Original Article

# Sexual dysfunction in women with interstitial cystitis/bladder pain syndrome: A case-control study

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## ABSTRACT

**Introduction:** Interstitial cystitis/bladder pain syndrome (IC/BPS) is a chronic debilitating illness characterized by urinary frequency, urgency, and pelvic pain. IC/BPS adversely affects the sexual well-being of the patients. We used the Female Sexual Function Index (FSFI) to compare sexual dysfunction (FSD) in women with IC/BPS versus controls in an Indian cohort where such data is lacking.

**Materials and Methods:** This case–control study was designed to compare the FSDs in patients with IC/BPS to that of asymptomatic controls. Pelvic Pain and Urgency/Frequency (PUF) Questionnaire scores and FSFI scores were used as tools for this study.

**Results:** Thirty-two patients were recruited in each group. Patients with IC/BPS had a significantly higher PUF score as compared to the control group (7.843 vs. 3.656). These patients also scored worse on the total adjusted FSFI score (18.678 ± 4.531 vs. 28.05 ± 4.318; $P < 0.05$) and individually in all domains of sexual function. Twenty-nine (90.62%) patients of the IC/BPS group had FSD as compared to 12 (37.5%) of patients in the control group. Pain was the most common presenting complaint and was seen in 65.25% of patients in the IC/BPS group as compared to only 31.25% of patients in the control group.

**Conclusion:** The results of our study show that women with IC/BPS have more pain and sexual dysfunction than controls.

## INTRODUCTION

Interstitial cystitis/bladder pain syndrome (IC/BPS) is a chronic illness which is characterized by urinary frequency, urgency, and pelvic pain.[1,2] The estimated female prevalence is about 300 per 100,000 women.[3] The disease mostly affects women in their sexually active age groups, with the average age of onset being 32–49 years.[4] Besides the debilitating urinary tract symptoms, IC/BPS adversely affects the sexual well-being of the patients.[4] However, patients who present with pelvic pain or pain during sexual intercourse are often misdiagnosed with vulvodynia, endometriosis, or vulvar vestibulitis.[5,6] There are a number of studies on the association of dyspareunia with IC/BPS.[7-10] However, very few studies have focused on the exact nature of the female sexual dysfunction (FSD) associated with IC/BPS. Moreover, there is a paucity of such data on Indian patients with IC/BPS. We evaluated the incidence of FSD in women with IC/BPS and compared this with a cohort of controls among the Indian population.

## MATERIALS AND METHODS

This case-control study was carried out in the urology outpatient department (OPD) of a tertiary care hospital. The period of the study was from January 1, 2017, to December 31, 2019. This study was designed to compare the sexual

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function of newly diagnosed patients with IC/BPS with those of asymptomatic controls. The institution's ethicas committee approved the study and all patients enrolled in the study provided informed, written consent to use the data so collected for research and publication.

The diagnosis of IC/BPS was based on the Global Interstitial Cystitis Bladder Pain Society guidelines.[11] Those patients who presented with pain or discomfort in the lower abdomen and/or urogenital area of more than 3 months duration, which was worse on a full bladder, were diagnosed to have IC/BPS. In addition, they were required to have one or more lower urinary tract symptoms such as frequency, urgency, and nocturia with or without standard stigmata on cystoscopy, provided that other discernible pathologies likely to cause these symptoms were excluded. For the purpose of diagnosis, a detailed history and clinical examination were carried out for each patient, which included a detailed pelvic examination to document any area of tenderness, the tone of the pelvic floor muscles, and any specific trigger points or myofascial bands. Urinalyses, urine culture, and urine cytology were carried out to exclude any urinary tract infection and malignancy. Cystoscopy was done as an outpatient procedure under local anesthesia to rule out any bladder pathology. A frequency volume chart was prepared for all patients and a pelvic ultrasound was also obtained to exclude any other pathology as the cause for the symptoms.

An equal number of female patients of 30–50 years who attended the urology OPD for any problem other than urinary complaints were enrolled as controls. Both the cases and the controls came from the same socioeconomic and educational background. The patients and controls were included only if they reported being sexually active within the past 1 month.

The patients with IC/BPS and controls were compared for the severity of the symptoms using the Pelvic Pain and Urgency/Frequency (PUF) score.[12] The FSFI, a 19-item self-reported questionnaire, is a validated tool for the assessment of FSD.[13,14] It assesses six domains of female sexual function: desire, arousal, lubrication, orgasm, satisfaction, and pain. Responses to these questions relate to the previous 4-week sexual activity and are scored from 0 (no sexual activity), 1 (dysfunction) to 5 (normal sexual activity). Individual domain scores are then obtained by multiplying the sum of the individual questions of the domain to the domain factor provided in the FSFI. Adding the scores of each domain gives the final score. The score can vary from a minimum of 1.2 to a maximum of 36. A final score ≤26.55 is classified as FSD.[15] FSFI was used in our study to test the hypothesis that there is an increased incidence of sexual dysfunction in patients with IC/BPS and the total score of ≤26.55 was defined as FSD. A female counselor, blinded to the diagnosis of the subjects, was utilized to administer the FSFI. The FSFI was administered in English language to all those subjects who were able to converse in the language and was translated to local language by the counselor for those who could not.

The sample size was calculated for hypothesis testing between two means. The minimum effect size we wanted to calculate was 0.8 with an alpha error as 5% and power as 80%. The calculated sample size was 27 in each arm using the data from the study by Ottem *et al*.[16] The data were compiled in Microsoft Excel worksheet and were analyzed using statistical software Statistical Package for the Social Sciences (SPSS) version 24.0 (IBM Corp., Released 2016. IBM SPSS Statistics for Windows, version 24.0. Armonk, NY, USA: IBM Corp.). Independent *t*-test was used for statistical comparisons and $P < 0.05$ was considered statistically significant.

## RESULTS

A total of 43 patients were diagnosed with IC/BPS during the study period. Of these, 4 patients had no sexual contact in the last 4 weeks and 7 refused to participate in the study and hence were excluded. A total of 32 patients were finally considered for the evaluation in each group.

The patients with IC/BPS had a significantly higher PUF scores as compared to the control group (17.843 vs. 3.656) [Table 1]. Pain during sexual activity was the most common complaint in patients with IC/BPS. Twenty-one (65.25%) patients in the IC/BPS group had pain during sexual activity as compared to only 10 (31.25%) patients in the control group. The scores of all the six domains of the FSFI, namely desire, arousal, lubrication, orgasm, satisfaction, and pain, were significantly lower in the IC/BPS group as compared to the control group [Table 2]. The overall satisfaction score in patients with IC/BPS was only 3.025 as compared to 4.387 in the control group ($P < 0.05$).

**Table 1: Group characteristics**

| Characteristics | IC/BPS group | Control group | *P* |
|---|---|---|---|
| Total number | 32 | 32 | <0.00001 |
| Mean age (years) | 41±5.25 | 40.28±6.34 | |
| Average PUF score | 17.843 | 3.656 | |

PUF=Pelvic pain and urgency/frequency, IC/BPS=Interstitial cystitis/bladder pain syndrome

**Table 2: Female sexual function index score**

| Domain | IC/BPS group | Control group | *t* | *P* |
|---|---|---|---|---|
| Desire | 2.343±0.767 | 4.537±1.246 | −8.475 | <0.05 |
| Arousal | 2.803±0.837 | 4.8±1.055 | −8.384 | <0.05 |
| Lubrication | 3.281±1.125 | 4.8±0.963 | −5.799 | <0.05 |
| Orgasm | 2.612±0.995 | 4.162±1.055 | −6.044 | <0.05 |
| Satisfaction | 3.025±0.793 | 4.387±1.124 | −5.601 | <0.05 |
| Pain | 4.612±1.4 | 5.362±1.055 | −2.419 | <0.05 |
| Total FSFI score | 18.678±4.531 | 28.05±4.318 | −8.468 | <0.05 |

FSFI=Female sexual function index, IC/BPS=Interstitial cystitis/bladder pain syndrome

Patients with IC/BPS scored worse on the total FSFI score (18.678 ± 4.531 vs. 28.05 ± 4.318; $P < 0.05$). Using a total FSFI score of ≤26.55 as the cutoff score, 90.62% ($n = 29$) of patients with IC/BPS were diagnosed to have FSD as compared to only 37.5% ($n = 12$) in the control group.

## DISCUSSION

IC/BPS is a chronic debilitating illness, which is characterized by frequency, urgency, and pelvic pain.[1,2] The etiology is poorly understood but inflammation, mast cell activation, urothelial damage, and autoimmunity are postulated to play a role. The urinary symptoms can be very debilitating, but are not the only symptoms which affect the quality of life of such patients. Sexual dysfunction is another important factor, which negatively impacts the quality of life in these patients,[17] besides the lack of sleep and the accompanying depression.[18,19]

Sexual dysfunction in patients with IC/BPS is not studied well specially in patients from the Indian subcontinent. To the best of our knowledge, this is the first study from the country on the subject. The social beliefs and stigma attached with discussing sexual matters are a big problem when we started this study. Laumann *et al*. had documented under-reporting of sexual problems and poor help-seeking behavior in women experiencing sexual problems.[20] A similar trend was seen in our patients also and most of them were shy to come out with their sexual problems, especially in front of a male urologist. Hence, to circumvent this issue, we sought help from a female counselor who spoke to each patient enrolled in the study and administered the FSFI. Despite this, seven patients were reluctant to discuss their problems and had to be excluded from the study.

The PUF patient symptom scale is a self-reported questionnaire-based diagnostic tool used to screen patients with chronic pelvic pain.[12] There are 12 items in the questionnaire, which are divided into two domains: the symptom and bother scores. The questions are scored from 0 to 3, 1–3, or 0–4. Increasing severity of each item is represented with an increasing score. The final scores range between 0 and 35, and a score >15 is indicative of significant symptoms.[12] The mean PUF score in the IC/BPS group was 17.843 as compared to only 3.656 in the control group. Our findings were consistent with those of Lee *et al*.[21] who also found an increased PUF score in patients with IC/BPS. On subgroup analysis, they found that patients who had dyspareunia had a worse PUF score as compared to those without (20.69 ± 5.8 vs. 18.18 ± 5.5). Many studies have included the assessment of PUF scale in the diagnostic workup for patients with IC/BPS.[22,23] Kahn *et al*. in their study found that patients with a PUF score of 15 and above had more than 87% chances of being diagnosed with IC/BPS.[23]

In our study, FSD was seen in 90.62% ($n = 29$) of patients with IC/BPS as compared to only 37.5% ($n = 12$) in the control group. Our results were similar to those of Bogart *et al*.[2] who had carried out a telephonic survey on 985 patients with bladder symptoms of IC/BPS, wherein 90% of patients reported sexual dysfunction. However, we feel that our study is more generalizable because we studied it in newly diagnosed, physician-confirmed cases. In another study, Gardella *et al*.[24] had 47 newly diagnosed patients with IC/BPS with 103 patients as controls and found a significantly lower FSFI score in the patients with IC/BPS (16.85 ± 8.73 vs. 27.34 ± 6.41; $P < 0.0001$). This score has also been found to be significantly lower in patients with IC/BPS in other studies,[16,25] similar to that in the Indian subset of patients of our study (18.678 ± 4.531 vs. 28.05 ± 4.318).

Pain was the most common presenting symptom in our study and, not surprisingly, the most commonly studied domain. It is also the most common cause for the avoidance of sexual activities in females.[24] It has also been seen that the FSFI pain scores do not vary with the menstrual cycle and the hormonal status of the patients.[26] Gardella *et al*. found that 23.4% of patients with IC/BPS avoided sexual activity because of the fear of pain as compared to only 9% of patients in the control group.[24] In our study, 65.25% of patients with IC/BPS had pain during sexual activity as compared to only 31.25% of patients in the control group. Similar results were seen in the study by Peters *et al*. who reported a figure of 67.2% and 39.8%, respectively.[25] These authors also found that resistance to penetration due to the fear of pain may provoke pelvic floor hypertonus, which, in turn, would cause further restriction to vaginal entry, dyspareunia, and vestibular mucosal trauma.[25] However, there is a significant improvement in the FSFI scores along with decrease in pain scores, after initiating the treatment for IC/BPS.[27]

In our study, IC/BPS affected all the six domains of the female sexual function. A similar finding has been documented by Ottem *et al*. and Tonyali and Yilmaz.[16,28] Our results prove that the FSD in Indian patients with IC/BPS is similar to those from outside the country.

Besides pain, the other domains assessed by FSFI are desire, arousal, lubrication, orgasm, and satisfaction. In our study, all these domains individually scored worse in the patients with IC/BPS. Although each one of them can be multifactorial in origin and the cause and effect relationship cannot be established by the present study, it underscores an important factor that IC/BPS affects the overall female sexual function. This effect is multidimensional, leading to an overall decline in the quality of life of such a patient with IC/BPS. Yoon and Yoon in their study focused on the correlation of IC/BPS and female sexual activity and found a positive correlation between them ($r = 0.259$).[29] Ottem *et al*. in their study with 75 patients with IC/BPS also found

a significantly lower score across all the six domains of female sexual function.[16]

Our study has certain limitations. Most important was the non validation of the FSFI in the local language.[30] We had to administer the FSFI in local language for 9 (28.125%) subjects in the IC/BPS group and 10 (31.25%) subjects in the control group. Further, we studied only those patients who were sexually active within the last 4 weeks of being administered the FSFI. This would have eliminated few severely symptomatic patients of newly diagnosed IC/BPS, thus underreporting the degree of sexual dysfunction. Furthermore, as pointed out, the various domains of the sexual function are multifactorial and this study only studied the effect of IC/BPS. However, the study fails to establish a cause and effect relationship between the IC/BPs and the sexual dysfunction.

## CONCLUSION

Sexual dysfunction is closely associated with IC/BPS. Patients with IC/BPS scored worse on all domains of the FSFI than controls with pain being the biggest contributor to this FSD.

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