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A Survey of Primary Care Physician Practices in the Diagnosis and Management of Women with Interstitial Cystitis/ Painful Bladder Syndrome

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Abstract

Objectives—To describe the practice patterns among primary care physicians' (PCPs') managing patients with symptoms suggestive of interstitial cystitis/ painful bladder syndrome (IC/PBS).

Methods—We developed a clinical vignette describing a woman with typical IC/PBS symptoms to elicit questions about etiology, management strategies, and familiarity with this syndrome. We mailed the questionnaire to 556 PCPs, including academicians and community physicians, in Boston, Los Angeles and Chicago.

Results—We received 290 completed questionnaires (response rate 52%). Nineteen percent of respondents reported they had "never" seen a patient like the one described in the vignette. Two-thirds of respondents correctly identified the hallmark symptom of IC/PBS (bladder pain/pressure). Regarding etiology, 90% correctly indicated that IC/PBS was a non-infectious disease, 76% correctly reported that it was not caused by a sexually transmitted infection, and 61% correctly indicated that it was not caused by a psychiatric illness. Common treatments included antibiotics and nonsteroidal anti-inflammatory agents. Referrals were often made to a specialist.

Conclusions—Although most PCPs indicate familiarity with IC/PBS, they manage the condition infrequently. They also appear to have significant knowledge deficits about the clinical characteristics of IC/PBS, and they indicate variable practice patterns in the diagnosis and

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treatment of the condition. Educational efforts directed at PCPs will likely improve the care of patients with IC/PBS.

Keywords

survey; knowledge; beliefs; pelvic pain

Introduction

Interstitial cystitis/painful bladder syndrome (IC/PBS) is an enigmatic condition characterized by bladder pain or discomfort, urinary frequency and a persistent urge to void¹. The pathophysiology is not understood, and consequently the multiple empiric treatments which exist are frequently ineffective or only partially effective in treating the symptoms. Delay in diagnosis is common, with a mean duration between symptom onset and diagnosis of 5–7 years^{2,3}. This diagnostic delay contributes to confusion, anxiety, and cost as patients visit multiple caregivers in search for an explanation for the symptoms. It also may worsen outcomes by delaying the initiation of disease-specific treatments⁴.

As with most conditions, patients with new onset IC/PBS often present initially to a primary care physician (PCP) for the evaluation and management of their symptoms. However, no systematic studies have examined PCP practice patterns regarding this condition. We conducted a multi-center survey of PCPs to ascertain the knowledge, attitudes and beliefs of primary care physicians about the diagnosis and treatment of IC/PBS.

Materials and Methods

Study Sample

In 2006, we accrued a convenience sample of 556 practicing primary care physicians from the participating institutions (Massachusetts General Hospital, Brigham and Women's Hospital, University of California Los Angeles, and Access Community Health Network). Access, located in Chicago, is the largest federally qualified health center organization in the United States. Lists of affiliated primary care physicians were obtained from the participating institutions, and these lists were refined using information provided by the General Medicine Divisions and the hospital directories to exclude physicians without direct patient care, residents and fellows, and those seeing only pediatric patients. A current interoffice mailing address was obtained for each physician.

Questionnaire Development

We conducted a series of focus groups of primary care physicians in Boston, Chicago and Los Angeles, and subsequently developed a preliminary questionnaire. This questionnaire was modified after several cognitive interviews with primary care physicians across the 3 study sites. The modified questionnaire was then pre-tested with primary care physicians as well as a panel of 5 experts in IC/PBS from North America and refined following the debriefing. The final questionnaire included 5 domains; familiarity and experience with IC/PBS, diagnosis (which included referral threshold), treatment, perceptions on managing patients with IC/PBS (which included knowledge questions), and demographics. A vignette was presented and used to “anchor” responses to questions regarding how the physicians would evaluate and treat such a patient. The vignette read as follows:

A healthy 48-year old woman reports several months of urinary frequency, urgency, and bladder area pain /pressure, and her urine cultures have all been negative. She has been treated with multiple courses of antibiotics, with no change

in her symptoms. She is sexually active, monogamous, and has no history of sexually transmitted diseases. Her pelvic and digital rectal examination is normal.

Study Design

The Institutional Review Board of each institution approved the study and survey. Brief (<15 minutes), self-administered, pre-tested questionnaires were mailed to the eligible physicians. The mailing included a cover letter from the Principal Investigator, a fact sheet describing the study, a \$5 coffee gift card, and a pre-stamped, pre-addressed return envelope. About 2 weeks after the initial mailing, all physicians were mailed a brief 1-page thank you/reminder letter. Nonrespondents were sent a second complete packet about 3 weeks after the initial mailing. No further attempts to contact nonrespondents were made. Voluntary completion and return of the survey implied informed consent.

Sample size

As part of the questionnaire development process, a set of correct answers was identified related to basic knowledge about IC/PBS, and the proportion of primary care physicians who provided correct responses was calculated for each question. A similar study evaluating practice patterns in primary care physicians for the diagnosis and treatment of benign prostatic hyperplasia (BPH) indicated that approximately one-third of these physicians followed all of the recommended guidelines⁵. Because IC/PBS is less familiar to PCPs than BPH, we expected that a lower proportion (estimated at 25%) would demonstrate adequate knowledge. Assuming a 25% population prevalence of PCP correct responses across all knowledge questions, and a 95% probability that the proportion obtained would be $\pm 5\%$ of the population value, the sample size required was calculated to be approximately 288 subjects. We anticipated a 50% survey response rate, yielding a required sample size of approximately 576 PCPs.

Statistical Analyses

The completed questionnaires were keyed into a data entry system, and double blind data entry provided 100% verification of coding and data entry. Descriptive statistics were used for all survey responses and physician characteristics. Chi-square and ANOVA were performed to detect variation in having familiarity with the IC/PBS condition, its symptoms, and etiology based on physician demographic characteristics. Ability to identify symptoms of IC/PBS and its etiology were considered as knowledge questions and responses were coded as correct and incorrect. Logistic regression analysis was used to predict which PCP characteristics were associated with correct responses to the knowledge questions. For descriptive purposes, diagnostic tests and treatment recommendations were stratified into common (at least 50% of respondents do it “more than half the time” or “almost always”) and uncommon (at least 50% obtain a test “rarely” or “never” and recommend treatment to “very few” or “none”). All analyses were performed at the data center (at the University of Illinois, Chicago) and utilized Statistical Package for the Social Sciences version 15 (SPSS, Chicago, IL).

Results

Sample characteristics

A total of 289 of the 556 primary care physicians returned completed questionnaires, yielding a response rate of 52%. Respondents were distributed approximately equally by gender (53% male). Mean duration of time from medical school graduation was 19 years (range 1–51). Respondent practice setting was community-based in 38%, hospital-based in 40%, and private practice-based in 22%. Race/ethnicity was 65% white, 23% Asian, 6% African American, 6% Hispanic and 1.1% other.

Diagnosis of IC/PBS

Fully 81% (239/289) of respondents reported ever seeing a patient like the one described in the vignette. Those physicians had seen a mean of 6.8 patients like this (range 0–80) over the past 12 months, and reported a mean of 6.5 patients in their practice with an IC/PBS diagnosis (range 0–100). Responders were asked, “When evaluating a patient like the one in the vignette to confirm the diagnosis, or to rule out other causes of his symptoms, how often do you do the following...”; their responses to 9 items are shown in Table 1. The majority (54%) of respondents indicated that they refer such patients to a specialist (28% almost always, 26% more than half the time). Commonly employed diagnostic tests included testing for Chlamydia and gonorrhea, serum creatinine determination, obtaining cervical cultures, and pelvic ultrasound imaging. Uncommon tests included post void residuals and abdominal/pelvic CT scans.

Treatment of IC/PBS

Physicians were asked, “For how many of your patients like the one described in the vignette have you recommended treatment (either initial treatment or follow-up treatment) with...”; their response to the following 12 items are shown in Table 2. Interestingly, none of the listed treatment options was commonly recommended, including treatments which have demonstrated a degree of success in reducing IC/PBS symptoms (pentosan polysulfate, amitriptyline)¹¹. Pentosan polysulfate, antihistamines, narcotics, complementary/ alternative therapies, and anticonvulsants were all particularly uncommon recommendations (range of 79% to 95%, treated very few or none).

Knowledge and Perception of Managing Patients with IC/PBS (Table 3)

The majority of respondents reported some knowledge about IC/PBS, with 19% reporting they were ‘very’ familiar, and 48% ‘somewhat’ familiar with IC/PBS, while only 6% were “not at all” familiar with the condition. Sixty seven percent of respondents correctly identified the hallmark symptom of IC/PBS as bladder area pain/ pressure. Regarding etiology, 90% correctly indicated that IC/PBS were non-infectious; however, 16% incorrectly indicated that it was caused by a sexually transmitted disease, and 22% incorrectly indicated that it was caused by a psychiatric illness. An additional 17% indicated they did not know if IC/PBS was caused by a psychiatric illness.

Predictors of Primary Care Physicians’ Responses

Using multivariate analyses, certain physician characteristics were significantly associated with the likelihood of (1) having familiarity with IC/PBS (female gender, more years of practice, and higher percentage of female patients); and (2) having knowledge in managing patients with IC/PBS (practice setting).

Comment

There is a growing understanding that IC/PBS may be more common than previously suspected, with recent studies identifying IC/PBS symptoms in 2–6% of the population^{6–8}, and in 4.3% of women in a primary care clinic setting⁹. Since IC/PBS patients often present to their PCPs at the onset of symptoms, it is important to understand the diagnostic, treatment, and management patterns for the condition that are exhibited by PCPs.

Our results indicate that many PCPs have erroneous beliefs about IC/PBS. Only 61% of PCPs correctly understood that IC/PBS is not caused by a psychiatric illness, and only 76% acknowledged that IC/PBS is not caused by a sexually transmitted disease. Furthermore, only 67% correctly identified bladder area pain/ pressure as the hallmark symptom of IC/PBS. Conversely, the vast majority (90%) understood that IC/PBS is non-infectious.

Most PCPs (81%) had encountered at least one IC/PBS patient as described in our vignette, but not unexpectedly, the diagnostic practices varied considerably. Referral to a specialist was quite common, as was testing for sexually transmitted diseases and other vaginal infections. Serum creatinine levels were also frequently ordered (39% 'almost always', 20% 'more than half the time') although the utility of this test might be questioned, since IC/PBS does not affect renal function. Urine cytology testing and measurement of post-void residual volumes were uncommon, possibly due to unfamiliarity with these tests and lack of the necessary equipment. These tests can be helpful to exclude bladder malignancy and poor bladder emptying, respectively, as causes for the irritative voiding symptoms.

For treatment, 33% of PCPs utilized antibiotics in 'almost all' (18%) or 'more than half' (14%) of IC/PBS patients, despite negative cultures and a lack of previous treatment response. This might be an area to focus educational efforts, as there is no evidence that repeated courses of antibiotics have any benefit in these patients. It is perplexing that the vast majority of PCPs endorse the statement that IC/PBS is non-infectious, and yet many treat with antibiotics anyway. One explanation for this dissonance is that the antibiotics may have been prescribed for a presumed sexually transmitted disease or vaginal infection, rather than for urinary coverage. Alternatively, they may be prescribed at the request of patients who are convinced that they have an infection despite the lack of evidence to support this.

The use of nonsteroidal anti-inflammatory medications (NSAIDs) and anticholinergic agents was also relatively common, although these agents are not commonly mentioned as options in the urologic literature due to lack of efficacy. Alternatively, many treatments that are used commonly in urology practices (amitriptyline, antihistamines) as well as the only oral drug approved by the Food and Drug Administration for interstitial cystitis, pentosan polysulfate, were prescribed very infrequently by PCPs. It may be that PCPs are unfamiliar with these agents, and tend to prescribe medications with which they have some familiarity. Therefore, another target for educational intervention may be a focus on treatments that are fairly specific for IC/PBS.

The findings in this study are similar to data we obtained related to chronic prostatitis/chronic pelvic pain syndrome (CP/CPPS) in men¹⁰. More PCPs reported seeing women with IC/PBS symptoms (81%) than men with CP/CPPS symptoms (62%) in their practices. Male PCPs were more knowledgeable about CP/CPPS, and female PCPs were more knowledgeable about IC/PBS. In both men and women with urologic pain complaints, testing for STDs is common, as is obtaining serum creatinine measurements. Antibiotics and NSAIDs are frequently prescribed in both men and women, while all other treatments are rare. Interestingly, initial referral to a specialist is more common for women with IC/PBS symptoms than it is in men with CP/CPPS symptoms. This may relate to the broader list of differential diagnoses, including gynecologic conditions, which are present in women.

Our study has several limitations. First, although our response rate of 52% is typical of physician surveys¹¹, it is possible that a degree of response bias is present, wherein PCP respondents differ in important ways from those who did not respond to the survey. Second, our clinical vignette was brief by necessity, and therefore could not provide an extensive description of the condition IC/PBS. Also, since the term 'painful bladder syndrome' is descriptive, it is possible that this term may have provided insight to PCPs who were unfamiliar with the condition. This could potentially have increased the correct responses, especially for the questions related to the 'cardinal symptoms' of IC/PBS. Third, our study population was chosen by convenience sampling from a limited number of urban settings, and therefore, our findings warrant replication in a larger sample that is more representative of PCP demographics across the country. Fourth, the data on PCP practice patterns were based on physician self-report, which may incompletely correlate with actual practice. Fifth,

our clinical vignette was for a woman and therefore the practice patterns in men with IC/PBS were not ascertained. Finally, it is important to acknowledge that no systematic survey of this type has been performed in a group of urologists or gynecologists. It is possible that the diagnostic and treatment modalities would vary just as widely in specialists with more familiarity with the disease.

The role of the PCP in the diagnosis and management of IC/PBS deserves further discussion. PCPs are often familiar with chronic pain management, and involvement of PCPs in the management of IC/PBS may be appropriate after a urologic evaluation has excluded other causes for the symptoms. However, our previous findings indicate that PCPs appear to be less familiar with chronic urologic pain conditions (IC/PBS and CP/CPPS) than they are with non-urologic chronic pain conditions (chronic headache, fibromyalgia, irritable bowel syndrome, chronic fatigue syndrome)¹⁰. This is surprising, as the prevalence of urologic pain conditions appears to be greater than many of these non-urologic conditions.

It should be noted that an evidence-based consensus diagnostic algorithm for IC/PBS does not exist, and that none of the currently available treatments are consistently effective in reducing IC/PBS symptoms¹². Therefore, it is not uncommon for IC/PBS patients to undergo a variety of diagnostic tests and to receive multiple therapies, even when they are seen by urologists¹³. Accordingly, it is not surprising that PCPs also utilize a variety of diagnostic and therapeutic approaches in patients with IC/PBS symptoms. Recently, significant efforts have been directed at achieving consensus regarding definitions, diagnosis, and treatment of IC/PBS^{14–16}. Hopefully, these efforts hopefully will provide additional guidance to specialists and PCPs who manage this condition. Meanwhile, research collaboratives funded by the NIDDK seek to elucidate the natural history, etiology, and pathophysiology (www.mappnetwork.org), such that early identification and intervention may result in improved outcomes for patients.

Conclusions

The results of this multi-center survey suggest that educational efforts targeting primary care physicians may improve the management of patients with IC/PBS. Survey responses identified specific ‘problem areas’ related to knowledge, diagnostic testing and treatment. These findings are similar to previous primary care physician survey related to chronic prostatitis/ chronic pelvic pain syndrome, suggesting that a single educational intervention related to both of these urologic pain conditions may be appropriate.

Acknowledgments

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Table 1

Reported Frequency of Primary Care Physicians' Performing Diagnostic Tests in the Evaluation of a Patient with Symptoms Suggestive of IC/PBS* (n= 239).

I refer to a specialist at this point	
Almost always	28%
More than half the time	26%
About half the time	15%
Less than half the time	15%
Rarely	11%
Never	6%
I obtain testing for Chlamydia and gonorrhea	
Almost always	62%
More than half the time	18%
About half the time	7%
Less than half the time	4%
Rarely	5%
Never	3%
I order post void residual	
Almost always	10%
More than half the time	8%
About half the time	10%
Less than half the time	12%
Rarely	29%
Never	31%
I order serum creatinine	
Almost always	39%
More than half the time	20%
About half the time	8%
Less than half the time	10%
Rarely	12%
Never	11%
I order abdominal/pelvic CT scan	
Almost always	9%
More than half the time	12%
About half the time	10%
Less than half the time	17%
Rarely	33%
Never	20%
I obtain cervical cultures for organisms such as yeast, trichomonas, bacterial vaginosis	

Almost always	42%
More than half the time	17%
About half the time	6%
Less than half the time	13%
Rarely	13%
Never	9%
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I order a urine cytology test	
Almost always	15%
More than half the time	8%
About half the time	12%
Less than half the time	18%
Rarely	24%
Never	23%
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I order a pelvic ultrasound	
Almost always	31%
More than half the time	27%
About half the time	16%
Less than half the time	8%
Rarely	9%
Never	8%
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Perform any other procedure	
Yes	5 %
No	95 %
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* Interstitial Cystitis / Painful Bladder Syndrome

Table 2

Reported Frequency of Primary Care Physicians' Treatment Recommendations for a Patient with Symptoms Suggestive of IC/PBS* (n= 239)

Antibiotics	
Almost all	18%
More than half	14%
About half	10%
Less than half	12%
Very few	23%
None	24%
Nonsteroidal anti-inflammatory medications	
Almost all	10%
More than half	24%
About half	15%
Less than half	16%
Very few	15%
None	21%
Anti-depressant medications	
Almost all	3%
More than half	8%
About half	12%
Less than half	24%
Very few	25%
None	29%
Anticholinergics (e.g., oxybutynin)	
Almost all	7%
More than half	20%
About half	20%
Less than half	15%
Very few	21%
None	17%
Bladder analgesics (e.g., pyridium)	
Almost all	4%
More than half	11%
About half	16%
Less than half	15%
Very few	26%
None	28%
Pentosan polysulfate (Elmiron®)	
Almost all	2%

More than half	2%
About half	1%
Less than half	5%
Very few	16%
None	75%
<hr/>	
Antihistamines	
Almost all	1%
More than half	0%
About half	1%
Less than half	3%
Very few	16%
None	79%
<hr/>	
Narcotic pain medications	
Almost all	0%
More than half	1%
About half	1%
Less than half	5%
Very few	26%
None	68%
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Complementary/ alternative medicine therapies	
Almost All	1%
More than half	2%
About half	7%
Less than half	11%
Very few	25%
None	54%
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Anticonvulsants (e.g., Neurontin®)	
Almost all	0%
More than half	1%
About half	1%
Less than half	5%
Very few	26%
None	68%
<hr/>	
Other	
Yes	4%
No	96%
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* Interstitial Cystitis / Painful Bladder Syndrome

Table 3**Physician Knowledge and Perception of Managing Patients with IC/PBS* (n=289)**

Number of female patients that carry the diagnosis (mean, SD)	6.54 ± 11.4
Familiarity with the condition of interstitial cystitis/ painful bladder syndrome	
Very familiar	19%
Somewhat familiar	48%
A little bit familiar	27%
Not at all familiar	6%
The “hallmark” symptom of interstitial cystitis/ painful bladder syndrome	
Bladder area pain/ pressure (correct answer)	67%
Urinary frequency	22%
Nocturia	1%
Other	2%
I do not know	7%
Interstitial cystitis/ painful bladder syndrome is non-infectious	
Strongly disagree	1%
Disagree	6%
Agree	45 %
Strongly agree	45%
I don't know	3%
Interstitial cystitis/ painful bladder syndrome is caused by sexually transmitted diseases	
Strongly disagree	21%
Disagree	55%
Agree	13%
Strongly agree	3%
I don't know	8%
Interstitial cystitis/ painful bladder syndrome is caused by psychiatric illness	
Strongly disagree	14%
Disagree	47%
Agree	18%
Strongly agree	4%
I don't know	17%

* Interstitial Cystitis / Painful Bladder Syndrome