UROGYNECOLOGY

Is there a high incidence of hysterectomy and other nonbladder surgeries before and after onset of interstitial cystitis/bladder pain syndrome?

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OBJECTIVE: The objective of the study was to compare with controls the incidence of nonbladder pelvic surgeries in the months before and after the onset of interstitial cystitis/bladder pain syndrome (IC/BPS).

STUDY DESIGN: The design of the study used an existing database from a retrospective case-control study of 312 incident IC/BPS cases and matched controls plus a longitudinal study of the cases that examined lifetime approximated annual incidence of surgeries with that in the months before and after the onset of IC/BPS.

RESULTS: In cases, in the month before the onset of IC/BPS, the approximated annual incidence of nonbladder pelvic surgeries was 15 times higher and of hysterectomy 25 times higher than the incidences of previous years and similarly higher than controls. This rate declined to preindex levels over the first 2 years of IC/BPS.

CONCLUSION: There may be a very high incidence of nonbladder surgeries just before IC/BPS onset that decreases to historical levels over the first years of the syndrome.

Key words: bladder pain syndrome, gynecologic surgery, hysterectomy, interstitial cystitis

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For almost a century, clinicians have noted large proportions of interstitial cystitis/bladder pain syndrome (IC/BPS) patients that reported a history of hysterectomy.[1,2] Over the last decade, investigators confirmed this impression by comparisons with controls.[3-5] Whether these surgeries preceded or followed the onset of IC/BPS remained unclear. Recently Ingber et al[4] asked 57 IC/BPS patients with histories of hysterectomies when the procedures were performed relative to the diagnosis of IC/BPS. Sixty-eight percent had hysterectomies before the diagnosis, 11% in the same year, and 21% after the diagnosis of IC/BPS.

These findings generated the hypothesis that hysterectomy before onset of IC/BPS might be a risk factor for it. Indeed, we subsequently demonstrated that more IC/BPS patients than matched controls reported hysterectomies, and other surgeries, prior to IC/BPS onset.[6] However, surgeries were reduced to nonsignificant association with IC/BPS when the variable, chronic pelvic pain (CPP), was added to the multivariable analyses.

Our case-control study evolved into a longitudinal history of IC/BPS in which the incident cases were followed by telephone interviews.[7] We were struck by what appeared to be large numbers of patients reporting hysterectomies and other pelvic operations also after IC/BPS onset. This study reports incidence of nonbladder pelvic surgeries in the months before and after the onset of IC/BPS.

Materials and Methods

Details of this case-control study have been outlined,[6-9] and all data used in this report were collected during the original investigation. Through IC/BPS support groups and physician organizations, 1177 American women were screened for IC/BPS symptoms. Inclusion criteria were perceived bladder pain (3 or greater on a scale of 10) plus at least 2 of the symptoms of urgency (3 or more of 10), frequency (8 or more times per 24 hours) or nocturia (1 or more per night) for 4 weeks or longer. Medical records were obtained to confirm the onset date of IC/BPS and rule out diseases that could resemble IC/BPS.

Respondents were excluded by self-report or medical record evidence of 12 diseases as listed in the 1990 definition of interstitial cystitis of the National Institute of Diabetes and Digestive and Kidney Diseases[10]; because of the possibility of a neurogenic bladder, exclusions also included stroke, spinal cord injury, Parkinson's disease, multiple sclerosis, and

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TABLE 1
Approximated annual incidences of surgeries of any type before the index date in IC/BPS cases and matched controls

Any type of surgery with more than local anesthesia	Period before index date					
	Before 12 mo		1-12 mo		Within 1 mo	
	Cases	Controls	Cases	Controls	Cases	Controls
Women, n	312	313	312	313	312	313
Surgeries, n	882	596	58	50	29	8
Interval	12.3 y[a]	12.9 y[a]	11 mo	11 mo	1 mo	1 mo
Approximated annual incidence	23%	15%	20%	17%	112%	31%

IC/BPS, interstitial cystitis/bladder pain syndrome.

[a] See text.

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spina bifida. For enrollment, cases required medical record diagnosis of interstitial cystitis by a urologist or gynecologist and/or treatment with IC/BPS-specific medications.

Three hundred twelve women 18 years old or older with IC/BPS symptoms of 12 months or less were enrolled. Of their 1088 medical records sought, 1062 (98%; 3.4/case) were obtained and reviewed to rule out mimicking diseases, confirm the onset date of IC/BPS symptoms, and record IC/BPS diagnostic and therapeutic initiatives.

IC/BPS symptom onset (the index date) was determined by a 5 step process[8]: (1) asking the date of the first symptom; (2) probing for earlier symptoms that "continued on most days": "bladder discomfort, pain, or pressure," "urinary frequency that was unusual for you," and "urinary urgency that was unusual for you"; (3) probing for an episode 4 or more weeks of similar urinary symptoms in the past 5 years; (4) concurrence with the medical record; and (5) patient confirmation.

Features of these cases[6] were characteristic of IC/BPS.[3,11] The mean score of worst IC/BPS pain was 8.4 of 10. Eighty-six percent of cases reported this pain to worsen with bladder filling, 81% to improve with voiding, and 83% to worsen with certain dietary products; 97% reported 1 or more of these. The mean urgency was 7.5 of 10, 87% had frequency of 11 or more per 24 hours and 71% reported nocturia of 3 or more per night. The mean Interstitial Cystitis Symptom Score[12] was 14.8. These patients met the definitions of IC/BPS proposed by 3 expert consensus groups.[13-15]

Control women were recruited by national random digit dialing. Exclusion criteria were 4 or more weeks of bladder pain of 2 or greater on a scale of 10, urgency of 2 or more on a scale of 10, or frequency of 8 or more per 24 hours at any time in their lives when not pregnant. Each was matched to a case by age and national region and assigned an index date at an equivalent interval before her baseline interview. As suggested by interviewers, 78% selected a date within 1 month of the assigned date that was personally important, such as an anniversary. This study was approved by the University of Maryland Baltimore Institutional Review Board, and all cases and controls gave signed informed consent.

The mean age of the 312 cases was 42.3 years, and the mean age of the 313 controls was 42.9 years. Other characteristics of the cases and controls have been well described.[6] At the baseline interview (for cases a mean of 9.5 months and controls 9.4 months after the index date), each case and control was asked: "At any time before your index date of _____, did you have any type of surgery that required anesthesia (ie, general anesthesia), an epidural or spinal, or a regional block, not including local anesthesia or intravenous (IV) sedation?"[6] If yes, she was asked the number of lifetime surgeries, then those within 12 months and within 1 month before her index date. In the same way, she was asked about hysterectomy, other uterine surgery, ovarian surgery, and "any other surgery to your urinary, reproductive organs, or pelvic region that I have not mentioned," which were then named or described. Medical records and baseline interview notes were reviewed to confirm a reported surgery within the month before the index date.

Cases but not controls had follow-up telephone interviews, at 6, 12, 18, 24, 36, and 48 months after the baseline interview.[7] Three hundred four cases (97%) participated in the follow-up. The 57 cases (18%) who withdrew over the follow-up period did not differ in important ways from those who maintained follow-up.[7] The median follow-up was 33 months after IC/BPS onset.[7] At each follow-up, cases were asked: "Since _____ (the last contact), have you had any of the following surgical procedures": hysterectomy, ovarian surgeries, bladder surgeries and "any other surgery to your urinary, reproductive organs, or pelvic region that I have not mentioned."

To minimize confounding by diagnostic or therapeutic surgeries for IC/BPS itself, we excluded bladder or urethral procedures, sacral neuromodulation, and cystocoele repair. Our earlier work showed that cases differed from controls on pregnancies (fewer) and infertility (higher).[16] To avoid confounding by surgeries for these issues, we removed from analyses procedures that appeared to be solely for fertility, contraception or pregnancy. Both sets of surgeries were excluded before and after the index date; participants with these surgeries, however, stayed in the study. The remaining surgeries are called nonbladder pelvic surgeries. Because the method of data collection precluded determination of multiple procedures performed at the same operation, we were forced to count hysterectomy and ovarian surgeries as separate surgeries.

Data from each time period were used to calculate approximated annual incidences of nonbladder surgeries: the number of surgeries was divided by the number of women and then by the number of years in the time period (a month