

A Review of inflammatory bowel disease status in USA college-aged individuals affecting the transition to and adjustment in college

Lauren E. PITTS¹, Amanda H. WILKERSON², Taylor S. FERRIS¹, Manish HARRIGILL¹, Himmat S. BRAR³, Manoj SHARMA⁴, Vinayak K. NAHAR⁵

Affiliations:

¹ School of Medicine, University of Mississippi Medical Center, Jackson, MS, United States of America, Email: lpitts@umc.edu. ORCID: 0000-0001-8855-0418.

² Department of Health Science, College of Human Environmental Sciences, The University of Alabama, Tuscaloosa, AL, United States of America. Email: awilkerson@ches.ua.edu. ORCID: 0000-0002-5116-9012.

³ Division of Digestive Diseases, School of Medicine, University of Mississippi Medical Center, Jackson, MS, United States of America, Email: hbrar@umc.edu. ORCID: 0000-0002-8819-8052.

⁴ Department of Social and Behavioral Health, School of Public Health, University of Nevada, Las Vegas, NV, United States of America, Email: manoj.sharma@unlv.edu. ORCID: 0000-0002-4624-2414.

⁵ Department of Dermatology, School of Medicine, University of Mississippi Medical Center, Jackson, MS, United States of America. Department of Preventive Medicine, School of Medicine/John D. Bower School of Population Health, University of Mississippi Medical Center, Jackson, MS, United States of America. Department of Clinical Research, School of Graduate Studies in the Health Sciences, The University of Mississippi Medical Center, Jackson, MS, United States of America. Email: vnahar@umc.edu. ORCID: 0000-0002-6771-1662.

***Corresponding Author:**

Vinayak K. Nahar, M.D., Ph.D., M.S., Associate Professor & Director of Clinical Research, Department of Dermatology, School of Medicine, University of Mississippi Medical Center, 2500 North State Street – L216, Jackson, MS 39216 USA, E-mail: naharvinayak@gmail.com

Abstract

Introduction: Inflammatory bowel disease (IBD) is a disease involving inflammation of the gastrointestinal tract and is comprised of Crohn's disease and ulcerative colitis. Attending college while suffering from IBD can have a significant impact on the disease's course, severity, and activity. The aim of this paper was to review previous studies on IBD in college students in order to analyze the influence of their disease on their ability to adjust to college life and perform well academically.

Methods: Searches in three databases (PubMed/Medline, ScienceDirect, and ERIC) were conducted to locate studies for the review. The review only included studies that looked into factors linked to IBD, such as Crohn's disease and ulcerative colitis; included USA college students as the target population; were empirical research studies (not reviews, meta-analyses, or prospective papers); were published in peer-reviewed journals, and were written in English.

Results: This review included a total of seven studies. According to current research on IBD among college students, there are specific disease-related problems that make the transition from living at home to living on a college campus challenging. Having easy access to acceptable food and private restrooms, transitioning treatment between physicians, transitioning to more independent care away from home, and dealing with the disease's perceived stigmatism and stress are the most important problems discovered among college students in the USA.

Discussion: This review suggests that students diagnosed with IBD earlier still encountered unexpected difficulties compared to their healthy peers, demonstrating the significant impact IBD may have on overall student success in college. This suggests that while a specific focus may need to be dedicated to newly diagnosed college students with IBD, any college student with IBD should be included in targeted programs aimed at providing resources and helping transition to college.

Take-home message: IBD may have a substantial impact on overall student success in college, as evidenced by the fact that students who were identified with the condition earlier than their healthy peers nevertheless experienced unexpected challenges.

Keywords: Crohn's disease; College students; Inflammatory bowel disease; Quality of life; Ulcerative colitis.

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INTRODUCTION

Inflammatory bowel disease (IBD) is a disease involving inflammation of the gastrointestinal tract and is comprised of Crohn's disease and ulcerative colitis. Both diseases have similar symptoms but can be distinguished from one another based on the specific area of the gastrointestinal tract which is inflamed [1,2]. Crohn's disease describes inflammation of the entire gastrointestinal tract while ulcerative colitis describes focused inflammation of the colon [3]. IBD is an autoimmune condition affecting the gastrointestinal tract which typically presents between 15 and 35 years of age. However, trends are showing an increase in the diagnosis of ulcerative colitis and Crohn's disease among individuals less than 20 years of age [4]. Once diagnosed, IBD is a lifelong condition with no current existing cure [5–7]. Nationally, IBD affects 2 to 4 people per 1,000 in the population. Of these diagnosed cases in the United States, many individuals living with IBD are college-aged individuals. It is estimated that as many as 67,000 students are affected by IBD on college campuses across the United States [6]. IBD has been linked to considerable morbidity, poor quality of life, and frequent complications that necessitate hospital stays and surgical operations [8].

Attending college with IBD can certainly impact the course, severity, and activity of the disease [9]. New lifestyle adjustments, dietary changes, disruption of habits formed prior to college, and interruptions to student health care, on top of the normal stress and emotions of transitioning to college, are all significant aspects which impact an individual's IBD disease [6,10]. Additionally, preliminary studies have shown that there exists a strong association between disease activity and college adjustment [11,12]. Adequate adjustment when starting college is required for overall student success including academic success. Academic success during college impacts graduation rates, which eventually affects an individual's future economic success [12]. For this reason, IBD in college students can be viewed as a public health issue, as these students diagnosed with IBD tend to have more difficulties adjusting to college than do their healthy peers. This may in part be attributed to increased absences from school due to health-related clinic visits [7]. A decrease in confidence due to their disease status may also impact academic success among college students with IBD [7]. The purpose of this paper was to review studies about IBD in college students in order to study how IBD is associated with the ease of transition and ability for academic success in college. This review looked specifically at research evaluating the impact of IBD on college students and does not include research surrounding IBD in other stages of life.

METHODS

Search strategy

Studies included in this review were located by searching the following keywords: "inflammatory bowel disease", "Crohn's disease", "ulcerative colitis", "college students," and "college", properly combined by Boolean operators, in PubMed/Medline, ScienceDirect, and ERIC databases. In addition to the databases searched, the authors attempted to locate any additional articles inadvertently missed by the selected search strategy by searching the same key terms in Google Scholar and the Primary Investigator's University library system. There were no attempts to

locate unpublished grey literature or difficult-to-access studies. Additional eligible studies were included after a hand search of their reference lists.

Data sources, criteria of inclusion, and data extraction

Inclusion criteria for the review were limited to studies: 1) investigating factors associated with IBD, including Crohn's and ulcerative colitis; 2) including USA college students as the population of interest; 3) empirical research studies (i.e., not a review, meta-analysis, or prospective paper); 4) published in peer-reviewed journals, and 5) published in English. Studies were excluded from the review if the study: 1) did not investigate factors associated with IBD; 2) included a population of interest other than USA college students; 3) did not conduct empirical research (i.e., was a review, meta-analysis, or perspective paper; 4) was not peer-reviewed; and 5) was not published in English. All relevant articles were included irrespective of the date of publication to assess a comprehensive review of this area of research. The selected studies that met the pre-defined inclusion/exclusion criteria and were related to the topic of interest were included in our review.

Two independent reviewers (LEP and VKN) conducted the search strategy independently. In February 2021, the initial search was carried out. To ensure that no pertinent study was overlooked, the search was then conducted again in June 2022. Following the independent search, each reviewer cross-referenced the other reviewer's search results to confirm that pertinent studies were not excluded from the search. Disagreements between the two reviewers were discussed and resolved. If necessary, a third reviewer (MS) was consulted to resolve any disagreements between the reviewers. The reviewers utilized a systematic distillation process to identify articles to include in the review. The authors carried out the data extraction process independently. The results of the studies were analyzed qualitatively, and when possible, also quantitatively. The findings obtained were discussed by all the authors. Figure 1 illustrates the paper extraction flow diagram for this review [15]. Data extracted from the reviewed studies are presented in Table 1.

RESULTS AND DISCUSSION

Population and demographics

The electronic searches identified a total of 106 articles. After removing duplicates ($n=21$), in the first phase of distillation, the reviewers conducted a preliminary assessment of the titles and abstracts of each article ($n=69$) located using the search strategy. Papers that were deemed ineligible ($n=48$) were excluded from the review at this phase, leaving 21 articles for full-text review, where 14 additional studies were excluded from the review. The distillation process resulted in a total of seven studies for inclusion in the review.

The studies ($n=7$) examined in this review all looked at students enrolled in either undergraduate or graduate school with the exception of one study [13] which included three college-aged participants who were not currently enrolled. Four of the studies looked only at students with an IBD diagnosis [6,7,13,14]. One study looked only at healthy students to examine different stigmas surrounding their peers with IBD [5]. Two studies looked at both healthy students and students diagnosed with IBD [11,12]. Of the students with IBD, participants ranged from 17-25 years of age [6,7,13,14]. The number of IBD participants ranged from eight to 97 [6,7,11–14]. In one study, the race of IBD participants was predominantly white [6]. In another study of 15 college students with IBD, eight participants identified as female and seven as male [14]. For the one study examining only healthy students ($n=127$), 86.6% of participants identified as female. The healthy student ages ranged from 19-29 with a mean age of 20.91 and were predominantly white with the second most common race being Asian [5].

Study design

One study design consisted of a questionnaire-based survey over a two-year period and included a clinical appointment with an IBD physician and a lecture by an IBD physician followed by an interactive segment between patients. The study gave educational material to the participants and allowed the participants to share their stories and ask questions in a safe group setting [13]. Two studies utilized surveys to compare healthy college students as a control to college students with IBD [11,12]. Specifically, one study used a college adjustment survey and QOL instrument [11]. Another

study used an online survey to assess the perceived control students living with IBD feel they have over their academics and their adjustment to college [7]. A different study investigated stigma surrounding IBD in undergraduate college students using an experimental survey given to healthy college undergraduates which utilized a between-subjects approach [5]. Another study asked 20 interview-guided questions to college participants with IBD [14]. Finally, one study led two 90-minute focus groups with eight student participants with IBD, and reflective journals were used to analyze the data [6].

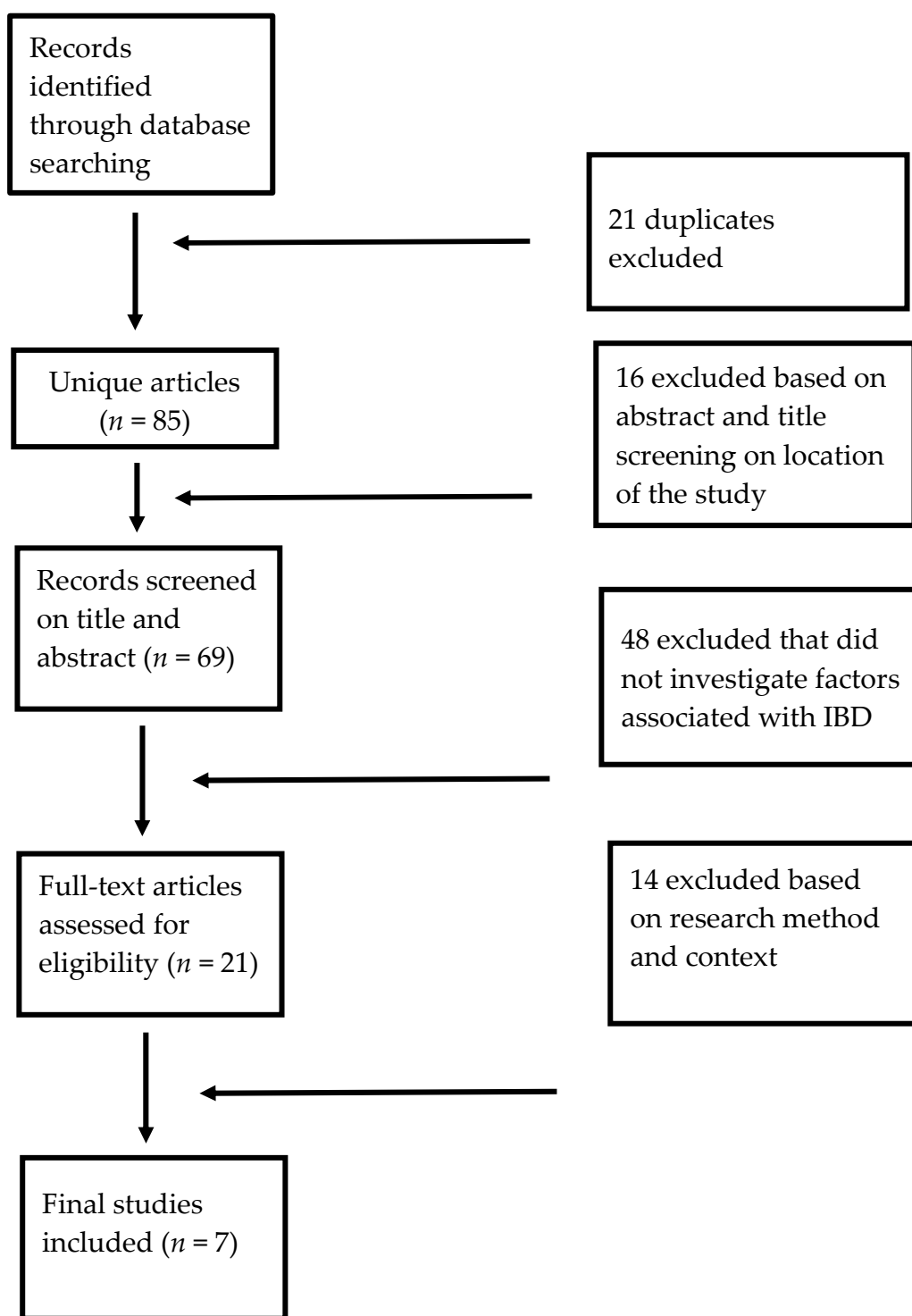


Figure 1. Literature search process.

Table 1. Summary of included studies (*n* =7).

Authors and year	Population and demographics	Study design and instruments	Findings/consequences of IBD in college students	Public health significance of the findings
Adler et al, 2008 [11]	Total participants: <i>n</i> = 37 (UC: <i>n</i> = 12 Crohn’s: <i>n</i> = 6 Healthy: <i>n</i> = 19) All participants were undergraduate students. USA	Cross-sectional (College Adjustment and Quality of Life Surveys) Two disease-independent surveys were given to all participants. Several disease-specific surveys were given to students with IBD.	Quality of life and disease activity were found to be inversely correlated during college adjustment in UC and Crohn’s students. (<i>R</i> = -0.6554, <i>p</i> = 0.0032) Physical QOL was lower for IBD students (SF-12) than controls (<i>p</i> = 0.0009). Student emotional adjustment was associated well with SIBDQ (<i>R</i> = 0.8228, <i>p</i> < 0.0001), and emotional adjustment was associated in CD students (<i>R</i> = 0.8619) than UC (<i>R</i> = 0.7946) students. CD students had worse mental QOL (SF-12) than UC students (<i>p</i> = 0.0211), but CD and UC did not differ from controls (<i>p</i> = 0.4, <i>p</i> = 0.6). IBD students adjust less well to college than their healthy counterparts. Physical quality of life was lower for IBD students and mental well-being was noted to impact Crohn’s disease more than UC, but neither differed significantly from controls.	Better emotional support during the transition to college for IBD students may result in happier and healthier students, which will impact academic performance leading to higher graduation rates.
Authors and year	Population and demographics	Study design and instruments	Findings/consequences of IBD in college students	Public health significance of the findings
Schwenk et al, 2014 [14]	Total participants: screened: <i>n</i> = 73 Interviewed: <i>n</i> = 15 (7 males, 8 females) Age range: 19-21 (19.73)	A qualitative study (Interview guided 20 questions Survey. Participants were individually interviewed over the phone using protection	Four main themes regarding the college experiences of those with IBD were examined: (1) IBD student change to college is influenced by the health status of the student, their	Clinical guidance along with assistance from family members, classmates, and college personnel may help these students make a smooth transition to college and

	They were all self-reported to be enrolled in college.	motivation theory and the chronic care model).	perceived readiness, and general preparedness. (2) Adaptive strategies are needed to cope with specific environmental elements of college. 3) IBD students entering college merge their illnesses with their identities, both social and individual. (4) Creating particular roles for themselves, their families, and their providers allow college students to navigate their health management. College is a time for young adults with IBD to demonstrate self-sufficient disease	protect their health status. Transition support for college-bound IBD youth should include a discussion of techniques for recognizing and accessing help at college, as well as pragmatic approaches and methods for dealing with the unique tribulations of college life.
	USA			

Authors and year	Population and demographics	Study design	Findings/consequences of IBD in college students	Public health significance of the findings
			managing practices and self-care. This should be promoted and focused on when transitioning to college.	
Almandi et al, 2014 [12]	Total participants: $n = 307$ IBD students: $n = 93$ (28 UC, 65 Crohn's) Healthy students: $n = 214$ Mean Age: UC: 20.3 Crohn's: 20.2 Healthy: 19.9 USA	Case-control study Online Survey (Online instrument was administered with a standardized adjustment to the college survey. A quality of life (QOL) questionnaire and a short IBD QOL (SIBDQ) instrument with disease activity measures were also included).	SIBDQ was associated with IBD student morbidity ($\rho = -0.79$; $p < 0.0001$). Higher scores on the quality of life survey were associated with high college adjustment scores (SACQ results). IBD students exhibited lesser mean SACQ scores when compared to controls (307 vs 290; $p < 0.0001$), and a slight inverse correlation was found between Crohn's and SACQ scores ($\rho = -0.24$; $p < 0.04$). A strong association was	Academic adjustment is important for academic success and graduation rates which go on to affect economic success later in life.

found between disease activity in CD students and their ability to stay up to date with work in school (self-reported) ($p < 0.0089$) and surety that they could meet future challenges arising academically ($p < 0.0015$).

Authors and year	Population and demographics	Study design and instruments	Findings/consequences of IBD in college students	Public health significance of the findings
Clarke et al, 2017 [13]	<p>Total participants: $n = 26$</p> <p>Age Range: 18-22</p> <p>Education: 23 enrolled in college 1 recent graduate 2 college-aged but not enrolled</p> <p>USA</p>	<p>Educational intervention study</p> <p>Questionnaire-based survey: A questionnaire was given to IBD students who participated in a program (consisting of a lecture with an IBD physician and clinical appointment, along with an interactive patient segment).</p> <p>Educational material was available for review and there were</p>	<p>Students with active IBD indicated that they did not feel successful academically ($p < 0.018$), while ulcerative colitis students indicated sporadic lecture attendance ($p = 0.043$).</p> <p>IBD students have a difficult time transitioning to college life compared to their due to myriad factors.</p> <p>Results showed that every patient who participated in the program believed it to be beneficial.</p> <p>96% of the participants rated the program experience as “awesome” or “very good.”</p> <p>77% of participants indicated that sharing their experience proved to be the most beneficial aspect.</p> <p>19% of participants indicated the physician lecture to be the most beneficial aspect.</p>	<p>A better understanding of IBD can be accomplished through targeted programs involving individuals with IBD. This could also lead to improvement with management plan compliance among vulnerable populations.</p>
Authors and year	Population and demographics	Study design and instruments	Findings/consequences of IBD in college students	Public health significance of the findings

		opportunities for patients to express their experiences and interact.	College-aged students with IBD benefited from a targeted approach to addressing their disease and being able to ask questions and discuss their experiences in a safe environment.	
Rohde et al, 2018 [5]	Total participants: <i>n</i> = 127 (86.6% Female) Age range: 19-29 (20.91) Race: 50.4% Caucasian 34.6% Asian 7.9% Hispanic 1.6% African American 0.8% Other Education: 97.7% of Undergraduate students Healthy students without IBD. USA	Experimental study: the study design consisted of a 2x3 experimental survey. (disclosure: yes or no) x (severity: low, moderate, high). There was a random presentation of one of six different scenarios with varying disclosure and severity status. Enacted stigma levels between participants with and without disclosure status were compared by t-test. ANOVA was conducted	When IBD was disclosed, lower levels of stigma were identified (<i>M</i> = 5.00, <i>SD</i> = 3.94) when in comparison of nondisclosure groups (<i>M</i> = 6.71, <i>SD</i> = 3.62). No significant difference between the three factors (low, moderate, high) was found when using a one-way analysis of variance test. No significant interactions were found between disclosure status, and the severity of stigma when the relationship was tested with a multiple analysis of variance test.	An examination of the presence of stigma among a targeted population of college students can provide a deeper understanding of the difficulties and effects of stigma on young people with a chronic illness, especially in light of the high prevalence of IBD diagnoses among young people, the associated social and psychological stresses, and the health-related stigma that accompany chronic illnesses like IBD.
Authors and year	Population and demographics	Study design and instruments	Findings/consequences of IBD in college students	Public health significance of the findings
		across 3 factors: low, moderate, and high.		
Chaudhry et al, 2020 [6]	Total participants: <i>n</i> = 8 (5 Females, 3 Males) Mean age: 20.38 +- 2.5 Race: 6 Caucasian	Qualitative study Focus Groups Eight IBD student-patients were placed into two 90-min focus groups.	College students with IBD related to 6 main themes identified: (1) college transition from high school (2) physicians-patient interaction	A variety of factors impacting the college experience of students with IBD were identified. One factor

<p>2 Hispanic Education: 6 Undergraduates 2 Graduates USA</p>	<p>Journaling was used to conduct a thematic assessment.</p>	<p>(3) social life changes due to IBD (4) disease management (self and supports) (5) coping approaches (6) facing challenges related to morbidity</p> <p>Diagnosis of IBD closer to the transition into college is associated with increased stress, leading to increased severity of the disease symptoms. Students generally expressed mild dissatisfaction regarding the absence of a consensus of physician guidance on diet. However, commonly beneficial or commonly adverse diets for IBD</p>	<p>highlighted was the importance of student resources on college campuses.</p>
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Authors and year	Population and demographics	Study design	Findings/consequences of IBD in college students	Public health significance of the findings
			<p>patients have been available according to some.</p>	
			<p>Most participant-students indicated frustration concerning their inability to participate in traditional college activities. Frustrations were also indicated surrounding limitations placed on their social experiences. Students adapted their diets and choices surrounding drinking, but moderate alcohol consumption was still an issue.</p>	
			<p>Many universities have disability resources and student health centers accessible to IBD students, but most are inexperienced in regard to IBD-specific issues.</p>	

The role of home-town physicians was highlighted.

The role of family education was emphasized.

Authors and year	Population and demographics	Study design and instruments	Findings/consequences of IBD in college students	Public health significance of the findings
Plevinsky et al, 2022 [7]	Total Participants: <i>n</i> = 97 (69 Females, 28 Males) Age Range: 18-25 (20.52) Race: 90 Caucasian 4 Hispanic 1 Black 1 Asian 1 Other All participants were currently enrolled in college at least part-time with a medical diagnosis of IBD. USA	Cross-sectional study Online survey Participants completed an online survey and researcher-developed instrument to ascertain the putative impact of IBD on studies in high school and planning for college.	The majority of participants reported average college adjustment in all areas with the exception of “personal-emotional adjustment.” 47% of participants scored within the very low-low range for this category. The choice of college was impacted by 49% of participants. Adjustments in college-bound youth, specifically surrounding college planning and decision-making, are greatly affected by IBD diagnosis.	Believing that chronic illnesses affect college planning, decision, and adjustment may cause increased adjustment difficulty for students with IBD, especially academically and socially.

Study findings

Two studies performed surveys comparing healthy college students to students with IBD. The studies demonstrated a correlation between disease activity and adjustment to college and quality of life in college [11,12]. Further, these studies showed a significant relationship between disease activity levels and the ability to keep up with academic work, the ability to meet future academic challenges, and mental quality of life when comparing the two groups [11,12].

One study performed using an online survey of college-aged participants looked at the effect IBD had on college planning, preparedness, and college decision-making [7]. This study found that diagnosis of IBD had a severe impact on all three areas. Of the participants, 49% reported that their choice of college was impacted by their condition. The majority of participants reported average adjustment to college in most areas. The one exception was “personal-emotional adjustment” in which 47% of participants with IBD scored in the “very low” or “low” range of this category [7].

The two studies that focused on the qualitative aspects of IBD’s impact on college students detailed important findings with respect to the timing of IBD diagnosis, facilities/support available on campuses, and stigma/social life [6,14]. Both studies found that students diagnosed closer to the time of starting college had increased stress and more difficulty making the transition to college. This

highlights the importance of having time to adapt to an IBD diagnosis, as both studies also demonstrated that students with time to develop disease management strategies had an easier transition experience [6,14]. However, extra time to adapt did not completely ease the transition, as both studies also showed that students with IBD faced many unexpected disease challenges and felt underprepared in their transition, regardless of whether they had time to adapt prior to college [6,14]. The two qualitative studies also demonstrated the importance of having adequate facilities for students with IBD to make the transition to college. Students with IBD in both studies detailed how the unique social challenges associated with their nutritional and digestive needs created specific importance for having facilities such as diverse dining options on and near campus, cooking facilities in residence halls, and access to private bathrooms [6,14].

A different study investigated stigma surrounding IBD in healthy college students, and analysis revealed that those familiar with IBD (i.e., those who have IBD or know someone who has IBD) exhibited lower levels of enacted stigma ($M = 4.35$, $SD = 3.36$) than those unfamiliar ($M = 6.44$, $SD = 3.92$). This study also demonstrated no significant difference between those participants who were familiar with chronic disease ($M = 5.48$, $SD = 3.90$) and the participants who were not ($M = 6.04$, $SD = 3.86$), $t(125) = 0.78$, $p = 0.44$. Participants exhibited significantly lower levels of stigma ($M = 2.92$, $SD = 3.07$) after a respondent had been diagnosed with a chronic disease compared to before he/she was diagnosed ($M = 6.29$, $SD = 3.84$), $t(118) = -3.04$, $p < 0.01$ [5]. Findings from this study also revealed that the severity of IBD does not correlate significantly to the level of stigma toward those with IBD, and familiarity with IBD decreases the chance that a participant stigmatizes one with IBD [5].

Lastly, a study utilizing a longitudinal questionnaire-based survey administered over a 2-year period including a clinical appointment with an IBD physician and a lecture by an IBD physician, found that all participants living with IBD believed that the program was beneficial. Specifically, 76.9% reported that the ability to share their story and reflect was the best feature of the program [13]. Overall, less than 20% of participants found the lecture helpful, which included participants without an IBD diagnosis [13]. This approach to further educating patients living with IBD about their diagnosis and providing resources received excellent feedback among college students living with IBD and shows promise for improvement of disease management in this population of interest.

Study limitations

The authors recognize that this review is not without limitations. First, the generalizability of the review is limited by several factors. Studies included in the review were heterogeneous with respect to their samples, study design, and purpose [16]. Therefore, it limits the ability to make comparisons across studies to inform generalizable statements about the literature in this stream of research. Second, the review was limited to only three databases: PubMed/Medline, ScienceDirect, and ERIC. The authors cross-referenced Google Scholar and the Primary Investigator's University library system to ensure that any articles were inadvertently missed using the search strategy and databases for the review. However, studies may still have been inadvertently missed using this search strategy. Finally, although the authors aimed to provide a comprehensive review of the literature in this area, a systematic analysis of our findings with meta-analysis was not performed, which limits the ability to draw quantitative implications from the findings of the review [17,18].

CONCLUSION

Current research on IBD in USA college students suggests that there are unique disease-related challenges that present difficulty when transitioning from living at home to living on a college campus. Such challenges include having easy access to an appropriate diet and private restrooms, transitioning care between physicians, transitioning to more independent care away from home, and dealing with potential perceived stigma from peers and stress that accompanies the disease. Students who were diagnosed with IBD earlier and had time to adjust to their disease prior to college reported having an easier transition than students who received their diagnosis later. However, students diagnosed with IBD earlier still encountered unexpected difficulties compared to their healthy peers, demonstrating the significant impact IBD may have on overall student success in college. This suggests that while a specific focus may need to be dedicated to newly diagnosed college students

with IBD, any college student with IBD should be included in targeted programs aimed at providing resources and helping transition to college. This review specifically analyzed research evaluating the impact of IBD on US college-aged individuals and does not include research surrounding IBD in other stages of life. A potential area for further research would be to explore the amount of perceived control college students with IBD feel they have over managing their disease given the appropriate strategies and resources on a college campus.

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