of confidence as a significant concern. Interestingly, another study found self-efficacy and resilience to also be predictors of transition readiness in IBD.[22] Addressing these issues requires fostering peer interactions to bolster the students' confidence in their abilities to thrive academically.[6,23]

Furthermore, our study showed that newly diagnosed students with IBD tend to be more challenged with college adjustment than those diagnosed earlier in life. This difficulty can be attributed to the challenges of adapting to a new environment without familiar support systems[2,3] with the added stressor of managing a new chronic illness. Prior studies demonstrate that transition readiness is not typically associated with disease duration[24,25] However, our findings, consistent with other literature,[26] suggest that newly diagnosed patients have different needs. For example, it is not usual for a freshman to leave campus over a holiday break and return with a new diagnosis of IBD, facing significant challenges the following semester. Surprisingly, there is a lack of information on the needs of newly diagnosed IBD patients of all ages, including college-aged individuals. Our group's prior work on this patient population using focus group discussions also revealed concerns about various college-related aspects, such as food, bathrooms, and transportation.[6] Newly diagnosed patients are eager for information and psychological support, which they often do not receive.[26]

While there was no difference in college adjustment between males and females, we discovered that male students face a higher risk of poor transition to adult IBD care based on their TRAQ scores This is contrary to recent work which suggested a trend for higher

TRAQ scores in males compared to females in tracking health issues.[27] In the present study, female students reported better health issue tracking and daily activity management. This finding aligns with previous research indicating that transition readiness is associated with female gender.[2]

Our goal was to identify the top risk factors for poor college adjustment in students with IBD, which can pave the way in the future to design an early recognition system for at-risk students.[1–3] Our analysis revealed that students at risk of low college adjustment scores typically lacked clear academic goals and expressed dissatisfaction with course quality and availability.[1] Social adjustment closely correlated with college adjustment, as students with low scores lacked a support network, felt deficient in social skills, and were dissatisfied with their social life at college.[1,6] Notably, students with IBD were more likely to live at home rather than independently, which could lead to exclusion from college extracurriculars and dormitory life.[6]

Despite the significant findings, our study has limitations. Recruiting participants for the study was challenging, and nonresponse bias may have affected the results.[28,29] The self-reported nature of the results, the inability to track academic outcomes over time due to the cross-sectional nature of the study, and limited disease activity and psychosocial data further restricted our analysis. No medical history was collected for controls. The cohort primarily consisted of patients from our University of Florida (UF) pediatric and adult IBD clinics, with limited representation from other care centers. Therefore, the findings may not be applicable to all populations. Additionally, respondents' biases and inaccuracies in self-reporting could have influenced the survey-based study. Finally, the study's generalizability is limited to universities similar to UF, which attract students from a national applicant pool.[2,3]

College success can lay the groundwork for future job prospects and career opportunities, which could have wide-ranging ramifications on health benefits which may be especially critical in those with a new chronic illness diagnosis such as IBD. Adult gastroenterologists caring for college-aged IBD patients cannot treat IBD in a vacuum and ignore the nuanced psychosocial and developmental needs of this important patient demographic. Our current management tools for college-aged patients with IBD are insufficient, as they overlook the need for continuous, collaborative support beyond the walls of clinic, which is the gap that our participants identified. We need to move beyond the idea of a patient-centered medical home to more of a patient-centered medical community that addresses not only disease-specific needs, but also bolsters a sense of social connectedness and offers comprehensive resources to address mental health, sexual health, nutrition, and fitness, which are all pivotal in any young adult's developmental trajectory.

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