HHS Public Access

Author manuscript

Res Nurs Health. Author manuscript; available in PMC 2021 January 01.

Published in final edited form as:

Res Nurs Health. 2020 January ; 43(1): 48–55. doi:10.1002/nur.21985.

Symptoms Among Emerging Adults With Inflammatory Bowel Disease: A Descriptive Study

Kendra Kamp, PhD, RN[1,*], **Sharon Dudley-Brown, PhD, FNP-BC, FAAN, FAANP**[2], **Margaret Heitkemper, PhD, RN, FAAN**[3] **[Professor]**, **Gwen Wyatt, PhD, RN, FAAN**[4] **[Professor]**, **Barbara Given, PhD, RN, FAAN**[5] **[Professor]**

[1]Post-doctoral Fellow, University of Washington

[2]Associate Professor, Director of the Doctor of Nursing Practice Program, University of Delaware

[3]Chair of the Department of Biobehavioral Nursing and Health Informatics, University of Washington

[4]Michigan State University

[5]Interim Associate Dean for Research, Michigan State University

Abstract

Individuals with inflammatory bowel disease (IBD) are commonly diagnosed when they are between the ages of 18-29, a developmental period known as emerging adulthood. Typically, emerging adults are subsumed into the category of adults even though emerging adults have unique developmental needs. In this descriptive study of IBD in emerging adults, the aims were to: 1) determine the prevalence of symptoms, 2) describe the severity of symptoms and their interference with daily activities, and 3) examine the association between individual symptom severity and presence of fatigue. Emerging adults with IBD were recruited using web-based convenience sampling. Sixty-one emerging adults met inclusion criteria. They had a mean age of 24.7 and disease duration of 6.4 years. The most prevalent symptoms reported were: fatigue (n = 44, 72.1%), abdominal cramps (n = 39, 63.9%), abdominal pain (n = 39, 63.9%), and diarrhea (n = 38, 62.3%). The symptom with the greatest severity and interference with daily activities was fatigue. Abdominal cramps, abdominal pain, diarrhea, passing gas, and abdominal tenderness were associated with fatigue when controlling for age, emerging adulthood, gender, time since diagnosis, and current steroid use. Emerging adults reported the symptom of fatigue as having the greatest prevalence, severity, and interference with daily activities. These results suggest a need for interventions aimed at reducing both fatigue and gastrointestinal symptoms among emerging adults with IBD.

Keywords

inflammatory bowel disease; ulcerative colitis; Crohn’s disease; symptoms; young adult

[*]**Correspondence** Kendra Kamp, PhD, RN, University of Washington, Box 357766, Seattle, WA 98185, kamp@uw.edu.

Conflict of Interest Statement: The authors declare no conflicts of interest.

1 INTRODUCTION

Both ulcerative colitis and Crohn's disease are types of inflammatory bowel disease (IBD), a chronic inflammatory condition of the gastrointestinal tract. IBD is characterized by periods of flares and remissions. Individuals with IBD often experience multiple gastrointestinal (GI) symptoms such as diarrhea, abdominal pain, cramping, and bloody stool. Additional non-GI symptoms such as fatigue, depression, and anxiety are also reported (Farrell, McCarthy, & Savage, 2016). Both GI and non-GI symptoms can result in life disruptions such as limited engagement in social activities, impaired work productivity, and decreased quality of life (Kemp, Griffiths, & Lovell, 2012). Thus, symptom management among people with IBD is important to overall health outcomes.

Individuals with IBD are commonly diagnosed between the ages of 15-30. Yet, adults with a mean age of 40-50 are the focus of most IBD symptom research (Conley, Proctor, Jeon, Sandler, & Redeker, 2017; Farrell et al., 2016; Singh et al., 2011). As such, there is a gap in our knowledge about symptoms experienced during emerging adulthood (ages 18-29). Emerging adulthood is an important developmental stage, representing a period of transition in which individuals become responsible for the management of their own lives and health (Arnett, 2015). Emerging adults have left the dependence of childhood and adolescence and may experience a period of instability, identity exploration, self-focus, increased optimism, and a sense of feeling in-between adolescence and adulthood (Arnett, 2000; 2015). Although emerging adulthood usually encompasses ages 18-25, the broader definition of emerging adulthood (ages 18-29) was used here because managing IBD has the potential to prolong the period of transition (Arnett, 2015). Focusing specifically on emerging adulthood supports creating developmentally appropriate symptom management interventions in the future. This may be important because symptoms that are poorly managed have the potential to lead to greater complications later in life (Herzog et al., 2017; Herzog et al., 2018).

IBD disease activity status is often elicited using clinical disease activity indices (Peyrin-Biroulet et al., 2016). Common clinical disease activity indices, including the Harvey Bradshaw Index, Crohn's Disease Activity Index, and the Mayo Score, have been integral to assessing outcomes in IBD drug trials. Although important, clinical disease activity measures assess limited GI symptoms such as abdominal pain, stool frequency, and blood in the stool (Peyrin-Biroulet et al., 2016). Furthermore, other disease activity measures often emphasize histological, endoscopic, and inflammatory markers. Yet, these indices provide limited information about the overall burden of symptoms. Incorporating traditional disease activity indices with patient-reported outcomes, such as symptom prevalence, severity, and interference with daily activities, enables a more comprehensive approach to disease management (Bojic, Bodger, & Travis, 2017).

Findings from previous symptom research studies involving middle aged adults with IBD indicate that fatigue is the most prevalent symptom (Conley, Proctor, Jeon, Sandler, & Redeker, 2017; Farrell, McCarthy, & Savage, 2016). Fatigue is an overwhelming sense of tiredness, lack of energy, and feeling of exhaustion (Hulme et al., 2018). Fatigue is not simply due to the effects of treatment because fatigue is common among recently diagnosed patients (Cohen et al., 2014) as well as those with long-standing disease (Huppertz-Hauss et

al., 2017). Fatigue in individuals with IBD has societal implications because fatigued individuals report greater work and activity impairment and reduced quality of life (Cohen et al., 2014). And yet, fatigue is poorly understood by healthcare providers and often providers do not ask about fatigue (Czuber-Dochan et al., 2014).

In persons with IBD, fatigue is associated with increased clinical disease activity (Artom, 2016). Yet, the relationship between fatigue and GI symptoms such as abdominal cramps and bloating is not clear because, on surveys, less than 50% of individuals with IBD report GI symptoms within the past two weeks (Kochar et al., 2018). Examining individual IBD symptoms in relationship to fatigue is a novel approach to understanding fatigue and informing future interventions.

As little to no research currently focuses on symptoms among emerging adults with IBD, this descriptive study represents a first step in inquiry. As such, a variety of online recruitment methods were used with the aim of recruiting a diverse sample in terms of symptom severity and geographical location. In this descriptive study of IBD in emerging adults, the aims were to: 1) determine the prevalence of symptoms, 2) describe the severity of symptoms and their interference with daily activities, and 3) examine the association between individual symptom severity and presence of fatigue.

2 METHODS

2.1 Sample

A descriptive cross-sectional design was used. Participants between the ages of 18-29 with a self-reported diagnosis of ulcerative colitis or Crohn’s disease were recruited using convenience sampling. Self-reported IBD diagnosis within online cohorts has high validity (Randell et al., 2014). Participants were included in the study if they were currently prescribed medication to manage their IBD, lived in the United States, understood written English, and had access to the internet. Participants were excluded if they were hospitalized within the past month or currently pregnant.

2.2 Procedures

Emerging adults were recruited online from January 2018 - February 2018 through ResearchMatch (an online database of individuals interested in participating in research), Facebook (a social media site), or word of mouth. Online recruitment was used to obtain participants with diverse symptom experiences and geographical locations within the United States. Although ResearchMatch was the primary recruitment method, only 15 individuals recruited using this approach completed study measures. Recruitment was expanded, therefore, to include posting in Facebook support groups for IBD and paid Facebook advertisements. Interested individuals completed a screening questionnaire to determine their eligibility for the study. The screening questionnaire was automatically scored and individuals meeting criteria continued to the survey. Qualtrics (Provo, UT) was used for the online data collection.

Institutional Review Board approval was obtained from Michigan State University. Participants were provided with an online consent form which explained that the research

was voluntary and participants could stop completing the survey at any time. Continuing with the survey indicated consent. Participants completed mandatory screening questions to determine their eligibility for the survey. All remaining questions were voluntary.

2.3 Measures

2.3.1 Participant characteristics—Participant characteristics were measured using an investigator-developed demographic questionnaire where participants were asked about their age, gender, marital status, job situation, financial independence, living arrangements, and parenthood. Dimensions of Emerging adulthood were measured using the 8-item short form of the Inventory of Dimensions of Emerging Adulthood (IDEA-8; Baggio, Iglesias, Studer, & Gmel, 2015). The original 31-item IDEA instrument reflected all five dimensions of emerging adulthood: possibilities/optimism, instability, identity exploration, feeling in-between, and self-focus. In subsequent work, Baggio and colleagues used exploratory factory analysis and factor loading criteria to develop the IDEA-8 which removed 23 items, including the self-focus subscale (Baggio et al., 2015). As expected, the emerging adulthood IDEA-8 score was negatively correlated with age, parenthood, stable relationship, financial independence, and having a job (Baggio et al., 2015).

In the study reported here, participants were asked to think of the past five years and respond to the IDEA-8 using a 4-point Likert scale (strongly disagree, somewhat disagree, somewhat agree, and strongly agree). Participants received a total score which was calculated as the average of individual items (potential range: 1-4). A higher score indicates that an individual more strongly agrees they are experiencing emerging adulthood. For the current study, Cronbach's alpha for the total scale was 0.70.

2.3.2 Disease-specific factors—Disease-specific factors are characteristics related to IBD and include the type of IBD (ulcerative colitis or Crohn's disease) and time since diagnosis in years. Medications were categorized into: aminosalicylates (e.g., Azulfidine, Asacol, Lialda), biologics (e.g., Remicade, Humira, Entyvio), corticosteroids (e.g., Prednisone, Hydrocortisone), and immunomodulators (e.g., Imuran, Methotrexate).

The Manitoba Inflammatory Bowel Disease Index (MIBDI) was used to measure disease activity. Participants selected a response to: "in the past 6 months, my disease has been*:* (1) constantly active, giving me symptoms every day; (2) often active, giving me symptoms most days; (3) sometimes active, giving me symptoms on some days (for instance 1-2 days/week); (4) occasionally active, giving me symptoms 1-2 days/month; (5) rarely active, giving me symptoms on a few days in the past six months; (6) I was well in the past 6 months, what I consider a remission or absence of symptoms." Scores are dichotomized to reflect active disease or inactive disease. Active disease included experiencing symptoms constantly to occasionally (response options 1-4); inactive disease included experiencing infrequent symptoms or feeling well (response options 5 or 6). Compared to other IBD disease activity measures, the MIBDI has good sensitivity and specificity. For individuals with ulcerative colitis, the MIBDI has a sensitivity of 0.84 and a specificity of 0.66 compared to the Harvey-Bradshaw Index. For individuals with Crohn's disease, the MIBDI

has a sensitivity of 0.66 and specificity of 0.61 compared to the Powell-Tuck Index (Clara et al., 2009).

2.3.3 Symptoms—Symptoms were assessed using two measures. The IBD Symptom Inventory, an investigator-adapted measure, was used to assess IBD-related symptoms. The second measure, the Patient-Reported Outcomes Measurement Information System (PROMIS®), was used to compare participant characteristics to the general population.

IBD Symptom Inventory.: Symptom prevalence, severity, and interference with daily activities were measured using an investigator-adapted IBD Symptom Inventory (45 items). The item wording was based on the Cancer Symptom Inventory (Given et al., 2008). Symptoms were modified based on previous IBD symptom research (Singh et al., 2011) to include 15 symptoms associated with IBD: diarrhea, constipation, abdominal pain, abdominal tenderness, abdominal cramps, bloating, passing gas, blood in stool, weight loss, weight gain, reduced appetite, increased appetite, nausea or vomiting, fatigue, and fever. Participants were asked if they experienced the symptom within the past two weeks (total symptom prevalence; potential range 0-15). Participants rated the severity (symptom at its worst) on a 0 to 9-point scale. Participants also reported how much the symptom interfered in daily activities on a 0 to 9-point scale. If a participant did not experience a symptom, the severity or interference with daily activities for that symptom was scored as 0. This symptom measure is an index and therefore, internal reliability is not applicable.

The IBD Symptom Inventory was pre-tested in-person with nine emerging adults diagnosed with IBD using cognitive interviewing. Cognitive interviewing is a method to understand how participants approach, process, and respond to questionnaires (Willis, 2005). Emerging adults were recruited from a local clinic and IBD support group. Using “think out loud” procedures with concurrent verbal probing, participants provided feedback on the questionnaires including timeframe for symptom assessment and clarity of item wording. The process used to refine the questionnaire is available elsewhere (Kamp et al., 2018).

Patient-Reported Outcomes Measurement Information System.: The PROMIS-29 Profile v2.1 contains symptom subscales of depression, anxiety, fatigue, pain interference (consequences of pain on one’s life), pain intensity, and sleep disturbance, as well as subscales of physical function and ability to participate in social roles and activities. All items are measured over the past 7 days on a 5-point Likert scale except for pain intensity which is rated from 0 to 10, with 0=no pain and 10=worst imaginable pain. This measure has been used with the IBD population (Kappelman et al., 2014) as well as young adults with other chronic diseases (e.g., sickle cell disease; Ameringer, Elswick, & Smith, 2014). In the initial validation study, all but one of the PROMIS-29 subscales had a reliability of >0.95; the exception was fatigue with a reliability estimate of 0.76 (Cella et al., 2010). For the current study, Cronbach’s alpha reliabilities ranged from 0.81 to 0.95, with the highest Cronbach’s alpha for the fatigue subscale.

PROMIS scores were summed and then converted to standardized T-scores using the HealthMeasures Scoring Service (Assessment Center[SM] www.assessmentcenter.net/ac_scoringservice). Increased symptom severity was reflected by higher scores for

depression, anxiety, pain interference, pain intensity, and sleep disturbance (0-55 within normal limits; 55-60 mild severity; 60-70 moderate severity; >70 severe; HealthMeasures, 2019). Conversely, improved functioning was reflected by higher scores for physical functioning and the ability to participate in social roles and activities (<30 severe functioning; 30-40 moderate functioning; 40-45 mild functioning; >45 within normal limits).

2.4 Statistical Analysis

Data analyses were conducted using Stata statistical software version 15.0 (StataCorp LC, TX). Means and standard deviations were calculated for continuous variables. Frequencies and percentages were calculated for categorical variables. For Aim 1, symptoms from the IBD Symptom Inventory were described using percentages. For Aim 2, total symptom severity and symptom interference with daily activities were reported as the average of severity and interference with daily activities, respectively. In addition, average severity and interference with daily activities for each individual symptom was calculated.

For Aim 3, univariable and multivariable logistic regression models were built to examine associations between severity of symptoms and the presence of fatigue based on the IBD Symptom Inventory. Multivariable models included covariates of gender, disease type, current steroid use, age, and the emerging adulthood IDEA-8 score. These covariates were included because both females and individuals with Crohn's disease are more likely to be members of higher symptom burden cluster groups (Conley et al., 2017). Current steroid medication use is included as a covariate to indicate the severity of disease because steroids are short-term use medications that quickly reduce inflammation and induce remission. The role of age and emerging adulthood was accounted for by including the emerging adulthood IDEA-8 score, age in years, and the interaction between emerging adulthood IDEA-8 score (continuous variable) and age as covariates. Variables with $p < 0.05$ were considered statistically significant.

3 RESULTS

3.1 Participant characteristics

Two-hundred and twenty-one individuals completed the screening questionnaire. Eighty-two individuals met eligibility criteria; the primary reason for exclusion was age. Twenty-one individuals had missing data on key indicators; they were excluded from analysis, leaving a sample of 61. Of these 61 participants, 44% were recruited from Facebook support groups, 25% from ResearchMatch, 23% from Facebook advertisements, and 8% were recruited by word of mouth.

Participants (Table 1) had a mean age of 24.7 ($SD = 2.9$). Ninety percent of the sample was female. The majority of participants were employed (65.6%, $n = 40$). Most participants did not cover their living expenses by themselves (55.7%, $n = 34$). On the emerging adulthood IDEA-8 score, participants reported a mean of 3.4 ($SD = 0.4$). As anticipated, age had a negative correlation with the emerging adulthood IDEA-8 score ($r = -0.41$, $p = 0.001$).

Participants 18-25 years old were more likely to report a higher emerging adulthood IDEA-8 score ($M = 3.5$, $SD = 0.4$) compared to participants 26-29 years old ($M = 3.1$, $SD = 0.5$).

Sixty-four percent of participants had Crohn's disease ($n = 39$) and thirty-six percent had Ulcerative Colitis ($n = 22$). Seventy-five percent of the sample had active disease based on the MIBDI ($n = 46$).

3.2 Aim 1: determine the prevalence of symptoms among emerging adults with IBD.

Participants reported a mean of 5.9 ($SD = 3.1$) symptoms on the IBD Symptom Inventory. The most prevalent symptoms (Table 2) were: fatigue ($n = 44$, 72.1%), abdominal cramps ($n = 42$, 68.9%), abdominal pain ($n = 39$, 63.9%), and diarrhea ($n = 38$, 62.3%).

3.3 Aim 2: describe the severity of symptoms and their interference with daily activities among emerging adults with IBD.

The following symptoms from the IBD Symptom Inventory reflected the greatest severity (Table 2): fatigue ($M = 4.1$, $SD = 2.9$), abdominal cramps ($M = 3.2$, $SD = 3.0$), and passing gas ($M = 3.2$, $SD = 3.0$). Participants reported low total symptom interference with daily activities ($M = 2.05$, $SD = 0.94$; on a 0-9 scale). The specific symptoms that most interfered with daily activities were: fatigue ($M = 3.3$, $SD = 2.6$), diarrhea ($M = 2.1$, $SD = 2.6$), and abdominal cramps ($M = 2.1$, $SD = 2.5$).

For the PROMIS measures, the symptoms of sleep disturbance ($M = 53.0$, $SD = 4.6$) and pain interference ($M = 50.7$, $SD = 8.1$) were within normal limits. Mild severity was reported for fatigue ($M = 58.9$, $SD = 10.0$), anxiety ($M = 58.1$, $SD = 9.4$), and depression ($M = 55.5$, $SD = 10.1$). Participants reported moderate physical functioning ($M = 39.0$, $SD = 7.2$) and severe dissatisfaction with their social roles ($M = 27.7$, $SD = 5.0$).

3.4 Aim 3: examine the association between individual symptom severity and the presence of fatigue among emerging adults with IBD.

In univariable models, participants with a greater severity of abdominal cramps ($p = 0.01$), abdominal pain ($p = 0.01$), diarrhea ($p = 0.01$), passing gas ($p = 0.02$), abdominal tenderness ($p = 0.02$) and bloating ($p = 0.03$) and had greater odds of reporting fatigue (Table 3). Multivariable models were adjusted for gender, age, emerging adulthood IDEA-8 score, disease type, and current steroid medication use. In the multivariable models, participants with a greater severity of abdominal cramps ($p = 0.01$), abdominal pain ($p = 0.01$), diarrhea ($p = 0.02$), passing gas ($p = 0.03$), abdominal tenderness ($p = 0.04$), and bloating ($p = 0.05$) had greater odds of reporting fatigue.

4 DISCUSSION

Using an internet-based survey, we aimed to examine symptom prevalence, severity, and interference with daily activities among emerging adults with IBD. Fatigue was the most commonly ascribed symptom both in terms of severity and interference with daily activities. Abdominal cramps, abdominal pain, diarrhea, passing gas, abdominal tenderness, and bloating were significantly associated with the presence of fatigue. Controlling for age,

emerging adulthood IDEA-8 score, gender, time since diagnosis, and current steroid use did not influence the results.

Similar to adults, emerging adults with IBD reported a variety of common GI symptoms including: abdominal cramps, abdominal pain, and diarrhea. This finding is expected as seventy-five percent of the sample reported active disease on the Manitoba IBD Index. IBD cohort studies typically report lower levels of active disease which may be due to different disease activity measures. We did not use measures of disease inflammation such as endoscopy or fecal calprotectin. The GI symptoms identified by emerging adults could be due to active inflammation or may represent an underlying functional GI disease, such as irritable bowel syndrome (IBS; Colombel, Shin, & Gibson, 2018; Kamal, Padival, & Lashner, 2018). Colombel, Shin, and Gibson (2018), in a review of functional GI symptoms in individuals with IBD, recommend ruling-out inflammatory activity for individuals with persistent GI symptoms. Thus, distinguishing inflammatory GI symptoms from functional GI symptoms is necessary to inform medical treatment and symptom management options.

Because the majority of the sample (75%) reported active disease, it would be expected to find a high prevalence of GI symptoms. Although GI symptoms such as abdominal pain and diarrhea were present among two-thirds of the sample, the symptom with the greatest severity and interference with daily activities was fatigue. The high prevalence of fatigue is similar to previous research among predominantly middle-aged adults with IBD in which fatigue was rated as the most prevalent and burdensome of the assessed symptoms (Conley et al., 2017; Farrell et al., 2016). The majority of existing studies do not assess both fatigue and GI symptoms.

Between 22-86% of adults with IBD experience fatigue (Artom, Czuber-Dochan, Sturt, & Norton, 2016), whereas 8-16% of the general United States population report fatigue (Blackwell & Clarke, 2013). A wide range of fatigue prevalence exists among individuals with IBD because those with inactive disease report less fatigue (22-41%) compared to patents with active disease (44-86%; Czuber-Dochan, Ream, & Norton, 2013). Individuals with IBD commonly report “living with exhaustion” (Fourie, Jackson, & Aveyard, 2018, p. 152). It should be noted that because individuals with irritable bowel syndrome also experience high levels of fatigue (Han & Yang, 2016), fatigue may also be related to non-inflammatory processes, such as genetic polymorphisms (Han et al., 2019).

A decade ago, fatigue was noted as an overlooked IBD symptom (Andrews, Mountifield, Van Langenberg, Bampton, & Holtmann, 2010). Although there has been increased attention on fatigue, limited interventions address this debilitating symptom (Artom et al., 2016). Potential modifiable factors associated with fatigue include: disease activity, medication type (i.e., corticosteroids and immunomodulators), physical fitness level, nutrition, anxiety, depression, stress, and sleep (Artom et al., 2016). Fatigue interventions among individuals with IBD focus on three intervention types: solution-focused therapy (Vogelaar et al., 2014; Vogelaar et al., 2011), stress management (Garcia-Vega & Fernandez-Rodriguez, 2004), and pharmacological interventions (Lichtenstein, Bala, Han, DeWoody, & Schaible, 2002; Loftus et al., 2008). Although the majority of study interventions occurred among participants under 50 years old, interventions do not appear to focus on the unique needs of

individuals who are in emerging adulthood. Thus, additional developmentally-appropriate interventions are needed to address the high prevalence of fatigue among emerging adults with both active and inactive clinical disease.

PROMIS measures can be used to compare symptoms and functioning to the general population as well as previous samples of adults with IBD (Conley et al., 2017; Kappelman et al., 2014). PROMIS measures in the current study were similar to the existing adult IBD literature conducted in online cohorts (age: $M = 44$, $SD = 14.8$) and outpatient settings (age: $M = 42.4$; $SD =$ not reported; IsHak et al., 2017; Kappelman et al., 2014). Based on PROMIS measures, symptoms are higher among individuals with IBD than the mean ($M = 50$) of adults in the general population (Kappelman et al., 2014). Although the PROMIS developers recommend reporting mean and standard deviations or using established t-score cut-points to indicate symptom severity, some authors use different reporting methods. Comparing PROMIS measures across studies is difficult due to the variation in the reporting. The best method for interpreting PROMIS measures among emerging adults remains unclear.

Clinical disease activity and fatigue have been extensively examined in the literature. The current study moves beyond clinical disease activity and identifies the specific GI symptoms associated with fatigue among emerging adults. Abdominal cramps, abdominal pain, diarrhea, passing gas, and abdominal tenderness were associated with fatigue when controlling for age, emerging adulthood, gender, time since diagnosis, and current steroid use. Examining these relationships can inform our understanding of co-occurring symptoms in IBD. The lack of a meaningful relationship between blood in the stool and fatigue in the current study is consistent with findings that anemia is often not associated with fatigue among individuals with IBD (Artom et al., 2016; Chavarria et al., 2019). Other non-significant findings may be due to the small sample size. Although there is evidence that females report higher levels of fatigue than males (Artom et al., 2016), we were unable to compare symptoms based on gender due to the small percentage of males in the current sample. Subgroup analysis within a sample that includes more males can be used to determine whether the factors influencing the presence of fatigue differ among men and women.

The generalizability of these findings is limited due to the small sample size, the cross-sectional design, and use of convenience sampling. The sample was predominantly educated females diagnosed for an average of 6.4 years. The potential influence of menstrual cycle and/or contraceptives still needs to be examined. Emerging adults who are recently diagnosed, of the male gender, not prescribed medication, and hospitalized may experience different symptom severity and interference with daily activities compared to the current sample. Study findings cannot be generalized to these populations. A selection bias may have occurred in which individuals with active disease and those interested in research were more willing to complete the survey. In addition, physiological measures were not used.

5 CONCLUSION

Emerging adults with IBD report the greatest symptom prevalence, severity, and interference with daily activities for the symptom of fatigue. In addition, symptoms among emerging adults are greater than the general population and may be greater than older adults with IBD. Interventions targeting symptoms may assist in the management of fatigue, GI, and other symptoms. Additional work is needed to verify these findings in an expanded sample including male emerging adults, recently diagnosed, and hospitalized patients with IBD.

Acknowledgments

Funding: This study was funded by Sigma Theta Tau International. This work was supported, in part, by the National Institutes of Health, National Institute of Nursing Research Aging and Informatics Training Program at the University of Washington (Grant Nr. T32NR014833) and the Jonas Center for Nursing Excellence.

References

Ameringer S, Elswick RK Jr., & Smith W (2014). Fatigue in adolescents and young adults with sickle cell disease: Biological and behavioral correlates and health-related quality of life. Journal of Pediatric Oncology Nursing, 31, 6–17. doi:10.1177/1043454213514632 [PubMed: 24378816]

Andrews JM, Mountifield RE, Van Langenberg DR, Bampton PA, & Holtmann GJ (2010). Un-promoted issues in inflammatory bowel disease: Opportunities to optimize care. Internal Medicine Journal, 40, 173–182. doi:10.1111/j.1445-5994.2009.02110.x [PubMed: 19849744]

Arnett JJ (2000). Emerging adulthood: A theory of development from the late teens through the twenties. American Psychologist, 55(5), 469–480. doi: I: 10.1037//0003-066X.55.5.469 [PubMed: 10842426]

Arnett JJ (2015). Emerging adulthood: The winding road from the late teens through the twenties (2nd ed., pp. 1– 29). New York, NY: Oxford University Press.

Artom M, Czuber-Dochan W, Sturt J, & Norton C (2016). Targets for health interventions for inflammatory bowel disease - Fatigue. Journal of Crohn's & Colitis, 10, 860–869. doi:10.1093/ecco-jcc/jjw029

Baggio S, Iglesias K, Studer J, & Gmel G (2015). An 8-Item Short Form of the Inventory of Dimensions of Emerging Adulthood (IDEA) among young Swiss men. Evaluation and the Health Professions, 38, 246–254. doi:10.1177/0163278714540681 [PubMed: 24973242]

Blackwell D, & Clarke TC (2013). QuickStats. MMWR. Morbidity and Mortality Weekly Report, 62, 275–275.

Bojic D, Bodger K, & Travis S (2017). Patient Reported Outcome Measures (PROMs) in inflammatory bowel disease: New data. Journal of Crohn's & Colitis, 11, S576–S585. doi:10.1093/ecco-jcc/jjw187

Cella D, Riley W, Stone A, Rothrock N, Reeve B, Yount S, … Hays R (2010). The Patient-Reported Outcomes Measurement Information System (PROMIS) developed and tested its first wave of adult self-reported health outcome item banks: 2005-2008. Journal of Clinical Epidemiology, 63, 1179–1194. doi:10.1016/j.jclinepi.2010.04.011 [PubMed: 20685078]

Clara I, Lix LM, Walker JR, Graff LA, Miller N, Rogala L, … Bernstein CN (2009). The Manitoba IBD Index: Evidence for a new and simple indicator of IBD activity. American Journal of Gastroenterology, 104, 1754–1763. [PubMed: 19455122]

Chavarria C, Casanova MJ, Chaparro M, Barreiro-de Acosta M, Ezquiaga E, Rivero M, … Gisbert JP (2019). Prevelance and factors associated with fatigue in patients with inflammatory bowel disease: A multicentre study. Journal of Crohn's and Colitis, 14, 996–1002. doi: 10.1093/ecco-jcc/jjz024

Colombel JF, Shin A, & Gibson PR (2018). AGA clinical practice update on functional gastrointestinal symptoms in patients with inflammatory bowel disease: Expert review. Clinical Gastroenterology and Hepatology, 17, 380–390. doi:10.1016/j.cgh.2018.08.001 [PubMed: 30099108]

Cohen BL, Zoega H, Shah SA, Leleiko N, Lidofsky S, Bright R, … Sands BE (2014). Fatigue is highly associated with poor health-related quality of life, disability and depression in newly-diagnosed patients with inflammatory bowel disease, independent of disease activity. Alimentary Pharmacology and Therapeutics, 39, 811–822. doi:10.1111/apt.12659 [PubMed: 24612278]

Conley S, Proctor DD, Jeon S, Sandler RS, & Redeker NS (2017). Symptom clusters in adults with inflammatory bowel disease. Research in Nursing & Health, 40, 424–434. doi:10.1002/nur.21813 [PubMed: 28833284]

Czuber-Dochan W, Ream E, & Norton C (2013). Review article: Descrption and management of fatigue in inflammatory bowel disease. Alimentary Pharmacology and Therapeutics, 37, 505–516. doi: 10.1111/apt.12205 [PubMed: 23311461]

Czuber-Dochan W, Norton C, Bredin F, Darvell M, Nathan I, & Terry H (2014). Healthcare professionals' perceptions of fatigue experienced by people with IBD. Journal of Crohns & Colitis, 8, 835–844. doi:10.1016/j.crohns.2014.01.004

Farrell D, McCarthy G, & Savage E (2016). Self-reported symptom burden in individuals with inflammatory bowel disease. Journal of Crohns & Colitis, 10, 315–322. doi:10.1093/ecco-jcc/jjv218

Fourie S, Jackson D, & Aveyard H (2018). Living with inflammatory bowel disease: A review of qualitative research studies. International Journal of Nursing Studies, 87, 149–156. doi:10.1016/j.ijnurstu.2018.07.017 [PubMed: 30125834]

Garcia-Vega E, & Fernandez-Rodriguez C (2004). A stress management programme for Crohn's disease. Behaviour Research and Therapy, 42, 367–383. doi:10.1016/s0005-7967(03)00146-3 [PubMed: 14998732]

Given B, Given CW, Sikorskii A, Jeon S, McCorkle R, Champion V, & Decker D (2008). Establishing mild, moderate, and severe scores for cancer-related symptoms: How consistent and clinically meaningful are interference-based severity cut-points? Journal of Pain and Symptom Management, 35, 126–135. doi:10.1016/j.jpainsymman.2007.03.012 [PubMed: 18158231]

Han CJ, Jarrett ME, Cain KC, Jun S, & Heitkemper MM (2019). Associations of fatigue with TPH2 genetic polymorphisms in women with irritable bowel syndrome. Biological Research for Nursing, 21, 72–79. doi: 10.1177/1099800418806055 [PubMed: 30309244]

Han CJ, & Yang GS (2016). Fatigue in irritable bowel syndrome: A systematic review and meta-analysis of pooled frequency and severity of fatigue. Asian Nursing Research, 10, 1–10. doi: 10.1016/j.anr.2016.01.003 [PubMed: 27021828]

HealthMeasures (2019). PROMIS® Score Cut Points. Retreived from: http://www.healthmeasures.net/score-and-interpret/interpret-scores/promis/promis-score-cut-points

Herzog D, Fournier N, Buehr P, Rueger V, Koller R, Heyland K, … Swiss IBD Cohort Study Group. (2017). Prevalence of intestinal complications in inflammatory bowel disease: A comparison between paediatric-onset and adult-onset patients. European Journal of Gastroenterology and Hepatology, 29, 926–931. doi:10.1097/meg.0000000000000896 [PubMed: 28471820]

Herzog D, Fournier N, Buehr P, Rueger V, Koller R, Heyland K, … Braegger CP (2018). Age at disease onset of inflammatory bowel disease is associated with later extraintestinal manifestations and complications. European Journal of Gastroenterology and Hepatology, 30, 598–607. doi: 10.1097/meg.0000000000001072 [PubMed: 29360691]

Hulme K, Safari R, Thomas S, Mercer T, White C, Van der Linden M, & Moss-Morris R (2018). Fatigue interventions in long term, physical health conditions: A scoping review of systematic reviews. PloS One, 13(10), e0203367. doi:10.1371/journal.pone.0203367 [PubMed: 30312325]

Huppertz-Hauss G, Hoivik ML, Jelsness-Jorgensen LP, Opheim R, Henriksen M, Hoie O, … Bernklev T (2017). Fatigue in a population-based cohort of patients with inflammatory bowel disease 20 years after diagnosis: The IBSEN study. Scandinavian Journal of Gastroenterology, 52, 351–358. doi:10.1080/00365521.2016.1256425 [PubMed: 27852169]

IsHak WW, Pan D, Steiner AJ, Feldman E, Mann A, Mirocha J, Danovitch I & Melmed GY (2017). Patient-reported outcomes of quality of life, functioning, and GI/psychiatric symptom severity in patients with Inflammatory Bowel Disease (IBD). Inflammatory Bowel Diseases, 23: 798–803. [PubMed: 28301432]

Kamal A, Padival R, & Lashner B (2018). Inflammatory bowel disease and irritable bowel syndrome: What to do when there is an overlap. Inflammatory Bowel Diseases, 24, 2479–2482. doi: 10.1093/ibd/izy277 [PubMed: 30169572]

Kamp K, Wyatt G, Dudley-Brown S, Brittain K, & Given B (2018). Using cognitive interviewing to improve questionnaires: An exemplar study focusing on individual and condition-specific factors. Applied Nursing Research, 43 121–125. DOI: 10.1016/j.apnr.2018.06.007 [PubMed: 29954654]

Kappelman MD, Long MD, Martin C, DeWalt DA, Kinneer PM, Chen W, … Sandler RS (2014). Evaluation of the patient-reported outcomes measurement information system in a large cohort of patients with inflammatory bowel diseases. Clinical Gastroenterology and Hepatology, 12, 1315–1323.e1312. doi:10.1016/j.cgh.2013.10.019 [PubMed: 24183956]

Kemp K, Griffiths J, & Lovell K (2012). Understanding the health and social care needs of people living with IBD: A meta-synthesis of the evidence. World Journal of Gastroenterology, 18, 6240–6249. doi:10.3748/wjg.v18.i43.6240 [PubMed: 23180944]

Kochar B, Martin CF, Kappelman MD, Spiegel BM, Chen W, Sandler RS, & Long MD (2018). Evalaution of gastrointestinal patient reported outcomes measurement information system (GI-PROMIS) symptom scales in subjects with inflammatory bowel diseases. American Journal of Gastroenterology, 113, 72–79. [PubMed: 28853727]

Lichtenstein GR, Bala M, Han C, DeWoody K, & Schaible T (2002). Infliximab improves quality of life in patients with Crohn's disease. Inflammatory Bowel Diseases, 8, 237–243. [PubMed: 12131606]

Loftus EV, Feagan BG, Colombel JF, Rubin DT, Wu EQ, Yu AP, … Mulani P (2008). Effects of adalimumab maintenance therapy on health-related quality of life of patients with Crohn's disease: Patient-reported outcomes of the CHARM trial. American Journal of Gastroenterology, 103, 3132–3141. doi:10.1111/j.1572-0241.2008.02175.x [PubMed: 18853973]

Matura LA, McDonough A, & Carroll DL (2016). Symptom interference severity and health-related quality of life in pulmonary arterial hypertension. Journal of Pain and Symptom Management, 51, 25–32. doi:10.1016/j.jpainsymman.2015.07.012 [PubMed: 26300023]

Peyrin-Biroulet L, Panés J, Sandborn WJ, Vermeire S, Danese S, Feagan BG, … Rycroft B (2016). Defining disease severity in inflammatory bowel diseases: Current and future directions. Clinical Gastroenterology and Hepatology, 14, 348–354.e317. doi:10.1016/j.cgh.2015.06.001 [PubMed: 26071941]

Randell RL, Long MD, Cook SF, Wrennall CE, Chen W, Martin CF, Anton K, Sandler RS, & Kappelman MD (2014). Validation of an internet-based cohort of inflammatory bowel disease (CCFA partners). Inflammatory Bowel Diseases, 20, 541–4. doi: 10.1097/01.MIB.0000441348.32570.34. [PubMed: 24451221]

Singh S, Blanchard A, Walker JR, Graff LA, Miller N, & Bernstein CN (2011). Common symptoms and stressors among individuals with inflammatory bowel diseases. Clinical Gastroenterology and Hepatology, 9, 769–775. doi:10.1016/j.cgh.2011.05.016 [PubMed: 21645640]

Vogelaar L, van't Spijker A, Timman R, van Tilburg AJ, Bac D, Vogelaar T, … van der Woude CJ (2014). Fatigue management in patients with IBD: A randomised controlled trial. Gut, 63, 911–918. doi:10.1136/gutjnl-2013-305191 [PubMed: 23884638]

Vogelaar L, Van't Spijker A, Vogelaar T, van Busschbach JJ, Visser MS, Kuipers EJ, & van der Woude CJ (2011). Solution focused therapy: A promising new tool in the management of fatigue in Crohn's disease patients psychological interventions for the management of fatigue in Crohn's disease. Journal of Crohns & Colitis, 5, 585–591. doi:10.1016/j.crohns.2011.06.001

Willis GB (2005). Cognitive interviewing: A tool for improving questionnaire design. Thousand Oaks, CA SAGE Publications.

Table 1

Participant and Disease-Specific Characteristics (N=61)

Characteristic	*N*	%
Gender		
Male	6	9.8
Female	55	90.2
Marital Status		
Single	47	77.1
Partnered	14	22.9
Type of IBD		
Ulcerative Colitis	22	36.1
Crohn's Disease	39	63.9
Disease Activity		
Active	46	75.4
Inactive	15	24.6
Medication type[a]		
Aminosalicylates	22	36.1
Biologics	37	60.7
Corticosteroids	11	18.0
Immunomodulators	16	26.2
Job Situation		
Employed (full or part time)	40	65.6
Unemployed/student	21	34.4
Financial Independence		
Covered own living expenses by themselves	27	44.3
Did not cover own living expenses by themselves	34	55.7
Living Arrangements		
Independent housing	34	40.4
Not living in independent housing	23	59.7
Parenthood		
Children	2	3.3
No children	59	96.7
	Mean	**SD**
Age (years)	24.7	2.9
Time since diagnosis (months)	76.3	57.3
Emerging Adulthood IDEA-8 Score[b]	3.4	0.4

[a]For medication types, 7 participants were not currently taking mediation and 28 participants were taking more than one medication type; therefore, n and percentage are greater than the sample size

[b]IDEA-8 Score potential range is 1 – 4; sample range was 2.1 to 4.0.

N = Number; % = Percentage; IBD = Inflammatory Bowel Disease; IDEA-8 = Inventory of Dimensions of Emerging Adulthood 8-items short form; *M* = Mean; *SD* = Standard Deviation

Table 2

Symptom Prevalence, Severity and Interference with Daily Activities among Emerging Adults with Inflammatory Bowel Disease (N=61)

	Prevalence N (%)	Severity M (SD)	Interference M (SD)	PROMIS T-score M (SD)
IBD Symptom Inventory				
Fatigue	44 (72.1%)	4.1 (2.9)	3.3 (2.6)	
Abdominal cramps	42 (68.9%)	3.2 (3.0)	2.1 (2.5)	
Abdominal pain	39 (63.9%)	2.8 (2.6)	1.5 (1.9)	
Diarrhea	38 (62.3%)	2.8 (2.7)	2.1 (2.6)	
Passing gas	37 (60.7%)	3.2 (3.0)	1.3 (2.0)	
Bloating	31 (50.8%)	2.3 (2.7)	0.9 (1.7)	
Abdominal tenderness	30 (49.2%)	2.3 (2.7)	1.1 (1.9)	
Nausea or vomiting	29 (47.5%)	2.0 (2.6)	1.2 (1.8)	
Reduced appetite	20 (32.8%)	1.3 (2.1)	0.5 (1.2)	
Constipation	18 (29.5%)	1.4 (2.4)	0.8 (1.7)	
Blood in stool	15 (24.6%)	1.1 (2.4)	0.4 (1.5)	
Increased appetite	6 (9.8%)	0.5 (1.6)	0.3 (1.5)	
Weight loss	5 (8.2%)	0.2 (0.8)	0.01 (0.1)	
Weight gain	3 (4.9%)	0.2 (1.2)	0.1 (1.2)	
Fever	3 (4.9%)	0.1 (0.7)	0.1 (0.5)	
PROMIS Symptom Measures				
Anxiety[a]				58.1 (9.4)
Depression[a]				55.5 (10.1)
Fatigue[a]				58.9 (10.0)
Sleep disturbance[a]				53.0 (4.6)
Pain interference[a]				50.7 (8.1)
Pain intensity (range 0-10)				2.4 (1.8)
PROMIS Functioning Measures				
Physical functioning[b]				39.0 (7.2)
Satisfaction with social role[b]				27.7 (5.0)

[a] A higher T-score indicates increased symptom severity

[b] A higher T-score indicates improved functioning

N = Number; % = Percentage; *M* = Mean; *SD* = Standard Deviation; IBD = Inflammatory Bowel Disease; PROMIS = Patient-Reported Outcomes Measurement Information System

Table 3

Association Between Individual Symptom Severity and Presence of Fatigue among Emerging Adults with Inflammatory Bowel Disease

	Unadjusted		Adjusted[a]	
	OR	***P***	**OR**	***P***
Abdominal cramps	1.49 [1.13, 1.95]	0.01	1.48 [1.09, 2.0]	0.01
Abdominal pain	1.5 [1.16, 2.14]	0.01	1.53 [1.11, 2.11]	0.01
Diarrhea	1.44 [1.09, 1.89]	0.01	1.41 [1.05, 1.91]	0.02
Passing gas	1.32 [1.05, 1.65]	0.02	1.30 [1.02, 1.68]	0.03
Abdominal Tenderness	1.49 [1.08, 2.05]	0.02	1.43 [1.01, 2.02]	0.04
Bloating	1.39 [1.04, 1.86]	0.03	1.38 [1.0, 1.92]	0.05
Reduced appetite	1.51 [0.97, 2.33]	0.07	1.64 [0.99, 2.72]	0.06
Blood in stool	1.28 [0.87, 1.87]	0.21	1.27 [0.83, 1.94]	0.28
Nausea or vomiting	1.18 [0.92, 1.51]	0.20	1.20 [0.90, 1.59]	0.21
Weight loss	1.09 [0.52, 2.27]	0.83	1.21 [0.56, 2.62]	0.63
Constipation	1.02 [0.8, 1.3]	0.86	0.96 [0.73, 1.26]	0.77
Increased appetite	1.01 [0.71, 1.43]	0.95	0.98 [0.67, 1.44]	0.93

OR = Odds Ratio

[a]Adjusted for age, emerging adulthood IDEA-8 score, the interaction between age and emerging adulthood IDEA-8 score, gender, disease type, and current steroid use.

Note: The interaction between age and emerging adulthood IDEA-8 score was included since the effect of age may differ based on developmental stage. All participants reporting weight gain ($n = 3$) and fever ($n = 3$) also reported the presence of fatigue.