Sexual Function and Sexual Distress in Women with Interstitial Cystitis: A Case-Control Study

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OBJECTIVES
To evaluate female sexual dysfunction (FSD) in women with interstitial cystitis (IC) versus a control group. Specific areas of FSD in women with IC have not been reported.

METHODS
A mailed survey was sent to 5000 randomly selected women from the United States (controls) and 407 women with IC from a large referral center (cases). The Female Sexual Distress Scale and questions about sexual function, desire, orgasm, and pain were included. The Student *t* test was used to compare the mean values, and the chi-square test was used to compare the proportions between the cases and controls.

RESULTS
During adolescence (the start of menstruation through age 18), having had intercourse, levels of sexual desire, and orgasm frequency did not differ significantly between the cases and controls. However, a significantly greater proportion of cases reported fear of pain (P = 0.018) and pain with intercourse (P = 0.001). In adulthood, a significantly greater proportion of cases reported having pelvic pain, fear of pain during intercourse, and dyspareunia (P <0.001 for all). Furthermore, after the diagnosis of IC, the number of cases reporting moderate to high desire (P <0.001) and orgasm frequently and very frequently declined significantly (P <0.001). The mean value of the Female Sexual Distress Scale was greater among established IC cases (18.5 ± 14.3) compared with controls (8.3 ± 10.2; P <0.001). A score of 15 or greater on the Female Sexual Distress Scale has been associated with sexual distress.

CONCLUSIONS
Women with IC have significantly more FSD and sexual distress than women without IC. Additional study is needed to explore the multiple factors contributing to FSD in IC.

INTRODUCTION

Interstitial cystitis (IC) is a chronic syndrome characterized by pelvic pain, urinary urgency, and urinary frequency whose etiology and trajectory is poorly understood. Prevalence estimates vary between 30 and 300/100,000 population,[1–3] with women being nine times more likely to be diagnosed with IC than men.[4] Female sexual dysfunction (FSD) has been characterized as alterations in sexual desire, arousal, orgasm, or pain that cause some degree of personal distress.[5] FSD affects approximately 43% of women in the United States[6] and is associated with lower urinary tract symptoms (LUTS) and pelvic floor disorders such as urinary incontinence (UI).[7] Of women with IC, 93.6% have reported varying degrees of lower abdominal, urethral, lower back, and vestibular or vaginal pain,[8] and 75% have reported that sexual intercourse exacerbates their urinary and pain symptoms.[9] Chronic dyspareunia associated with IC can also lead to loss of libido, arousal disorders, and orgasmic difficulties.

Previous findings have supported a link between chronic pain syndromes and sexual dysfunction. In a study of men and women in the United Kingdom experiencing chronic pain,[10] 73% of men and women reported current sexual difficulties in the areas of arousal, confidence, performance, position, fear of worsening pain, and relationship problems associated with their pain. Although the type of pain was predominantly musculoskeletal, 5.5% did report pelvic, genital, or perineal pain. Similarly, Kwan *et al.*[11] used self-report measures to study 151 patients (77 were women) with noncancer pain. The findings suggested that those with high pain levels had greater sexual dysfunction. Sexual dysfunction was also associated with greater overall disability and greater levels of depression. Kwan *et al.*[11] further examined the quality of life in 41 patients with chronic pain (49% women), and although sexual dysfunction was prevalent, sexual life was rated as the least important aspect of quality of life.[11]

UI and LUTS are frequently encountered disorders seen in urology practices that affect sexual function in women. An analysis of data from the National Health and Social Life Survey to determine sexual dysfunctions by risk factors showed that, in women, urinary tract symptoms were associated with arousal disorders (odds ratio 4.2, 95% confidence interval 2.75 to 5.89) and sexual pain disorders (odds ratio 7.61, 95% confidence interval 4.06 to 14.26).[6] Salonia and colleagues[7] compared women with UI and/or LUTS to a matched control group to determine the prevalence of FSD and concluded that significantly more women reporting UI or LUTS complained of FSD compared with healthy women without urinary symptoms.[7] In another large prospective study, sexual complaints such as dyspareunia and anorgasmia were strongly associated with UI.[12]

In men, adequate sexual functioning is key to overall life satisfaction and quality of life.[13] Only a few studies, however, have examined this relationship in women with IC. Investigators in the United Kingdom found that 30.4% of respondents to a postal questionnaire sent to members of an IC support group (94.6% were women) indicated that IC's impact on their sexual relationships was a considerable problem.[14] In another study, sexual functioning was identified as one of the strongest predictors of poorer quality of life in women with refractory IC.[15]

Because few researchers have examined sexual function in women with IC, the purpose of this survey study was to evaluate FSD and sexual distress in women diagnosed with IC and a matched control group without IC in the United States.

MATERIAL AND METHODS

The study used a cross-sectional case-control design that was approved by the institutional review board. The investigators developed a questionnaire to be mailed to women 18 years of age and older with known IC (cases) and a slightly modified corresponding survey to be sent to a randomly selected group of women in the community (controls). Both surveys aimed to explore predisposing factors and comorbidities associated with IC. The surveys were field-tested using focus groups, and feedback was incorporated into the final versions.

The cases consisted of 406 women with established IC diagnosis confirmed by National Institute of Diabetes and Digestive and Kidney Diseases criteria, including hydrodistension from the investigators' clinical database at a large Midwestern referral center in the United States and 5000 control women in the community. The control group names were purchased from a marketing list vendor and mirrored the distribution of IC cases in terms of age, sex, and residential zip code. All surveys were mailed in March 2005 with a cover letter explaining the purpose of the study. A stamped, addressed return envelope was included, and 2 weeks after the initial mailing, a reminder postcard was sent to all subjects. No incentives were offered, and no participant identifiers were included on the questionnaire or return envelope.

All respondents were asked to supply demographic and personal and family health history data and to recall their sexual and voiding history during childhood, adolescence, and adulthood. Childhood was defined as from birth until the start of menstruation, adolescence as the start of menstruation through age 18, and adulthood as age 19 and older. For the purposes of this study, sexual intercourse was defined as sexual activity with vaginal penetration of any kind. The IC group was asked to supply the year they were diagnosed with IC and to recall the timing of certain events in relationship to their diagnosis.

The Female Sexual Distress Scale (FSDS), a self-report screening tool shown to be a valid and reliable measure for assessing sexually related personal distress in women,[16] was included in both surveys. The 12-item instrument has participants relate their feelings during the past 30 days concerning sexuality on a five-point scale. A summative score of 15 or more indicates sexually related personal distress.

Cases with missing values of the study variables were not included in the analysis, and no value imputations were performed. The two-tailed Student *t* test was used to compare age and FSDS mean scores, and the chi-square test was used to compare proportions between cases and controls, using Fisher's exact test when numbers were small.

RESULTS

A total of 215 women (53%) with IC (cases) and 823 presumably healthy women (16%; controls) returned completed questionnaires. The two groups were similar with respect to age, ethnicity, and current living arrangement (Table 1). Although part of a larger study, we are reporting here only the results related to sexual function.

All the cases and 98.4% of the controls stated they had had sexual intercourse during adolescence. The levels of sexual desire and frequency of orgasm did not differ significantly between groups. However, a greater proportion of cases (30 of 215) reported they had fear of pain than did the controls (69 of 823), and this difference was statistically significant ($P = 0.018$). Furthermore, a significantly greater proportion of

women with IC (39.8%) than controls (21.1%) reported that they had pain with intercourse during adolescence ($P = 0.001$).

In adulthood, similar proportions of cases and controls (79.1% and 78.5%, respectively) reported having had sexual intercourse. However, a significantly greater proportion of women with IC (67.2%) than controls (18%) reported having pelvic pain ($P < 0.001$; OR 3.75, 95% confidence interval 3.1 to 4.5). Fear of having pain during sexual intercourse was reported significantly more by cases (108 of 215) than controls (111 of 823; $P < 0.001$), and in those having intercourse, dyspareunia was reported more by the cases (132 of 177) than controls (193 of 646; $P < 0.001$).

All respondents were asked to indicate their level of sexual desire and frequency of orgasm in adolescence and adulthood, and cases were also asked to relate their responses to when IC was diagnosed. Before the diagnosis of IC, 86% of cases recalled having moderate to high sexual desire compared with 78% of the controls ($P = 0.016$). After the IC diagnosis, sexual desire in the moderate- high category for the cases declined from 86% to 40% ($P < 0.001$). Cases were asked to categorize orgasm frequency as very frequently/frequently (75% to 100% of the time), frequently (50% to 75% of the time), sometimes (25% to 50% of the time) never, or "cannot remember". Before IC, the rate of orgasm (frequently or very frequently) was similar in both groups (cases, 63% and controls, 61%). After the IC diagnosis, those reporting orgasm frequently or very frequently was significantly lower (44%) among the cases ($P < 0.001$).

Analysis of the FSDS revealed mean values that were statistically significantly greater among established IC cases (18.5 ± 14.3) compared with controls (8.3 ± 10.2; $P < 0.001$). A score of 15 or more on the FSDS is associated with sexually related personal distress.15 Cases were more likely to have an FSDS score of 15 or more (109 of 188) than controls (162 of 737; Table 2). When categorizing FSDS scores according to severity of distress, cases were represented in greater proportions in the moderate and severe categories (Table 2). Analysis of variance of the FSDS scores by age stratum in each study group showed a statistically significant decline in FSDS scores with advancing age (cases, $P = 0.007$; controls, $P < 0.001$; Table 3). Additional analysis of FSDS scores between premenopausal and postmenopausal cases with or without the use of hormonal replacement therapy revealed no statistically significant differences. Although a statistically significant difference was found among premenopausal and postmenopausal controls, the difference was not clinically significant (mean FSDS score 9.41 versus 7.09, respectively). Grouping cases by the time interval since the IC diagnosis (in 5-year increments) revealed no significant differences in FSDS scores between groups as well ($P = 0.834$).

COMMENT

The response rate to the mailed survey in the known IC group (53%) was similar to studies using a mailed survey design to investigate IC and/or sexuality.[14,17,18] The willingness of patients with IC to complete a seven-page survey asking highly personal questions supports the need for studies that explore various aspects of the impact of IC on sexual function. The response rate in the control group was low and might be further attributed to the lack of monetary incentives and inability to follow-up with telephone calls because of the anonymous nature of the survey.

It is particularly revealing that in this study, women with IC had significantly more pain and fear of pain during intercourse even in adolescence. Resistance to penetration resulting from fear of pain may provoke pelvic floor hypertonus, restricting vaginal entry and causing both dyspareunia and mechanical trauma of the vestibular mucosa and urethra.[19] Each noxious stimulus triggers mast cell activation, degranulation, and upregulation of the pain system. Repeated noxious stimuli potentiate the shift from nociceptive to neuropathic pain, resulting in a chronic pain syndrome and, consequently, alterations in sexual functioning.[19] Although women with IC in this study had significantly more pelvic pain, dyspareunia, and fear of having pain during sex in adulthood, the proportions of women engaging in intercourse in adolescence and adulthood was similar between cases and controls.

The cases in our study were likely at various stages of treatment; therefore, not all women with IC reported pelvic pain. However, significantly more cases reported pelvic pain and dyspareunia, and other dimensions of sexual functioning such as desire and orgasm declined significantly after IC was diagnosed. Considering that sexually related personal distress is a key component of FSD,[5] the inclusion of the validated FSDS adds strength to the study's findings. The criterion of distress discriminates between women who perceive their sexual function as problematic and those who do not. Although women with IC indicated a decline in sexual functioning after diagnosis, FSDS scores suggested that in older women less distress was experienced as a result (Table 3).

Because multiple factors contributing to sexual dysfunction (including biopsychosocial comorbidities such as stress, abuse, or chronic illness) can be present in women with IC, a variety of treatments might be required. It is also important to consider that some typical IC treatments, such as antidepressants and

opioids used to manage pelvic pain, can exacerbate sexual dysfunction. Hypertonic pelvic floor dysfunction is prevalent in patients with IC,[20] and contracted muscles can result in dyspareunia, vulvodynia, and vaginismus.[19] The pelvic floor muscles play an important role in female responsiveness and sexual function; thus, therapies aimed at treating the pelvic floor might be even more efficacious in improving sexual function, the woman's self-esteem, and her relationship with her partner.[19] Some therapies that have been reported to be helpful include pelvic floor therapy, biofeedback, neuromodulation, and botulinum toxin type A.[20]

Barriers to identifying and treating sexual dysfunction in women include embarrassment or misinformation regarding the availability of treatments, and practitioners' lack of time or concerns about offending the patient.[21] Because of the critical interrelationship between urogynecologic conditions and sexual disorders, a clear need exists for these healthcare providers, in particular, to be aware of potential predisposing factors in childhood or adolescence and to address sexual functioning and health with their patients.

CONCLUSIONS

The results of this study suggest that most women with IC experience not only pelvic pain, but also dyspareunia, sexually related distress, and significant declines in desire and orgasm frequency. Urinary tract symptoms and sexual dysfunction are highly comorbid conditions, and their shared pathophysiology deserves careful consideration. The link between IC and sexual dysfunction has signifi- cant implications for urology and gynecology specialists alike, and a unique opportunity exists to play a crucial role in initiating relevant discussions and treatments. Much is still unknown about the precursors of IC; however, pelvic floor dysfunction seems to be a powerful predisposing factor for dyspareunia, LUTS, and IC.[19,20]

Although dyspareunia might be anticipated in any chronic pelvic pain syndrome, the prevalence of arousal disorders and the impact of sexual dysfunction on overall quality of life in women with IC is less clear and warrants further investigation. Considering the complexities of treating IC and the chronicity of the condition, a definitive need exists to gain a deeper understanding of the characteristics of the impact of FSD in women with IC to improve overall well-being and quality of life.

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Table 1. Sample description

Variable	Cases (n)	Controls (n)
Race		
White*	209 (97.2)	716 (87.0)
Black	2 (0.9)	65 (7.9)
Hispanic	2 (0.9)	11 (1.3)
Asian	1 (0.5)	10 (1.2)
Other	0 (0.0)	9 (1.1)
Missing data	1 (0.5)	12 (1.5)
Mean ± SD age (yr)	50.6 ± 14.83	50.66 ± 14.43
Age distribution (yr)		
18–29	21 (9.9)	50 (6.4)
30–39	31 (14.6)	128 (16.4)
40–49	50 (23.5)	216 (27.6)
50–59	54 (25.4)	181 (23.1)
60–69	32 (15.0)	110 (14.1)
70–79	19 (8.9)	71 (9.1)
≥80	6 (2.8)	26 (3.3)
Living arrangement		
With a spouse or partner	158 (73.5)	586 (71.2)
Significant relationship but not together	13 (6.0)	60 (7.3)
Not in a relationship	42 (19.5)	167 (20.3)
Missing data	2 (0.9)	10 (1.2)

Data presented as number of patients, with percentages in parentheses, unless otherwise noted.
* Patients with interstitial cystitis reported being white significantly more often than did controls ($P = 0.000$, odds ratio 5.206, 95% confidence interval 2.305–11.751).

Table 2. Comparison of FSDS score category distribution

FSDS Severity Classification	Cases (n = 188)	Controls (n = 737)
Four categories*		
None (score 0–7)	56 (29.8)	460 (62.4)
Mild (score 8–17)	41 (21.8)	154 (20.9)
Moderate (score 18–30)	43 (22.9)	85 (11.5)
Severe (score 31–48)	48 (25.5)	38 (5.2)
Dichotomous score†		
0–14 (no distress)	79 (42)	575 (78)
15–48 (distress)	109 (58)	162 (22)

FSDS = Female Sexual Dysfunction Scale.
Data presented as number of patients, with percentages in parentheses.
†Chi-square 91.977, df = 1, $P < 0.001$.
* Chi-square 97.55, df = 3, $P < 0.001$.

Table 3. FSDS score by age

	Cases		Controls	
Age (yr)	n	FSDS Score	n	FSDS Score
18–29	19	24.0 ± 12.7	49	9.1 ± 11.8
30–39	31	23.3 ± 15.4	121	10.6 ± 11.4
40–49	49	16.9 ± 12.7	195	8.7 ± 10.2
50–59	53	19.9 ± 14.7	167	9.0 ± 9.9
60–69	26	13.0 ± 12.9	102	7.1 ± 8.7
70–79	11	9.1 ± 15.7	53	3.3 ± 7.2
>80	0		19	2.7 ± 7.0
P value	0.007*		<0.000*	

FSDS = Female Sexual Dysfunction Scale.
Data presented as mean ± SD.
* Significance set at $P < 0.05$.