

# Inflammatory Bowel Diseases Can Adversely Impact Domains of Sexual Function Such as Satisfaction with Sex Life

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## Abstract

**Background** Aspects of sexual health, which can be adversely affected by chronic disease, have been inadequately explored in inflammatory bowel disease (IBD).

**Aims** We evaluated patient-reported interest in sexual activity and satisfaction with sex life in a large cohort of IBD patients.

**Methods** We conducted a cross-sectional study within the Crohn's and Colitis Foundation Partners Internet cohort. Sequential participants completed a 6-question supplemental online survey to examine sexual interest and satisfaction using the Patient-Reported Outcome Measurement Information System<sup>®</sup> (PROMIS<sup>®</sup>) Sexual Function and Satisfaction measures. One-sample *t* tests were used to compare interest and satisfaction scores to general population norms.

**Results** Among 2569 individuals, 1639 had Crohn's disease (CD), 930 had ulcerative colitis (UC) or indeterminate colitis, and 71% were women. Mean PROMIS scores for sexual interest were comparable to the general US population in men (CD: 49 and UC: 48 vs. population mean 50) and women (CD: 41 and UC: 40 vs. population mean 42). However, sexual satisfaction scores were lower than the US population in men (CD: 48 and UC: 48 vs. 51) and women (CD: 47 and UC: 46 vs. 49),  $p < 0.01$  for both. Older age, disease activity, depression, anxiety, and pain were associated with lower interest and satisfaction and lowered IBD-specific quality of life.

**Conclusions** IBD patients in a large online survey had similar levels of sexual interest but decreased sexual satisfaction compared to the general population. Exploring these sexual health domains during clinical encounters can aid in improving IBD quality of life.

**Keywords** Sexual dysfunctions · Physiological · Sexual health · Inflammatory bowel disease · Quality of life

## Introduction

Patients with inflammatory bowel disease (IBD), including Crohn's disease (CD) and ulcerative colitis (UC), can have impaired quality of life as a result of depression [1], anxiety [2], and fatigue [3, 4]. Sexual interest and satisfaction are other important aspects affecting quality of life, but it is unclear how these domains are impacted by IBD. Existing reports have been mixed, with some studies showing

no differences in sexual activity [5] or frequency of sexual intercourse [6] between IBD patients and controls.

Conversely, one of the earliest studies reported that nearly a quarter of female CD patients completely abstained from sexual activities primarily due to abdominal pain, diarrhea, and fear of fecal incontinence [7]. Other studies [8–10] have also shown that sexual dysfunction is reported in approximately 50% of women with IBD. In both men and women, depression appears to be a major driver of impaired sexual activity [5, 11, 12].

While these studies quantified differences in sexual function broadly and identified some contributing factors to decreased function, few studies have focused on particular aspects of sexual health such as sexual interest and sexual satisfaction among IBD patients. Marin et al. showed that women reported worsened sexual desire and satisfaction compared to men after being diagnosed with IBD [10].

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Factors associated with lower levels of sexual satisfaction in women are longer duration of CD, presence of complex fistulae or abscesses, and impaired pelvic floor function [13]. Another report described higher levels of desire and satisfaction among IBD patients following proctocolectomy or proctectomy in male patients and ileal pouch anal anastomosis (IPAA) in female patients [14].

Given the limited literature on sexual health in IBD and the importance of understanding this domain to improve the overall psychosocial well-being of IBD patients, we aimed to evaluate interest in sexual activity and satisfaction with sex life among participants in the Crohn's and Colitis Foundation Partners Internet cohort using the Patient-Reported Outcomes Measurement Information System® (PROMIS®) Sexual Function and Satisfaction (SexFS) measures [15–18], which have undergone rigorous development and validation based on qualitative research and psychometric evaluation in a large US sample [19–21]. We hypothesized that among IBD patients, female sex, depression, current ostomy, prior IPAA, perianal disease, and active steroid use would be associated with lower interest in sexual activity and satisfaction with sex life.

## Methods

### Study Population

Crohn's and Colitis Foundation Partners is a longitudinal Internet-based cohort of patients with IBD. The development of the cohort has been described in detail previously [22]. Participants older than 18 years with a self-reported diagnosis of UC, CD, or indeterminate colitis (IC) were recruited through the Crohn's and Colitis Foundation e-mail rosters, the Crohn's and Colitis Foundation website, social media outlets, and at educational and fundraising events. All participants completed a baseline survey including demographic information and questions about their IBD history, symptoms, and medication use. Follow-up questionnaires every 6 months tracked changes in disease treatments, symptoms, and other patient-reported outcomes (PROs). A prior validation study demonstrated 97% accuracy of self-reported diagnoses of CD or UC in the cohort [23].

For this study, consecutive survey respondents between February and June of 2012 were invited to complete an optional 6 question supplemental survey in addition to their baseline or regularly scheduled follow-up survey (Supplementary Table). The items measured interest in sexual activity, satisfaction with sex life, and when applicable, the impact of having an ostomy or IBD symptoms on satisfaction with sex life. The study protocol was reviewed and approved by the Institutional Review Board of the University of North Carolina.

### PROMIS SexFS Assessments

The interest in sexual activity and satisfaction with sex life scales were developed and validated as part of the NIH PROMIS initiative. The PROMIS Sexual Function and Satisfaction item bank has undergone rigorous development and validation based on qualitative research and item response theory similar to all PROMIS measures [15–17, 24, 25]. It was designed to be used in diverse populations, both with and without chronic disease. As such, the SexFS items are not disease-specific, though items are available that ask about disease- and symptom-specific effects on satisfaction. All items ask about sexual function and satisfaction in the past 30 days. For measuring interest and satisfaction in a sample of both men and women, PROMIS offers advantages over other measures in that it uses the same scales and scoring for both men and women. Items were scored according to the strategy of SexFS measure (version 2.0).

Higher scores on the SexFS indicate more of the domain being measured. Hence, higher scores for the domains of interest in sexual activity and satisfaction with sex Life imply higher interest and greater satisfaction. Scores are expressed as t-scores, where the mean  $\pm$  SD for the general US sexually active adult population is  $50 \pm 10$ . US population norms for SexFS measures differ by sex [17], based on a nationally representative sample weighted to the 2012 Current Population Survey of 1758 men and 1757 women, with mean age 47 (SD 17). The mean  $\pm$  SD for sexual interest is  $50 \pm 10$  for males and  $42 \pm 14$  for females. Because of differential item functioning based on recent sexual activity [17], the sexual satisfaction measure is only scored in persons who were sexually active in the past 30 days. Sex-specific population means for satisfaction are  $51 \pm 9$  and  $49 \pm 11$  for males and females, respectively. We considered a difference in score of 2–4 as a clinically meaningful difference similar to other PROMIS measures [26–28].

### Other Self-Report Assessments

The Short IBD Questionnaire (SIBDQ) was administered as a disease-specific measure of HRQOL [29]. Disease activity was evaluated using validated measures such as the short Crohn's Disease Activity Index (sCDAI) for CD [30] and the Simple Clinical Colitis Activity Index (SCCAI) for UC and IC. A sCDAI  $< 150$  is categorized as clinical remission for CD, and an SCCAI  $\leq 2$  is categorized as clinical remission for UC and active disease as values above this threshold [30, 31]. Surveys also included PROMIS items from the depression, anxiety, fatigue, sleep

disturbance, and pain interference item banks. These PROMIS domains are expressed as t-scores where the mean  $\pm$  SD for the general US adult population is  $50 \pm 10$ . We also measured patient demographics, IBD medication use such as oral 5-aminosalicylates, prednisone, immunomodulators, and biologic therapies (infliximab, adalimumab, certolizumab pegol, golimumab, and natalizumab), perianal disease and pouch and ostomy status by self-report.

## Statistical Analysis

For each domain, one-sample *t* tests were used to compare means of interest and satisfaction scores to the corresponding general sex-specific population means within groups of UC and CD patients. Chi-square tests and ANOVA *F*-statistics were used to assess the relationship between interest and satisfaction t-scores and patient demographics, disease activity, quartiles of SIBDQ scores, current corticosteroid use, and categorical disease characteristics (current ostomy, prior IPAA, perianal disease).

In addition, mean PROMIS scores for interest and satisfaction were compared across quartiles (as these scores were not normally distributed) of disease activity, SIBDQ scores, and other PROMIS measures (depression, anxiety, fatigue, sleep, pain) using a nonparametric test of trend for the ranks across ordered groups. Comparator variables such as disease activity, steroid use, ostomy/IPAA, and active perianal disease were dichotomized, and mean interest and satisfaction scores were compared between the two groups for each variable using Student's *t* tests. Analyses were stratified by sex and disease type (UC/IC or CD). Finally, a multivariable analysis was performed for sexual interest and satisfaction scores in UC and CD patients adjusted for sex, age, race, ethnicity, education, disease activity scores, and PROMIS measures for (depression, anxiety, fatigue, sleep). Statistical analyses were performed using SAS version 9.4.

## Results

### Study Population

Of 3811 individuals who were offered the optional online survey on sexual interest and satisfaction, 2581 (68%) completed the survey. This response rate was comparable to other surveys administered through the CCFA Partners to a subset of patients, with response rates ranging from 59 to 71%. Twelve respondents whose sex was unknown were excluded, leaving a total 2569 individuals for analysis. In this sample, 1639 (64%) had CD and 930 (36%) had UC or IC (Table 1). The mean  $\pm$  SD age of respondents was  $42 \pm 14$  years, and 71% were female. The majority was white

(91%) and had a college or graduate degree. The mean time of disease duration was  $13 \pm 11$  years. Seventy-seven percent of the sample was sexually active with a similar proportion among men (78%) and women (77%), and subjects with CD (76%) and UC (78%). Additional characteristics of the study population are provided in Table 1.

### Interest in Sexual Activity and Satisfaction with Sex Life

The mean PROMIS score for interest in sexual activity was 41 for CD women and 40 for UC women, comparable to the US general population mean of 42 (Table 2). However, satisfaction with sex life was lower for women with IBD (mean T scores of 47 for CD and 46 for UC) compared to the population mean of 49,  $p < 0.01$ . Similar to women, levels of interest in sexual activity in men with IBD were comparable to the general population (mean T scores for CD: 49 and UC: 50 vs. population mean 50); however, mean sexual satisfaction T scores were 3 points lower in men with IBD than the general population (CD and UC: 48 vs. population mean 51,  $p < 0.01$ ). Based on the established MID for PROMIS measures (2–4), the difference in sexual interest among men and women with IBD versus the general population are small but clinically meaningful.

The relationships between sexual interest and satisfaction scores and age, race/ethnicity, and educational status are shown in Tables 3 and 4. Scores for both domains decreased with increasing age in men and women, except for sexual satisfaction in CD men (non-significant trend observed) and UC women. No consistent differences were observed for race/ethnicity. Associations with educational level were also mixed, though most comparisons showed direct associations between sexual interest and satisfaction and educational level.

In multivariable analysis, factors associated with lower sexual interest scores in UC and CD patients were female sex, increasing age, and fatigue ( $p < 0.05$  for all). In addition, increasing anxiety was also found to be significantly associated with lower sexual interest scores in UC patients ( $p = 0.03$ ). Factors associated with lower satisfaction scores in both UC and CD were female sex, increasing age, anxiety, and sleep disturbance ( $p < 0.05$  for all).

### Associations with Disease Severity, HRQOL, and Other PROs

As expected, mean PROMIS scores for interest in sexual activity and satisfaction with sex life were lower with increasing levels of disease activity, with the exception of UC women (Tables 5, 6). The magnitude of decreased interest and satisfaction with more severe disease activity was greater for men with a larger difference in PROMIS

**Table 1** Characteristics of the study population

Characteristics	CD ( <i>n</i> = 1639) Mean (SD) or %	UC ( <i>n</i> = 930) Mean (SD) or %	Overall IBD ( <i>n</i> = 2569) Mean (SD) or %
<b>Demographics</b>			
Age, years	42 (14)	42 (14)	42 (14)
Female sex	72	69	71
<b>Race/ethnicity</b>			
White	93	88	91
African-American	3	2	3
Asian	0.3	3	2
Other	4	6	5
Hispanic	3	5	4
<b>Education completed</b>			
< 12th grade	1	0.4	1
12th grade	7	5	6
Some college	22	18	20
College	43	43	43
Graduate school	28	34	31
Current smoker	10	8	9
<b>Disease characteristics</b>			
Disease duration	15 (12)	11 (10)	13 (11)
≥ 1 hospitalizations in the past year	19	11	16
≥ 1 bowel surgery	52	15	39
IPAA or Koch pouch	3	10	6
Ostomy	9	5	7
sCDAI or SCCAI	153 (100)	4 (3)	n/a
SIBDQ	5 (1)	5 (1)	5 (1)
<b>Current medication use</b>			
5-aminosalicylates	34	66	46
Prednisone	9	13	10
Immunomodulators <sup>a</sup>	28	23	26
Biologic therapy <sup>b</sup>	42	19	34
<b>General PROMIS<sup>c</sup> measures</b>			
Anxiety	54 (10)	55 (9)	55 (10)
Depression	52 (10)	52 (10)	52 (10)
Fatigue	57 (11)	55 (11)	56 (11)
Sleep disturbance	52 (9)	52 (9)	52 (9)
Satisfaction with social role	47 (10)	48 (10)	48 (10)
Pain	54 (10)	52 (10)	53 (10)
<b>Sexually active<sup>d</sup></b>			
Yes	76	78	77
Male	77	78	78
Female	76	79	77

<sup>a</sup>6-mercaptopurine, azathioprine, or methotrexate deviation is 10. Higher scores indicate more of the domain being measured

<sup>b</sup>Infliximab, adalimumab, certolizumab pegol, or natalizumab

<sup>c</sup>Patient-Reported Outcome Information Measurement System items are calibrated so that the mean of the US general population is 50 and the standard

<sup>d</sup>Sexually active within past 30 days

**Table 2** Mean PROMIS sexual interest and satisfaction\* scores in IBD patients compared to the general population stratified by sex and disease type

	<i>N</i>	CD (mean, 95% CI)	General population (mean)	<i>p</i> value	<i>n</i>	UC (mean, 95% CI)	General population (mean)	<i>p</i> value
Interest in sexual activity								
Men	453	49 (48–50)	50	<0.01	287	50 (48–51)	50	0.24
Women	1186	41 (40–41)	42	<0.01	643	40 (39–41)	42	<0.01
Satisfaction with sex life								
Men	350	48 (48–49)	51	<0.01	225	48 (47–49)	51	<0.01
Women	897	47 (46–47)	49	<0.01	505	46 (45–47)	49	<0.01

All scores are T-scores ( $M=50$ ,  $SD=10$ )

\*Satisfaction with sex life scores calculated from among those who were sexually active within past 30 days

**Table 3** Relationships between patient characteristics and PROMIS sexual interest and satisfaction<sup>a</sup> scores in men

	Interest in sexual activity Mean (SD)				Satisfaction with sex life Mean (SD)			
	CD ( <i>n</i> =453)	<i>p</i> value	UC ( <i>n</i> =287)	<i>p</i> value	CD ( <i>n</i> =350)	<i>p</i> value	UC ( <i>n</i> =225)	<i>p</i> value
Age, years								
18–30	52 (10)	<0.01	51 (9)	<0.01	50 (6)	0.21	49 (7)	<0.01
30–40	49 (11)		53 (8)		47 (7)		50 (7)	
40–50	47 (11)		49 (11)		48 (8)		47 (7)	
50–60	48 (11)		48 (9)		48 (8)		46 (6)	
> 60	48 (9)		44 (11)		48 (7)		46 (7)	
Race/ethnicity								
White	48 (11)	0.43	49 (10)	0.41	48 (7)	0.75	47 (7)	0.26
Black	40 (3)		38 (–)		45 (9)		n/a	
Asian	n/a		53 (6)		n/a		52 (8)	
Other	48 (10)		52 (11)		49 (6)		50 (9)	
Hispanic	49 (8)	0.82	54 (12)	0.22	47 (8)	0.54	50 (7)	0.46
Education								
<12th grade	60 (8)	0.16	27 (8)	0.01	38 (5)	0.22	n/a	<0.01
12th grade	48 (11)		46 (9)		47 (7)		48 (6)	
Some college	48 (11)		49 (12)		48 (6)		47 (7)	
College	48 (11)		50 (9)		48 (7)		48 (7)	
Graduate	50 (9)		50 (10)		49 (7)		49 (6)	

*p* values comparing differences between groups in each category

<sup>a</sup>Satisfaction with sex life scores calculated from among those who were sexually active within past 30 days

scores between the lowest quartile (Q1) and highest quartile (Q4) when compared to CD women. Additionally, sexual interest and satisfaction scores were positively associated with disease-specific quality of life.

Increasing levels of depression, anxiety, fatigue, sleep disturbance, and pain interference were associated with decreased sexual interest and satisfaction, and the magnitude and strength of each of these associations were independent of gender and disease type.

### Additional Associations

Prednisone use and perianal disease did not greatly impact interest and satisfaction scores, even though CD women with current steroid use had a lower interest score (39 vs. 41,  $p=0.04$ ). Having an ostomy was also not associated with lower sexual interest or satisfaction. Finally, among UC patients, sexual interest and satisfaction scores were identical for patients with and without IPAA.

**Table 4** Relationships between patient characteristics and PROMIS sexual interest and satisfaction<sup>a</sup> scores in women

	Interest in sexual activity Mean (SD)				Satisfaction with sex life Mean (SD)			
	CD (n = 1186)	<i>p</i> value	UC (n = 643)	<i>p</i> value	CD (n = 897)	<i>p</i> value	UC (n = 505)	<i>p</i> value
Age, years								
18–30	44 (11)	<0.01	42 (11)	<0.01	48 (8)	0.04	46 (8)	0.72
30–40	41 (11)		41 (10)		48 (8)		47 (6)	
40–50	39 (11)		39 (11)		46 (8)		46 (8)	
50–60	38 (11)		37 (11)		46 (8)		45 (8)	
>60	37 (10)		37 (9)		46 (8)		46 (8)	
Race/ethnicity								
White	41 (11)	0.22	40 (11)	0.04	47 (8)	0.58	47 (8)	0.67
Black	41 (12)		49 (10)		45 (7)		46 (4)	
Asian	57 (4)		35 (11)		51 (5)		43 (5)	
Other	39 (13)		37 (12)		50 (6)		45 (8)	
Hispanic	38 (10)	0.29	42 (11)	0.32	47 (8)	0.96	48 (6)	0.11
Education								
<12th grade	41 (10)	0.71	35 (12)	0.02	47 (8)	0.23	44 (–)	0.01
12th grade	42 (11)		35 (11)		48 (9)		42 (6)	
Some college	41 (12)		39 (11)		46 (8)		45 (8)	
College	41 (11)		41 (11)		47 (8)		47 (8)	
Graduate	40 (11)		40 (10)		47 (8)		46 (7)	

*p* values comparing differences between groups in each category

<sup>a</sup>Satisfaction with sex life scores calculated from among those who were sexually active within past 30 days

## Discussion

Our data suggest that, while women and men with IBD report similar levels of interest in sexual activity compared to the general population, they experience significantly lower satisfaction with their sex lives than their counterparts in the US general population. Additionally, we found that sexual interest and satisfaction among IBD patients were directly associated with disease-specific quality of life. Interest in sexual activity and satisfaction with sex life decreased with older age (except in CD men), and women had lower interest in sexual activity compared to men. Sexual interest and satisfaction were inversely associated with disease activity as measured by self-reported symptom-based disease activity indices (SCDAI and SCCAI), particularly among men. As anticipated, depression, anxiety, fatigue, sleep disturbance, and pain interference were associated with decreased interest and satisfaction scores. Perianal disease and presence of ostomy or IPAA did not impact either interest or satisfaction.

The findings from this study add to the limited literature focusing on specific aspects of sexual health among IBD patients. Differentiating between the various components of sexual health, such as interest and satisfaction, is important because there may not always be a positive correlation between them. For example, one study in IBD patients showed that despite an increase in vaginal dryness,

dyspareunia, and pain after surgery that interfered with sexual function, there was no significant change in sexual desire or satisfaction [32]. Similar incongruent findings between satisfaction with sex life and indicators of sexual dysfunction (such as erectile dysfunction) were found in cancer patients [15].

Our results are consistent with another study that found lower sexual interest for women than men, as compared to the general population [10]. However, the overall satisfaction with sex life was lower in men compared to women in our study. The lack of difference in both interest and satisfaction between those with and without an ostomy or IPAA is similar to previous findings reported by Bambrick et al. [32]. The inverse association between interest in sexual activity and satisfaction with increasing disease activity was also observed in a study that focused on sexual function in German IBD patients [11]. Men in that study reported higher levels of erectile dysfunction with increasing disease activity; however, disease activity did not affect sexual function in women.

The association between concurrent anxiety and depressive symptoms and lower sexual interest and satisfaction is also consistent with emerging literature. Anxiety and depression are common in patients with IBD [33], and decreased interest in sex is a common symptom in patients with depression [34]. Our study as well as three surveys by Timmer

**Table 5** Relationships of sexual interest and satisfaction<sup>a</sup> and quality of life, patient outcome measures and disease characteristics in men

	Interest in sexual activity Mean (SD)				Satisfaction with sex life Mean (SD)			
	CD (n=453)	p value	UC (n=287)	p value	CD (n=350)	p value	UC (n=225)	p value
<b>Disease activity</b>								
Q1	52 (10)	<0.01	51 (9)	0.02	50 (7)	<0.01	50 (6)	0.01
Q2	50 (10)		50 (10)		49 (7)		48 (8)	
Q3	47 (11)		48 (9)		48 (7)		47 (6)	
Q4	45 (10)		46 (11)		44 (6)		46 (8)	
<b>SIBDQ<sup>b</sup></b>								
Q1	51 (11)	<0.01	52 (9)	<0.01	51 (6)	<0.01	50 (7)	<0.01
Q2	50 (10)		49 (9)		49 (7)		47 (5)	
Q3	48 (10)		48 (10)		47 (7)		47 (8)	
Q4	45 (11)		46 (12)		45 (6)		44 (7)	
<b>Depression</b>								
Q1	51 (10)	<0.01	51 (9)	<0.01	50 (7)	<0.01	49 (7)	<0.01
Q2	49 (10)		50 (9)		49 (7)		49 (6)	
Q3	49 (10)		49 (11)		47 (7)		47 (5)	
Q4	45 (11)		45 (11)		45 (6)		44 (7)	
<b>Anxiety</b>								
Q1	51 (11)	<0.01	50 (9)	<0.01	50 (7)	<0.01	48 (7)	<0.01
Q2	49 (10)		53 (9)		48 (7)		50 (6)	
Q3	46 (10)		47 (11)		45 (7)		49 (6)	
Q4	45 (11)		46 (11)		46 (6)		43 (6)	
<b>Fatigue</b>								
Q1	51 (10)	<0.01	51 (9)	<0.01	50 (7)	<0.01	49 (6)	<0.01
Q2	50 (11)		49 (9)		49 (7)		47 (6)	
Q3	47 (10)		48 (11)		47 (7)		47 (8)	
Q4	43 (10)		41 (12)		44 (6)		40 (6)	
<b>Sleep</b>								
Q1	51 (11)	0.04	49 (10)	0.25	50 (7)	<0.01	50 (7)	<0.01
Q2	49 (10)		51 (10)		49 (7)		48 (6)	
Q3	48 (11)		49 (10)		46 (7)		46 (7)	
Q4	46 (10)		47 (10)		46 (7)		44 (7)	
<b>Pain</b>								
Q1	50 (9)	<0.01	52 (9)	0.04	50 (7)	0.40	51 (7)	<0.01
Q2	51 (12)		47 (8)		49 (6)		45 (7)	
Q3	45 (11)		48 (8)		47 (7)		45 (8)	
Q4	44 (10)		45 (15)		47 (7)		46 (8)	
<b>Prednisone use</b>								
Yes	48 (10)	0.67	49 (9)	0.63	47 (8)	0.19	48 (7)	0.97
No	49 (11)		50 (10)		48 (7)		48 (7)	
<b>Perianal disease</b>								
Yes	48 (11)	0.66	n/a	n/a	47 (6)	0.34	n/a	n/a
No	49 (11)		n/a		48 (7)		n/a	
<b>Current ostomy</b>								
Yes	49 (11)	0.93	55 (7)	0.09	47 (9)	0.24	47 (9)	0.82
No	49 (11)		49 (10)		48 (7)		48 (7)	
<b>IPAA</b>								
Yes	n/a	n/a	53 (10)	0.11	n/a	n/a	48 (9)	0.97
No	n/a		49 (10)		n/a		48 (7)	

p values comparing differences between groups in each category

<sup>a</sup>Satisfaction with sex life scores calculated from among those who were sexually active within past 30 days

<sup>b</sup>SIBDQ scores range from 10 to 70

**Table 6** Relationships of sexual interest and satisfaction<sup>a</sup> and quality of life, patient outcome measures and disease characteristics in women

	Interest in sexual activity Mean (SD)				Satisfaction with sex life Mean (SD)			
	CD (n = 1186)	p value	UC (n = 643)	p value	CD (n = 897)	p value	UC (n = 505)	p value
<b>Disease activity</b>								
Q1	43 (11)	<0.01	41 (10)	0.11	48 (8)	<0.01	47 (7)	0.10
Q2	41 (11)		39 (10)		47 (8)		46 (7)	
Q3	40 (11)		40 (11)		47 (8)		46 (8)	
Q4	39 (12)		39 (12)		45 (8)		45 (8)	
<b>SIBDQ<sup>b</sup></b>								
Q1	43 (11)	<0.01	42 (10)	<0.01	49 (8)	<0.01	49 (7)	<0.01
Q2	41 (11)		41 (10)		48 (8)		47 (7)	
Q3	41 (11)		39 (11)		46 (8)		45 (8)	
Q4	39 (12)		38 (11)		44 (8)		44 (7)	
<b>Depression</b>								
Q1	43 (11)	<0.01	41 (11)	0.01	49 (8)	<0.01	48 (8)	<0.01
Q2	42 (11)		41 (10)		48 (8)		47 (7)	
Q3	40 (11)		40 (10)		46 (7)		45 (7)	
Q4	39 (12)		38 (12)		44 (8)		44 (8)	
<b>Anxiety</b>								
Q1	43 (11)	<0.01	40 (10)	<0.01	49 (8)	<0.01	47 (7)	<0.01
Q2	41 (11)		42 (10)		48 (8)		47 (8)	
Q3	40 (11)		40 (11)		46 (8)		46 (7)	
Q4	39 (12)		37 (11)		44 (8)		44 (7)	
<b>Fatigue</b>								
Q1	43 (11)	<0.01	42 (10)	<0.01	49 (8)	<0.01	48 (8)	<0.01
Q2	41 (11)		41 (10)		48 (8)		47 (7)	
Q3	41 (11)		38 (10)		46 (8)		44 (7)	
Q4	38 (12)		38 (12)		45 (9)		44 (7)	
<b>Sleep</b>								
Q1	42 (11)	0.03	41 (10)	<0.01	49 (8)	<0.01	48 (7)	<0.01
Q2	41 (11)		41 (11)		47 (8)		46 (7)	
Q3	41 (11)		39 (11)		46 (8)		45 (7)	
Q4	40 (12)		37 (11)		46 (8)		44 (7)	
<b>Pain</b>								
Q1	43 (11)	0.04	43 (11)	<0.01	49 (8)	<0.01	48 (8)	<0.01
Q2	41 (11)		39 (11)		48 (8)		46 (7)	
Q3	41 (11)		40 (11)		47 (8)		46 (7)	
Q4	39 (13)		36 (11)		46 (9)		43 (8)	
<b>Prednisone use</b>								
Yes	39 (12)	0.04	40 (11)	0.96	46 (8)	0.34	47 (8)	0.38
No	41 (11)		40 (11)		47 (8)		46 (7)	
<b>Perianal disease</b>								
Yes	40 (12)	0.16	n/a	n/a	46 (8)	0.08	n/a	n/a
No	41 (11)		n/a		47 (8)		n/a	
<b>Current ostomy</b>								
Yes	42 (13)	0.47	40 (10)	0.95	48 (8)	0.14	45 (8)	0.67
No	41 (11)		40 (11)		47 (8)		46 (8)	
<b>IPAA</b>								
Yes	n/a	n/a	39 (11)	0.31	n/a	n/a	46 (8)	0.97
No	n/a		40 (11)		n/a		46 (8)	

*p* values comparing differences between groups in each category

<sup>a</sup>Satisfaction with sex life scores calculated from among those who were sexually active within past 30 days

<sup>b</sup>SIBDQ scores range from 10 to 70

et al. confirmed an inverse relationship between depression and sexual function [5, 9, 11, 12]. It is possible that depression is more common in patients with IBD with a resultant decrease in interest in sexual activity and satisfaction with sex life. Alternatively, decreased sexual interest and satisfaction secondary to IBD itself may result in depression. It seems likely that both of these theoretical models exist in patients with IBD.

Our study has important strengths. First, we surveyed a well-characterized population of patients with IBD from an existing registry. The study was the largest to date to assess interest in sexual activity and satisfaction with sex life in patients with IBD with more than 2500 participants. Although we did not do an a priori sample size determination, the large study population provided a high degree of statistical power and precision for our analyses. Our study is also the only one to our knowledge that reports on these specific aspects of sexual health in patients in the USA, except for one retrospective series of patients before and after IPAA. In addition, the high survey response rate (68%) likely reduced reporting bias, and using an electronic survey instead of a face-to-face survey likely decreased reticence among participants to answer questions about sex. Lastly, we used a rigorously tested and validated measure, PROMIS SexFS, to measure interest in sexual activity and satisfaction with sex life that offers a built-in comparison to US general population norms.

Despite the numerous strengths of the study, several limitations exist. First, as we sampled a volunteer-based cohort, our results may not be generalizable to the IBD community at large in the USA. As the study was cross-sectional, we could not evaluate the causality of any of the associations between sexual interest and satisfaction and other indicator of disease severity or patient-reported outcomes. Longitudinal studies are needed to further explore the impact of clinical factors and medical and/or surgical treatments on subsequent sexual interest and satisfaction. An additional limitation is that the diagnosis of IBD within our cohort is by self-report. Therefore, it is possible that misclassification exists. However, in a validation study including a random sample from CCFA Partners, >97% had their IBD diagnosis confirmed by medical records [23]. Similarly, although we assessed disease activity through self-reported, symptom-based indices, it was not practical to perform endoscopic assessment. Finally, other variables relevant to sexual health such as number of sex partners and information on body image were not collected in this study and should be included in future investigations.

Our findings raise awareness of the scope of the problem of sexual health among IBD patients in the USA and identify a health issue that many patients may be embarrassed to discuss with their provider. Accordingly, providers should consider querying patients about how their IBD might be

affecting their sex life. Such conversations could be facilitated by the administration of measures such as the PROMIS SexFS. If problems pertaining to sexual interest and satisfaction are identified by clinicians, targeted treatment of active disease, management of concurrent psychiatric disease, and selected referral to providers specializing in sexual disorders may improve these important health domains and lead to an improved overall quality of life.

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## Compliance with ethical standards

**Conflict of interest** All the authors declare that they have no conflict of interest.

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