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Sexual Interest and Satisfaction in an Internet Cohort of Patients with Inflammatory Bowel Diseases

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Background and Aims: Although GI and other somatic symptoms, concerns about body image, medication side effects, and surgical treatments and ostomies may impair sexual functioning in patients with inflammatory bowel diseases (IBD), few studies have examined this. We sought to evaluate sexual interest and satisfaction in a large cohort of adult patients with IBD and identify clinical and demographic factors associated with these patient-reported outcomes.

Methods: CCFA Partners is an ongoing internet cohort study of over 12,000 patients with IBD. We invited a randomly selected subset of the cohort to complete a six question supplemental survey regarding sexual interest and satisfaction, and whether IBD symptoms or ostomy (if applicable) affected sexual satisfaction. Measures were developed and validated as part of the NIH Patient Reported Outcome Measurement Information System (PROMIS) initiative. Demographic information, self-reported disease indices [Short Crohn's Disease Activity Index (SCDAI), Simple Clinical Colitis Activity Index (SCCAI), and Manitoba Index], the Short IBD questionnaire (SIBDQ) quality of life index, and additional PROMIS outcomes were also measured. We used descriptive statistics and bivariate comparisons to assess relationships between sexual interest and satisfaction and the other measures.

Results: A total of 2581 individuals completed the supplemental survey (68% response rate). Mean age was 42(SD=14); 71% female. Of 2151 patients who reported active IBD symptoms, 80% indicated that their symptoms affected their sexual satisfaction and 33% indicated their symptoms affected their sexual satisfaction "quite a bit" or "very much". Of 110 patients with an ostomy, equal numbers reported that their ostomy affected their satisfaction "not at all" or "a little bit" versus "quite a bit" or "very much". On average, males had higher sexual interest and satisfaction than females ($p < 0.001$), while there was no difference in sexual interest or satisfaction among those with CD versus UC. Among CD patients, active perirectal disease was associated with lower levels of sexual interest and satisfaction. Sexual interest and satisfaction were both negatively associated with increasing disease activity as measured by SCDAI, SCCAI, and Manitoba Index and positively associated with higher levels of health-related quality of life as measured by SIBDQ ($p < 0.001$ for all comparisons). Sexual interest and satisfaction were both negatively associated with increasing levels of fatigue, anxiety, and depression.

Conclusions: IBD patients are willing to respond to questions regarding their sexual interest and satisfaction, as indicated by the high response rate. IBD, particularly active disease, is associated with impaired sexual functioning. Only about half of patients with ostomies indicated that their appliances affected sexual satisfaction. This knowledge can be used to counsel and screen appropriate patients.

	Sexual Interest Mean Z score	p	Sexual Satisfaction Mean Z score	p
IBD type				
Crohns disease	0.093	0.9028	0.067	0.9745
Ulcertative colitis	0.082		0.063	
Indeterminate colitis	0.051		0.045	
Perianal disease				
Yes	-0.028	0.0448	-0.093	0.0042
No	0.108		0.094	
Simple Colitis Activity Index				
Q1	0.367	<.0001	0.306	<.0001
Q2	0.039		0.122	
Q3	0.041		0.010	
Q4	-0.133		-0.195	
Short Crohn's Disease Activity Index				
Q1	0.354	<.0001	0.385	<.0001
Q2	0.105		0.105	
Q3	-0.003		-0.009	
Q4	-0.102		-0.161	
Short IBD Questionnaire				
Q1	-0.150	<.0001	-0.281	<.0001
Q2	-0.001		-0.015	
Q3	0.140		0.171	
Q4	0.378		0.401	
Manitoba index				
well or rarely active	0.241	<.0001	0.251	<.0001
occasionally active	0.077		0.036	
often/constantly active	-0.055		-0.085	
PROMIS depression				
Q1	0.285	<.0001	0.361	<.0001
Q2	0.174		0.128	
Q3	0.001		-0.017	
Q4	-0.147		-0.270	
PROMIS anxiety				
Q1	0.267	<.0001	0.287	<.0001
Q2	0.191		0.206	

	Sexual Interest Mean Z score	p	Sexual Satisfaction Mean Z score	p
Q3	0.028		0.011	
Q4	-0.128		-0.238	
PROMIS fatigue				
Q1	0.329	<.0001	0.331	<.0001
Q2	0.136		0.090	
Q3	0.047		0.043	
Q4	-0.160		-0.212	