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ORIGINAL ARTICLE / ОРИГИНАЛНИ РАД

Sexual dysfunction in patients with inflammatory bowel disease

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SUMMARY

Introduction/Objective Inflammatory bowel disease (IBD) is often diagnosed during patients' sexually active years, and factors like disease severity, treatment, and surgery may impact sexual function. This study aimed to assess the sexual quality of life in IBD patients.

Methods Patients with IBD and control groups (n = 45) were prospectively included in this study. Demographic data of patients and duration of illness, laboratory and endoscopic data, and treatment information were recorded. Participants completed the Patient-Reported Outcomes Measurement Information System (PROMIS) Sexual Activity Index.

Results In total, 103 patients were included (41 patients with ulcerative colitis and 17 patients with Crohn's disease). The mean age of patients with IBD was 34.26 ± 10.1 years, while the control group had a mean age of 32.93 ± 10.5 years (p = 0.518). The mean total PROMIS was found to be lower in the patient group (men: 29.8 ± 7.4; women: 28.1 ± 7.7) than in the control group (men: 38.5 ± 5.4; women: 34.8 ± 11.6), but the difference was statistically significant only in men (p < 0.001). The median value of the Sexual Life Quality Index was found to be lower in the patient group [men: 3 (1–5); women: 3 (1–4)] than in the control group [men: 5 (3–5); women: 4 (1–5)]. The low Sexual Life Quality Index difference was significant in both men (p < 0.001) and women (p = 0.042).

Conclusion IBD patients showed lower sexual quality of life compared to the general population. Assessing sexual well-being alongside disease activity may positively impact disease management.

Keywords: inflammatory bowel disease; PROMIS; sexual dysfunction

INTRODUCTION

The term "sexual function" refers to the ability to complete the sexual cycle – sexual interest, arousal, orgasm, resolution, and satisfaction – after a sexual stimulus (tactile, visual, olfactory, etc.) without any limitations (e.g., physical, psychological, or psychosocial). Many physiological, psychosocial, and sociocultural factors influence sexual function. A problem in any of these factors limits sexual function in the person [1].

Inflammatory bowel disease (IBD) predominantly affects individuals of young and reproductive age. Consequently, factors such as disease type, disease activity, and medications administered may negatively impact sexual quality of life. Therefore, treatment should be personalized based on disease activity and individual clinical conditions, in consultation with physicians [2–5].

IBD can alter patients' physical appearance — and their perception of it — through fistulae, ostomies, and surgical scars [6]. Distorted body image is present in seventy percent of patients with IBD and has been shown to affect women more than men (75% *vs*. 51%) [7, 8]. Female patients with Crohn's disease (CD) state that they avoid sexual activity owing to fear of abdominal pain, diarrhea, and fecal incontinence [9]. Although sexual dysfunction and distorted body perception are common in patients with IBD, these issues are rarely discussed by clinicians and patients [10].

Given the sociocultural characteristics of the region, this study aimed to evaluate sexual dysfunction among patients with IBD – a topic often overlooked because it is seldom addressed. The purpose of this study is to enhance patient support, improve disease management, raise physician awareness, and contribute meaningfully to the medical literature.

METHODS

Fifty-eight patients diagnosed with IBD in the Gastroenterology Clinic of the Dicle University Faculty of Medicine between 2009 and 2020 and 45 healthy controls with matching demographic characteristics were included.

Sexually active patients aged 18 – 65 years with an endoscopic and histopathological diagnosis of IBD were included. Exclusion criteria were as follows:

- receipt of medications other than standard IBD therapy that could affect sexual life;
- prior surgical intervention for IBD; and

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• current treatment for sexual dysfunction.

Remission in IBD, including CD and ulcerative colitis (UC), was evaluated using the following criteria:

- **Clinical remission:** CD = Crohn's Disease Activity Index (CDAI) < 150; UC = Mayo score ≤ 2 with no sub-score > 1.
- **Biochemical remission:** normalization of inflammatory biomarkers, such as C-reactive protein (CRP) and fecal calprotectin.
- **Endoscopic remission:** absence of visible inflammation on endoscopy, indicating mucosal healing.
- **Histologic remission:** lack of microscopic inflammation in biopsies, indicating deep-tissue healing [11].

Demographic and clinical data were recorded, including age, socio-economic status, education level, marital status, disease duration, total protein, albumin, white-blood-cell count, hemoglobin, CRP, site of endoscopic involvement, clinical activity status, medications used, and type of treatment (local or systemic). The Turkish version of the internationally validated Patient-Reported Outcomes Measurement Information System (PROMIS) questionnaire was administered to patients and controls (Tables 1 and 2). Lower scores indicate dissatisfaction with sexual life, whereas higher scores reflect greater satisfaction.

For men, the score range is 8 – 45: 8–13 very low, 14–20 low, 21–33 medium, 34–39 high, 40–45 very high.

For women, the score range is 10 – 53: 10–17 very low, 18–25 low, 26–36 medium, 37–44 high, 45–53 very high. In questions 3–7, the more sexual complaints patients have, the fewer points they receive.

Table 1. PROMIS survey questions and scoring addressed to male participants

Question number	Questions	Points
1	To what extent is your desire for sexual activity present?	1–4
2	How often do you want to have sex?	1–5
3	Difficulty getting an erection [hardening] when you want during sexual activity?	1–6
4	How difficult is it for you to maintain an erection [hardening] whenever you want during sexual activity?	1–6
5	How would you describe your ability/grade to be erect?	1–5
6	How would you rate your ability to have a satisfying orgasm?	1–6
7	How much pleasure do you get during sexual activity?	1–6
8	How would you describe your degree of satisfaction during sexual activity?	1–6

Table 2. PROMIS survey questions and scoring addressed to female participants

Question number	Questions	Points
1	To what extent is your desire for sexual activity present?	1–5
2	How often do you want to have sex?	1–5
3	How often have you been lubricated during sexual intercourse in the last 4 weeks?	1–6
4	When you want to be lubricated [wet]; How often do you experience difficulties?	1–5
5	How would you describe your vaginal discomfort during sexual activity? [1: high –5: low]	1–5
6	How often do you have problems with sexual activity due to vaginal pain and/or discomfort?	1–5
7	How often do you have to stop your sexual activity due to vaginal pain and discomfort?	1–5
8	How would you rate your ability to have a satisfying orgasm?	1–5
9	How much pleasure do you get during sexual activity?	1–6
10	How would you describe your degree of satisfaction during sexual activity?	1–6

Statistics

The research was conducted prospectively, and the data obtained were cross-sectional in two groups. The survey was administered, and survey scores – total score and sexual-life indices – were evaluated with the one-sample Kolmogorov–Smirnov test, Student's t-test, and Mann–Whitney U test. Normality of the data was tested with the one-sample Kolmogorov–Smirnov test. Values with non-normal distribution were evaluated with the Mann–Whitney U test, and those with normal distribution were evaluated with the Student's t-test. Parametric values were expressed as mean ± SD, and non-parametric values were expressed as median (min–max). Yates' correction and Pearson's χ^2 test were used to analyze cross-tabulations. Student's t-test was used to compare normally distributed data of the patient and control groups, and the Mann–Whitney U test was used to compare non-normally distributed data. A value of $p < 0.05$ was considered statistically significant. Statistical analyses were performed using PASW for Windows, Version 18.0 (SPSS Inc., Chicago, IL, USA).

Ethics: The protocol was approved by the Dicle University Faculty of Medicine Clinical Research Ethics Committee (16 July 2020; No. 132, Annex 4).

RESULTS

A total of 58 patients, 41 with UC and 17 with CD, were included in this study. Forty-two (63.4%) of these patients were male and 16 (27.6%) were female. In the control group, 25 (55.6%) were male and 20 (44.4%) were female. The mean age of patients with IBD was 34.26 ± 10.1 years, while the control group had a mean age of 32.93 ± 10.5 years. There was no statistically significant difference between the patient and control groups for either sex distribution ($p = 0.075$) or mean age ($p = 0.518$).

The duration of disease in patients with UC was 70.6 ± 42.5 months, and in patients with CD it was 52 ± 33.5 months ($p = 0.112$). When the patients were examined in terms of clinical and endoscopic activity/remission, 37 were in remission, 63.8% (UC = 23, 39.7%; CD = 14, 24.1%), 20 were active, 34.5% (UC = 18; CD = 2), and one patient (1.7%) had newly diagnosed CD.

Table 3. Data of patients with ulcerative colitis and Crohn's disease

Patient data	Ulcerative colitis		Crohn's disease		p
Number of patients	41		17		> 0.05
Sex	Female	13	Female	3	
	Male	28	Male	14	
Diagnosis time (mean + SD)	70.6 ± 42.5		52 ± 33.5		0.112
Localization	Proctitis (E1)	8 (13.8%)	Ileal (L1) İleo-colonic (L2)	9 (15%) 2 (3.4%)	
	Left colon (E2)	22 (37.9%)	Isolated colonic (L3)	2 (3.4%)	
	Extensive	11 (19%)	Fistulized (p)	4 (29.3%)	
Disease activity	Active	N: 18 (31%)	Active	N : 3 (5.2%)	0.026
	Remission	N: 23 (39.7%)	Remission	N: 14 (24.1%)	

Table 4. Male PROMIS survey scores and sexual life quality index results

Question number	Patients	Control	p
1*	4 [1–5]	5 [3–5]	< 0.05
2*	3 [2–5]	4 [3–5]	< 0.05
3*	4 [1–5]	6 [1–6]	< 0.001
4*	4 [1–5]	6 [1–6]	< 0.001
5*	3 [2–5]	4 [4–6]	0.067
6*	4 [1–6]	5 [4–6]	0.009
7	5 [1–6]	6 [4–6]	< 0.001
8*	3 [1–5]	5 [4–6]	< 0.001
Total scores**	29.8 ± 7.4	38.5 ± 5.4	< 0.001
Sexual Life Quality Index*	3 [1–5]	5 [3–5]	< 0.001

*Mann–Whitney test;
**Student's t-test

Table 5. Women's PROMIS survey scores and sexual life quality index results

Question number	Patients	Control	p
1*	2.5 [1–4]	4 [1–5]	< 0.05
2*	2 [1–3]	3 [1–5]	< 0.05
3*	3 [1–6]	4 [1–6]	0.727
4**	3.4 ± 0.3	3.5 ± 0.3	0.892
5**	2.3 ± 0.2	3.3 ± 0.3	< 0.05
6*	3.5 [1–5]	4 [1–5]	0.912
7**	3.4 ± 0.3	3.3 ± 0.3	0.794
8*	3 [2–4]	4 [2–5]	< 0.001
9*	3 [1–4]	4.5 [1–6]	< 0.001
10**	3.1 ± 0.3	3.8 ± 0.3	0.191
Total scores**	28.1 ± 7.7	34.8 ± 11.6	0.060
Sexual Life Quality Index*	3 [1–4]	4 [1–5]	< 0.05

*Mann–Whitney test;
**Student's t-test

Disease-activity rates were significantly higher in patients with ulcerative colitis (p = 0.026) (Table 3).

The individual scores, total scores, and Sexual-Life-Quality Index (SLQI) values for the male patient and control groups are shown in Table 4. The PROMIS total score was statistically significantly lower in male patients (29.8 ± 7.4) than in male controls (38.5 ± 5.4) (p < 0.001). In addition, the SLQI based on this total score was 3 (1–5) in male patients and 5 (3–5) in male controls, which was also statistically significantly lower (p < 0.001).

Individual scores, total scores, and SLQI values for the female patient and control groups are shown in Table 5. Although the PROMIS total score was lower in female patients (28.1 ± 7.7) than in female controls (34.8 ± 11.6), the difference was not statistically significant (p > 0.05). The SLQI based on the total score was 3 (1–4) in female patients and 4 (1–5) in female controls, and this difference was statistically significant (p = 0.042).

DISCUSSION

Our aim in this study was to investigate regional epidemiological data on the SLQI in male and female patients with IBD. The relationship and frequency of IBD-related SLQI, male erectile dysfunction, and female sexual dysfunction, which have a wide place in the medical literature, were investigated in individuals with IBD followed in our clinic. IBD is a disease that generally affects both sexes equally and has serious negative effects on quality of life [12]. It generally has a negative impact on physical appearance and self-perception owing to fistulae, surgical scars, and ostomy operations. However, symptoms such as abdominal pain, diarrhea, and fecal incontinence also have negative effects on sexuality and body image.

IBD is a disease that is generally more common in young adults, and sexual dysfunction may negatively affect this group more than expected [13, 14]. To our knowledge, there is no study investigating the quality of sexual life in patients with IBD in our region. The main aim of this study was to assess the sexual-life quality of patients using a validated survey and contribute to the literature.

Sexual dysfunction is a complex biological, psychological, and social process. Physiologically, it involves many body systems, especially the neurological, vascular, and endocrine systems [15]. Sexual dysfunction seen in IBD has both psychological and physiological dimensions and these dimensions are closely intertwined. For example, physiological conditions such as fatigue, joint pain, abdominal pain, and dyspareunia can cause psychological diseases such as depression and anxiety, and these symptoms can decrease with the correction of the disease by a gastroenterologist [6]. Women with IBD are at greater risk for vaginal infection and decreased lubrication than the normal population. Men with IBD experience decreased sexual function and erectile dysfunction more than those without IBD or those with IBD in remission [16–20].

In a study conducted by Rivière et al. [21] on 358 patients with inflammatory bowel disease, 238 had CD and 120 had UC. These patient groups were compared with normal control groups, and the rate of sexual dysfunction in female patients with IBD was found to be higher than in the normal population. This rate was 53.6% (women with IBD) and 28% (control group). Male patients with IBD were evaluated for erectile dysfunction, and the rate

of erectile dysfunction was found to be higher than the healthy control group. In patients with IBD, sexual dysfunction was detected in 54% of women and erectile dysfunction in 43% of men. These rates were quite high compared to healthy control groups. The result of our study is consistent with the result found by Rivière et al. [21], and the sexual-life quality index in both groups of men and women is lower than the control group.

In a study conducted by Marin et al. [22] on 555 patients, 355 of whom had inflammatory bowel disease and 200 of whom were healthy controls, they showed that one-half of the women and one-third of the men had a decrease in sexual desire and satisfaction after the diagnosis of IBD. These patients have significantly lower sexual-function-index scores compared to the control group. Corticosteroids and biological agents used in the treatment of the disease, depression, and diabetes mellitus have been identified as independent predictors of sexual dysfunction in patients with IBD [23–26]. According to the results we obtained in our study, when the quality of sexual life was evaluated statistically, the quality of sexual life of the patient group was found to be significantly lower in women and men compared to the control group, more prominently in men [22]. The survey we applied was more comprehensive and included questioning erectile dysfunction in men, and according to the results of our study, when evaluated based on the total survey score in male and female patients, the scores of the patient group were statistically significantly lower than the control group.

In the multicenter study conducted by Bel et al. [27] on 168 female and 119 male inflammatory-bowel patients, no significant difference was found in terms of sexual dysfunction compared to the normal control group. In this study, sexual dysfunction was 54% in female patients with IBD and 44% in the normal group. It was 25% in both male patients and the control group. IBD patients with active disease had impaired sexual function compared to patients in remission and the control group. There was a significant relationship between sexual dysfunction and disease activity, fatigue, depressive state, and quality of life in both male and female patients. The main characteristic of the relationship between disease activity and sexual dysfunction was depression. Patients with active IBD had more sexual dysfunction than patients in remission and the control group, and depression was found to be the strongest determinant. In our study, the patients' relationship with depression was not questioned. The fact that Bel et al. [27] did not find a significant relationship between sexual dysfunction and IBD may be because they focused on its relationship with depression. Again, the larger number of patients in the study by Bel et al. [27] may have produced different results than our study, since it was multicentric.

As a result of this study, we showed that the total score of the PROMIS survey was lower in the patient group of both sexes than in the control group, although statistical significance was reached only in men. Again, we found that the sexual-life quality index was statistically significantly lower in both male and female patient groups compared to the control group. These results revealed that the quality of sexual life was low in both male and female patients with inflammatory bowel disease.

Although our study is the first to investigate sexual dysfunction in patients with inflammatory bowel disease in our region, it has some limiting factors. The first is that the number of our patients, especially women, is relatively low. The main reason for this is that it was a study conducted during the COVID-19 pandemic, the lower literacy rate of women, and the fear of sexual evaluations due to the cultural structure of the region. Defining and finalizing the survey form for patients on the internet increases patient participation, even if it is not at the level we want. Secondly, the quality of sexual life of the patients could not be correlated with disease activation, medication used, and socioeconomic level because responses were anonymous. This situation is related to the fact that it is not possible to see which patient filled out which survey because the study must comply with ethical rules. Another limiting factor was that, although a small number of our patients were illiterate, the questionnaires were answered with the help of the patients' relatives, which may have caused incorrect scoring in this group. One of the primary limitations of this study is the relatively small sample size. Additionally, some patients were reluctant to share detailed information on this sensitive topic, which may have affected the depth of the data collected. It is evident that future studies with larger patient cohorts and well-defined control groups will provide more comprehensive insights and contribute significantly to the literature.

CONCLUSION

Inflammatory bowel disease is usually diagnosed at sexually active age; it is a chronic inflammatory disease with relapses and remissions. Considering the sociocultural structure of our region, during routine follow-up of IBD patients the quality of sexual life – which seriously affects overall quality of life – should be assessed proactively, without waiting for the patient to raise the issue, and the necessary support should be provided to maintain both psychological and physiological well-being.

Conflict of interest: None declared.

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Сексуална дисфункција код болесника са запаљенском болешћу црева

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САЖЕТАК

Увод/Циљ Запаљенска болест црева (ЗБЦ) често се дијагностикује током сексуално активних година, а тежина болести, начин лечења и хируршки захвати могу утицати на сексуалну функцију.

Циљ ове студије био је да процени квалитет сексуалног живота код болесника са ЗБЦ.

Методе У студију су проспективно укључени болесници са ЗБЦ и контролна група ($n = 45$). Забележени су демографски подаци, трајање болести, лабораторијски и ендоскопски налази и подаци о терапији. Сви испитаници попунили су *PROMIS* индекс сексуалне активности.

Резултати Укупно је укључено 103 испитаника (41 са улцерозним колитисом и 17 са Кроновом болешћу). Просечна старост болесника са ЗБЦ износила је 34,26 ± 10,1 година, а контролне групе 32,93 ± 10,5 година ($p = 0,518$). Средњи укупни скор *PROMIS*-а био је нижи у групи болесника (29,8 ± 7,4 код мушкараца; 28,1 ± 7,7 код жена) него у контролној групи (38,5 ± 5,4 код мушкараца; 34,8 ± 11,6 код жена), а статистички значајна разлика утврђена је само код мушкараца ($p < 0,001$). Медијана Индекса квалитета сексуалног живота такође је била нижа у групи болесника [3 (1–5) код мушкараца; 3 (1–4) код жена] у поређењу са контролном групом [5 (3–5) код мушкараца; 4 (1–5) код жена]. Разлика је била статистички значајна и код мушкараца ($p < 0,001$) и код жена ($p < 0,042$).

Закључак Болесници са ЗБЦ су показали нижи сексуални квалитет живота у односу на општу популацију. Процена сексуалног благостања уз активност болести може позитивно утицати на управљање болестима.

Кључне речи: запаљенска болест црева; *PROMIS*; сексуална дисфункција