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Sexual dysfunction in patients with inflammatory bowel disease

Сексуална дисфункција код болесника са запаљенском болешћу црева

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SUMMARY

Introduction/Objective Inflammatory bowel disease (IBD) is often diagnosed during sexually active years, and factors like disease severity, treatment, and surgery may impact sexual function. This study aims to assess 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. The PROMIS sexual activity index asked the patients.

Results In total, 103 patients were included (41 patients with UC 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 score of the PROMIS was found to be lower in the patient group (29.8 ± 7.4 vs. 28.1 ± 7.7 respectively) compared to the control group (38.5 ± 5.4 vs. 34.8 ± 11.6 , respectively) in both men and women. However, the difference was statistically significant only in males ($p < 0.001$). The median value of the sexual life quality index was found to be lower in the patient group [3 (1–5) vs. 3 (1–4), respectively] in both men and women compared to the control group [5 (3–5) vs. 4 (1–5), respectively]. The low sexual life quality index was statistically significant in both men and women ($p < 0.001$ vs. $p < 0.042$, respectively).

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

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 Болесници са ЗБЦ и контролна група ($n = 45$) проспективно су укључени у ову студију. 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); 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 контролама [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

INTRODUCTION

The term sexual function defines the state of being able to complete the sexual cycle (sexual interest, arousal, orgasm, resolution and satisfaction) after a sexual stimulus (tactile, visual, sensory, olfactory, etc.) without any limitations (e.g., physical, psychological, and psychosocial). Many physiological, psychosocial and sociocultural factors are effective on sexual function. The problem in one or more of these factors limits sexual functions 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

used 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].

It is a chronic disease that can change the physical appearance or perception of physical appearance of patients due to reasons such as fistula and surgical scars [6]. Distorted body image is present in 70% of patients with inflammatory bowel disease, and it has been shown that this condition affects women more than men (75% in women and 51% in men) [7, 8]. Female patients with Crohn's disease state that they avoid sexual activity due to fear of abdominal pain, diarrhea, and fecal incontinence [9]. Although sexual dysfunction and distorted body perception are common in patients with IBD, this condition is rarely discussed by the clinician and the patient [10].

Given the social characteristics of the society, this study aimed to assess sexual dysfunction in IBD patients – a topic often overlooked due to lack of inquiry. The purpose of this work 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 Dicle University Faculty of Medicine between 2009 and 2020 and 45 healthy people (control group) with the similar demographic characteristics were included in this study. This thesis study was approved by the decision of Dicle University Faculty of Medicine Clinical Research Ethics Committee, dated 16.07.2020 and with the number 132 (Annex 4).

Sexually active patients over the age of 18–65 diagnosed with endoscopic and pathological IBD were included. As exclusion criteria, patients with the following characteristics were not included in this study: those who receive treatment that will affect sexual life (except treatments for IBD, which can also affect sexual life), and those with a history of surgical intervention for IBD, those who receive treatment for sexual activity.

Remission in IBD, including Crohn's disease (CD) and ulcerative colitis (UC), is evaluated through several criteria:

Clinical Remission: Crohn's Disease: defined by a Crohn's Disease Activity Index (CDAI) score of less than 150. Ulcerative Colitis: often assessed using the Mayo Score, where clinical remission corresponds to a total score of ≤ 2 , with no individual subscore exceeding 1.

Biochemical Remission: Characterized by normalization of inflammatory biomarkers, such as C-reactive protein (CRP) and fecal calprotectin, indicating reduced inflammation.

Endoscopic Remission: Absence of visible inflammation during endoscopic examination, suggesting mucosal healing.

Histologic Remission: Lack of microscopic inflammation in tissue biopsies obtained during endoscopy, indicating deeper tissue healing [11].

Demographic and clinical data of the patients 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 presented to the patients and the control group (Tables 1 and 2). Lower scores indicate that patients are dissatisfied with their sexual life, whereas higher scores reflect greater satisfaction.

For men, the lowest score will be 8 points and the highest score will be 45 points; Those with scores 8–13 are very low, 14–20 low, 21–33 medium, 34–39 high, and 40–45 very high.

For women, the lowest score will be 10 points and the highest score will be 53 points; Those with scores 10–17 are very low, 18–25 low, 26–36 medium, 37–44 high, and 45–53 very high.

In questions 3–7, the more sexual complaints patients have, the fewer points they receive.

Statistics

The research was conducted prospectively, and the data obtained was cross-sectional in 2 groups. The survey was applied and the survey scores; Total score and sexual life indices were evaluated with one-sample Kolmogorov–Smirnov, Student’s t-test and Mann–Whitney U tests. Normality of the data was tested with the one-sample Kolmogorov–Smirnov test. Those with non-normal values were evaluated with the Mann–Whitney U test, and those with normal values 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 χ^2 test were used in the analysis of cross-tabulations. Student's t-test was used to compare normally distributed data of the patient and control groups, and Mann Whitney U test was used to compare non-normally distributed data. $P < 0.05$ was considered a statistically significant result.

Statistical analyzes were performed using the SPSS 18.0 for Windows (SPSS Inc, Chicago, IL, USA) package program.

RESULTS

A total of 58 patients, 41 with UC and 17 with CD, were included in this study. 42 (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 ± 10.10 years, while the control group had a mean age of 32.93 ± 10.50 years. There was no statistically significant difference between the patient and control groups in terms of gender distribution and average age (gender distribution: $p=0.075$; mean age, $p=0.518$).

The duration of disease from beginning in patients with UD was 70.6 ± 42.5 months, and in patients with CD it was 52.0 ± 33.5 months ($p = 0.112$). When the patients are examined in terms of clinical activity and remission in terms of clinical and endoscopic, 37 of them are in remission, 63.8% (UC = 23, 39.7% and CD = 14, 24.1%), 20 of them are active, 34.5% (UC = 18; CD = 2) and one was a newly diagnosed CD (1.7%) clinically. Disease activation rates were significantly higher in ulcerative colitis patients ($p = 0.026$) (Table 3).

The individual scores, total scores and sexual life quality index scores of the answers to the survey questions in the male patient and control groups are shown in table 4. The PROMIS survey total score was found to be statistically significantly lower in male patients (29.8 ± 7.4) compared to the male control group (38.5 ± 5.4) ($p < 0.001$). In addition, the sexual life quality index obtained based on this total score was 3.0 (1–5) in male patients and 5.0 (3–5) in men in the control group, which was found to be statistically significantly lower ($p < 0.001$).

Individual scores, total scores and sexual life quality index scores of the answers to the survey questions in the female patient and control groups are shown in table 5 and. Although the PROMIS survey total score was lower in female patients (28.1 ± 7.7) compared to the female control group (34.8 ± 11.6), the difference was not statistically significant ($p>0.05$). The sexual life quality index obtained based on the total score was found to be 3.0 (1–4) in female patients and 4.0 [1–5] in women in the control group, and was found to be statistically significantly lower ($p < 0.042$).

DISCUSSION

Our aim in this study was to investigate regional, epidemiological data of sexual quality of life index in male and female patients with IBD. The relationship and frequency of IBD-sexual quality of life index, 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 genders equally and has serious negative effects on quality of life [12]. It generally has a negative impact on physical appearance and perception due to fistula, 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 question the sexual life quality of patients using a world-class survey and contribute to the literature.

Sexual dysfunction is a complex biological, psychological and social process. And this process is physiologically affected by many systems in our body, especially the neurological, vascular and endocrine systems [15]. Sexual dysfunction seen in IBD has both psychological and physiological dimensions and are intertwined in many places. For example, physiological conditions such as fatigue, joint pain, abdominal pain, dyspareunia can cause psychological diseases such as depression and anxiety, and these are symptoms that 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 Riviere et al. on 358 patients with inflammatory bowel disease, 238 of the patients were diagnosed with Crohn's disease, and 120 were diagnosed with Ulcerative colitis. 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 found to be 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 normal 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 found to be quite high compared to healthy control groups. The result of our study is consistent with

the result found by Riviere et al., and the sexual life quality index in both groups of men and women is lower than the control group [21].

In a study conducted by Marin et al. on 555 patients, 355 of whom had inflammatory bowel disease and 200 of whom were normal healthy population, they showed that 1/2 of the women and 1/3 of the men had a decrease in sexual desire and satisfaction after the diagnosis of IBD [22]. 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 on our patients, 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. 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 [27]. In this study, sexual dysfunction was found to be 54% in female patients with IBD and 44% in the normal group. It was found to be 25% in both male patients and the control group. In this study, 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 the activity of the disease and sexual dysfunction was depression. In this study, 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. did not find a significant relationship between sexual dysfunction and IBD may be because they questioned its relationship with depression. Again, the larger number of patients in Bel et al.'s study may have produced different results than our study, since it was multicenter [27].

As a result of this study, we showed that the total score of the PROMIS survey was lower in the patient group of both genders than in the control group, although the statistical significance was only in men. Again, in our study, 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 study investigating sexual dysfunction in patients with inflammatory bowel disease in our region, it has some limiting factors. The first of these 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; The reason is that the relationship between disease activation, medication used, and socioeconomic level cannot be evaluated. 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 patient's relatives. This may have caused incorrect scoring in the answers of this patient 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 socio-cultural structure of our region; During the routine controls of IBD patients, the quality of sexual life, which seriously affects the quality of life of the patient, should be questioned without waiting for the patient to express himself, and the necessary support should be provided for the continuity of the psychological and physiological well-being of the patients.

Conflict of interest: None declared.

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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

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)	9 (15%)	
	Left Colon (E2)	22 (37.9%)	Ileocolonic (L2)	2 (3.4%)	
	Extensive	11 (19%)	Isolated colonic (L3)	2 (3.4%)	
Disease activity	Active	N: 18 (31%)	Fistulized (p)	4 (29.3%)	0.026
	Remission	N: 23 (39.7%)	Active	N: 3 (5.2%)	
			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