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Prevalence and Correlates of Sexual Dysfunction among Women with Bladder Pain Syndrome/Interstitial Cystitis (BPS/IC)

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Abstract

Objectives—Sexual dysfunction can contribute to reduced quality of life among women with bladder pain syndrome/interstitial cystitis (BPS/IC). We examined prevalence and correlates of general and BPS/IC-specific sexual dysfunction among women in the RAND Interstitial Cystitis Epidemiology Study (RICE) based on a probability sample survey of U.S. households.

Methods—We telephoned 146,231 households to identify women who reported bladder symptoms or a BPS/IC diagnosis. Those who reported either were subject to a second-stage screening using RICE high-specificity symptom criteria (pain, pressure, or discomfort in pelvic area; daytime urinary frequency 10+ times or urgency due to pain, pressure, or discomfort (not fear of wetting); pain worsens as the bladder fills; bladder symptoms did not resolve after antibiotic treatment; and never treated with hormone injections for endometriosis). Women who met RICE criteria (n = 1,469) completed measures of BPS/IC-specific and general sexual dysfunction symptoms, bladder symptom severity, general physical health, depression, medical care-seeking, and socio-demographic characteristics.

Results—Of those with a current sexual partner (75%), 88% reported ≥ 1 general sexual dysfunction symptom and 90% reported ≥ 1 BPS/IC-specific sexual dysfunction symptom in the past 4 weeks. In multivariate models, BPS/IC-specific sexual dysfunction was significantly associated with more severe BPS/IC symptoms, younger age, worse depression symptoms, and worse perceived general health. Multivariate correlates of general sexual dysfunction included non-Latino race/ethnicity, being married, and having depression symptoms.

Conclusions—Women with BPS/IC symptoms experience very high levels of sexual dysfunction. Sexual dysfunction covaries with symptoms.

Keywords

Painful Bladder Syndrome; Interstitial Cystitis; sexual dysfunction; women

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Introduction

Bladder pain syndrome/interstitial cystitis (BPS/IC) is characterized by a constellation of bladder symptoms, including bladder/pelvic pain, and urinary frequency or urgency.¹ Sexual dysfunction issues have been reported among women with BPS/IC and can contribute to reduced quality of life.² Sexual dysfunction symptoms among women with BPS/IC have included deep dyspareunia (i.e., deep or burning pain during or after intercourse), symptomatic flares (e.g., pelvic pain) after sexual intercourse, and decreased sexual desire, arousal, and orgasm frequency.^{3–5} Similar sexual dysfunction symptoms have been reported among women with disorders related to BPS/IC, including overactive bladder, endometriosis, urinary incontinence, and vulvodynia.^{6–12}

The prevalence of sexual dysfunction among women with BPS/IC is unknown. Representative samples of the U.S. or specific areas of the U.S. suggest that about 40% of women in the general population report at least one sexual dysfunction, such as lack of interest (31%), arousal difficulties (19%), inability to achieve orgasm (25%), performance anxiety (12%), pain (15%), and lack of pleasure (23%).^{10,13,14} In convenience samples of women with BPS/IC, the range of dysfunction across studies is wide (from 13–87%).^{2,15–19} Research has found significantly worse sexual functioning among BPS/IC patients than those in the general population or age-matched control patients on several different sexual functioning domains, including lack of desire, reduced arousal, lubrication difficulties, low orgasm frequency, dissatisfaction, and pain.^{3,4,20} However, to determine the full extent of sexual dysfunction issues among women with BPS/IC, representative probability samples of women with BPS/IC are needed.

Almost no research has been conducted regarding risk factors for sexual dysfunction among women with BPS/IC, or whether women with BPS/IC receive medical help for sexual dysfunction issues. Studies of women in the general population find that greater sexual dysfunction is associated with lower socio-economic status, being married, non-Latino ethnicity, poor mental and physical health, stress-related symptoms, and depression.^{10,13,14,21–24} Some types of dysfunction (e.g., lubrication) are associated with older age, whereas other types (e.g., pain during sex) are associated with younger age. A small proportion (about 10–20%) of those U.S. women with sexual dysfunction seek medical help for the condition.¹⁰

As part of the RAND Interstitial Cystitis Epidemiology Study (RICE), we conducted a probability sample survey of women in U.S. households. After identifying women with BPS/IC symptoms using symptom reports,²⁵ we assessed presence of sexual dysfunction symptoms, as well as medical help-seeking for dysfunction. We assessed several risk factors for sexual dysfunction, including mental health factors (anxiety and depression), co-morbid diseases, and socio-demographic characteristics. Such information is critical for developing clinic-based interventions to identify and treat sexual dysfunction among women with BPS/IC, as well as to increase awareness among providers about the extent of dysfunction in BPS/IC populations.

Materials and Methods

Sample and Eligibility

The RAND Human Subjects Protection Committee approved all study procedures. We screened 146,231 households with telephones to identify those with a female aged 18 or older who had bladder symptoms or who reported a diagnosis of BPS/IC. Among those reporting symptoms or a prior BPS/IC diagnosis, we conducted second-stage telephone screening to identify women who met the following high-specificity RICE symptom criteria,

based on our prior research^{1,25}: (1) pain, pressure, or discomfort in pelvic area; (2) daytime urinary frequency 10+ times or urgency due to pain, pressure, or discomfort (not fear of wetting); (3) pain worsens as the bladder fills; (4) bladder symptoms did not resolve after treatment with antibiotics; and (5) never treated with hormone injections for endometriosis. Following prior BPS/IC research (i.e., the Interstitial Cystitis Database),¹⁸ participants were excluded if they were ever diagnosed with genital herpes, bladder cancer, diverticulum of the urethra, a spinal cord injury, stroke, Parkinson's disease, multiple sclerosis, spina bifida, tuberculosis affecting the bladder, or cancer of the uterus, ovaries, vagina, or urethra; ever had Cyclophosphamide (Cytosan) therapy, or radiation therapy to pelvic area; or were currently or possibly pregnant. A total of 1,469 women met the RICE criteria for BPS/IC symptoms and completed a 1-hour telephone interview. We applied population weights derived from data obtained in the first stage of screening.

Non-response weights were created using the inverse of predicted probabilities from a logistic regression model predicting whether or not the household was successfully screened. The model included households that had at least one female with either bladder symptoms or diagnosis, and that provided permission for future contact by RAND interviewers. The model controlled for whether the potentially eligible woman had symptoms only, a self-reported diagnosis only, or both; general respondent characteristics (gender, age, race/ethnicity, educational attainment, whether head of household, employment, and marital status); and household characteristics (total income, home owned by household, and indicators of children under 6, 6–11, and 12–17 years-old). Within this nonresponse model, simple imputation of missing predictors was done for observations that were missing values for household income (median imputed) and children indicators (categorical means imputed).

Measures

Sexual behavior and dysfunction—Women who had a current partner were asked the number of times that they engaged in vaginal sex in the past year, and the extent to which they experienced six BPS/IC-specific sexual dysfunction symptoms and five general sexual dysfunction symptoms in the past four weeks (“not a problem”; “a little of a problem”; “somewhat of a problem”; or “very much a problem”). Items were averaged within each scale; internal consistency was very good [$\alpha = .88$ for general and $\alpha = .84$ for BPS/IC-specific scale, the RICE-Bladder Specific Sexual Dysfunction (BSSD-6) scale]. Scale values were also dichotomized to indicate presence of any symptom (i.e., any response to any item other than “not a problem”). General sexual dysfunction items were drawn from a prior general population survey.¹⁰ The content of the RICE BSSD-6 items was developed based on a literature review and our formative work, which suggested key symptoms of BPS/IC that could be related to sexual function.^{1,26} Items are shown in Table 2.

For descriptive purposes, we assessed medical help-seeking for sexual dysfunction symptoms: “Sometimes when people have problems like this, they go to someone like a doctor or other health professional for help. In the past 12 months, have you tried to get help from a doctor or other health professional for the sexual problem(s) you have experienced?” If participants responded in the affirmative, they were next asked “Was the problem resolved?” with response options “completely,” “partly,” and “not resolved.”

BPS/IC symptoms—BPS/IC symptom severity was assessed with the Interstitial Cystitis Symptom Index (ICSI), which assesses the presence and degree of IC symptoms in the past month ($\alpha = 0.59$).²⁷

Socio-demographic characteristics—We used standard questions to assess age, income, education, and marital status. For those women who were missing a response to the RICE income question, we used the response provided at the first stage of screening. When that response was also missing ($n = 107$; 10.9%), we imputed the mean income across non-missing cases.

Mental health—The PHQ-8 (Patient Health Questionnaire-8 items) was used to assess depression symptoms.²⁸ A score of 10 or greater corresponds with moderately severe depression and is indicative of probable depressive disorder. The PHQ has a sensitivity of 73% and a specificity of 98% for the diagnosis of major depression.

Physical health—Health-related quality of life was measured using the SF-36 physical health scale, which includes items for physical functioning, role functioning, bodily pain, general health, vitality, social functioning, and mental health.²⁹ SF-36 scales were scored on a standardized T-score metric with a mean of 50 and standard deviation of 10, derived from the U.S. general population of adult females.

Statistical Analysis

We first examined descriptive statistics, including the weighted percentage of women reporting each type of sexual dysfunction symptom; average general sexual dysfunction and BPS/IC-specific sexual dysfunction scores; and percentage of women who sought medical help for sexual dysfunction issues, and if so, their satisfaction with help-seeking. We also examined sexual behavior patterns, including the percentage with a current sexual partner and frequency of vaginal intercourse in the past year. We conducted bivariate and multivariate linear regressions predicting each type of sexual dysfunction as a function of BPS/IC symptom severity. Multivariate models controlled for age, race/ethnicity, income, education, marital status, depression symptoms, and perceived physical health. Scales measuring depression, physical health, and BPS/IC symptom severity were standardized. Analyses were performed in SAS version 9.1 and accounted for the design effects of weights using the linearization method implemented by SAS survey procedures.³⁰

Results

Sample Description

Our analysis is based on the women who reported having a current sexual partner ($n=985$, 74.6% weighted). Mean age of the sample was 43.6 years ($SD=16.7$). Mean scores on the PHQ depression scale and SF36 physical function scale were 8.1 ($SD=7.2$) and 39.2 ($SD=14.9$), respectively. For the ICSI, the average score was 11.5 ($SD=4.1$). As shown in Table 1, the majority (81%) was White and about 30% had a four-year college degree. About a third had annual incomes below \$35,000.

Prevalence of Sexual Behavior, Sexual Dysfunction, and Help-seeking

Nearly all (98%) had ever had sexual intercourse. Among the 72% of women in the sample who engaged in vaginal sex in the past year, the median annual frequency of vaginal sex was 36; a quarter of women reported an annual frequency of 12 or fewer times, and 75% reported an annual frequency of 100 or fewer times.

Table 2 shows the percentages of women with a current partner who experienced each type of symptom. Most women (88%) with a current partner endorsed at least one general sexual dysfunction symptom in the past 4 weeks; 90% of those with a current partner reported any BPS/IC-specific sexual dysfunction symptoms during the same time period. Of all the BPS/IC-specific symptoms, bladder pain during and/or after sex was the most prevalent,

experienced by about two-thirds of women with a current partner in the past 4 weeks. Lack of sexual interest was the most common general sexual dysfunction symptom, experienced by 65% of women with a current partner in the past 4 weeks. A quarter of women with current sex partners reported seeking medical help for their sexual dysfunction symptoms, and of those, 4% said that the problem was resolved completely and 26% said it was resolved partly.

Relationship of BPS/IC Symptom Severity to Sexual Dysfunction

In bivariate models, greater BPS/IC symptom severity was associated with both general sexual dysfunction [$b(SE) = .03 (.005)$, $p < .0001$] and BPS/IC specific sexual dysfunction [$b(SE) = .05 (.005)$, $p < .0001$]. As shown in Table 3, in multivariate models, more severe BPS/IC symptoms were related to BPS/IC-specific sexual dysfunction (partial $R^2 = .05$, $p < .001$). Predictors of BPS/IC-specific sexual dysfunction also included being younger, having depression symptoms, and perceiving worse general health. BPS/IC symptom severity was not associated with general sexual dysfunction in multivariate models; multivariate predictors of general sexual dysfunction included non-Latino race/ethnicity, being married, and having depression symptoms.

Comment

The results of the RICE study, the first population-based representative sample of women with BPS/IC symptoms, indicated that women with BPS/IC symptoms experience very high levels of sexual dysfunction compared to the general population. In a prior general U.S. representative sample, 43% of women reported general sexual dysfunction,¹⁰ versus 88% of women in RICE. Among women in the general U.S. population, 31% report lack of sexual interest as a problem,¹⁰ versus 64% of BPS/IC patients with a current partner in RICE; and 19% of women in the general population report arousal difficulties,¹⁰ versus 61% of BPS/IC patients with a current partner in RICE. Only 15% of women report pain as a problem,¹⁰ whereas about two-thirds of women with BPS/IC symptoms in RICE experienced bladder pain before or after sex, and over half (52%) reported pain in the genital area. Multivariate results indicated that sexual dysfunction covaries with BPS/IC symptoms. This suggests that sexual intercourse may amplify current BPS/IC symptoms.

Although sexual dysfunction is common among women with BPS/IC, most women do not seek medical help, and those who do seek help seldom get treatment. Clinicians should be aware of the extent of dysfunction in BPS/IC populations, as well as ways to identify and treat sexual dysfunction among BPS/IC patients. Clinicians need to be proactive in asking women with BPS/IC about sexual issues, since women may be unlikely to initiate discussion, most likely due to stigma and discomfort with discussing sexual behavior during the medical encounter. Brief questions about sexual behavior could be integrated into the medical interview, as part of symptom elicitation, to potentially identify such individuals. The use of the RICE Bladder Specific Sexual Dysfunction scale (RICE BSSD-6), developed for this study, may assist researchers in pursuing this topic, although additional data are needed on its psychometric properties.

Treatment for sexual dysfunction may be challenging and require a coordinated team of clinicians with expertise in urology, physical therapy, and sex therapy. When possible, treatment and counseling should involve the patients' sexual partner, so that couples can learn how to communicate openly about sexual issues and concerns about pain. Cognitive-behavioral therapy (CBT) can teach patients pain self-management, which enables them to alter unwanted thoughts, feelings, and behaviors in order to gain control over sexual experiences. For example, CBT has been used effectively to reduce vulvar pain among women with vulvodynia (a disorder that has overlapping symptoms with BPS/IC).³¹ If the

pain of intercourse is too severe and therapy is insufficient, couples could be taught non-coital ways to achieve sexual satisfaction and intimacy.

Conclusions

Findings from the RICE cohort suggest that BPS/IC symptoms are related to sexual dysfunction. Further, although about three-quarters of women with BPS/IC do not seek help for their sexual dysfunction symptoms, a larger percentage of women with BPS/IC symptoms seek help compared to women in the general public. Because women may be reluctant to discuss dysfunction during the medical encounter, clinicians are advised to initiate discussion of sexual dysfunction issues, as well as to help coordinate care with sexual health specialists, including psychologists, physical therapists, and counselors.

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Table 1

Socio-Demographic and Background Characteristics of the Sample of 985 Women with BPS/IC Symptoms

	Weighted %
Socio-Demographic Characteristics	
Race/Ethnicity	
White	81.1
Latino	8.1
African American	6.1
Other	4.7
Education	
No College	32.1
Some College, but no 4-Year Degree	37.3
Received 4-Year College Degree	30.6
Annual Household Income	
<\$35,000	27.8
\$35,000–\$59,999	25.6
≥\$60,000	46.5
Married	72.6

Table 2
Percentages of Women with a Current Partner (n = 985) who Experienced Sexual Dysfunction Symptoms in the Past 4 Weeks

	Not a problem (%)	A little of a problem (%)	Somewhat of a problem (%)	Very much of a problem (%)	N/A (%)
BPS/IC-Specific Symptoms					
Bladder pain during sex	32.5	23.2	23.4	18.9	1.9
Bladder pain after sex	33.2	21.9	23.8	19.4	1.8
Fear sex would exacerbate bladder problems	42.7	16.8	19.0	20.4	1.0
Urge to urinate during sex	40.4	22.1	21.1	14.8	1.6
Pain in genital area	47.1	19.3	20.7	11.7	1.4
Lack of sensation in genital area	65.2	13.7	13.9	6.1	1.1
General Symptoms					
Lack of sexual interest	35.3	19.2	22.7	22.3	0.5
Can't relax and enjoy sex	38.2	21.4	18.4	20.7	1.3
Difficulty becoming sexually aroused	37.9	23.5	20.1	17.7	0.7
Difficulty having orgasm	39.6	18.3	18.1	22.8	1.2
Dryness/poor lubrication	42.6	16.5	20.4	19.3	1.1

Table 3

Multivariate Linear Regressions Predicting General and BPS/IC-Specific Sexual Dysfunction

	General Sexual Dysfunction	RICE Bladder Specific Sexual Dysfunction (RICE BSSD-6)
	b(SE)	b(SE)
BPS/IC Symptom Severity^a	0.044(0.032)	0.203(0.028)***
Health Status		
SF36 Physical Function ^a	−0.060(0.035) ⁺	−0.110(0.032) [*]
Depression Symptoms ^a	0.450(0.035)***	0.204(0.034)***
Socio-Demographic Characteristics		
Age (decades)	0.044(0.023) ⁺	−0.115(0.021)***
Race/Ethnicity (vs. White)		
Latino	−0.235(0.107) [*]	−0.021(0.103)
African American	−0.049(0.123)	−0.196(0.102) ⁺
Other	−0.107(0.103)	0.092(0.115)
Education (vs. ≥College)		
No College	0.118(0.078)	0.051(0.074)
Some College, but No 4-Year Degree	0.021(0.070)	0.043(0.064)
Annual Household Income (vs. ≥\$60,000)		
\$0–34,999	0.018(0.080)	−0.006(0.075)
\$35,000–59,999	0.069(0.073)	0.105(0.071)
Married	0.144(0.070) [*]	0.031(0.063)
Model R ²	.29	.29

b (se) = unstandardized beta (standard error)

^a Standardized⁺ p < .10;^{*} p < .05;

*** p < .0001