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The Diagnostic and Treatment Patterns of Urologists in the United States for Interstitial Cystitis/Painful Bladder Syndrome

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Abstract

Introduction: Interstitial cystitis/bladder pain syndrome is not completely understood, making it challenging to diagnose and treat. The current literature elucidating this disease process is inconsistent. Without a clear consensus regarding management it is important to evaluate how urologists are treating these patients.

Methods: Urologists across the United States completed a 19-item survey addressing diagnostic and treatment methods for interstitial cystitis. Participation was voluntary and no compensation was provided to complete the survey.

Results: A total of 95 surveys were completed and returned between December 2012 and January 2013. Of the respondents 92% considered themselves general urologists and most prefer to manage interstitial cystitis/bladder pain syndrome themselves with only 33% referring these patients. Of the respondents 47% believed that the etiology of interstitial cystitis is still unknown. Cystoscopy with hydrodistention was the most common approach to diagnosis (70% of respondents) followed closely by validated symptoms scores (65%). Oral medication was the most commonly used treatment (92% of respondents), of which pentosan polysulfate was the most commonly used agent. Oral medication was followed by intravesical and bladder hydrodistention at 77% and 74% of respondents, respectively. Most urologists ultimately used multimodal therapy. AUA (American Urological Association) guidelines were followed by only 15% of respondent urologists.

Conclusions: The treatment of patients with interstitial cystitis/bladder pain syndrome is variable and many urologists use multiple modalities for diagnosis and treatment. This variability in diagnosis and/or treatment reflects the deficiency of our current understanding of this disease process. Until the pathophysiology is better delineated diagnosis and treatment will remain without consensus.

Key Words: urinary bladder; cystitis, interstitial; pain; diagnosis; practice patterns, physicians'

Abbreviations and Acronyms

BPS = bladder pain syndrome

DMSO = dimethyl sulfoxide

IC = interstitial cystitis

PPS = pentosan polysulfate

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Interstitial cystitis is an elusive disease process that remains a clinical syndrome encompassing a constellation of chronic symptoms, including pain with bladder filling, urgency and frequency without an identifiable cause. SUFU (Society of Urodynamics, Female Pelvic Medicine and Urogenital Reconstruction) defines IC as "an unpleasant sensation (pain, pressure, discomfort) perceived to be related to the urinary bladder, associated with lower urinary tract symptoms of more than six weeks duration, in the absence of infection or other identifiable causes".[1]

Because the disease process is poorly understood and there is no strict definition or identifiable cause, diagnosis is not standardized and treatment requires a close working relationship between physician and patient. Treatment typically involves cycling through multiple treatment modalities and combinations of modalities until patients report symptom improvement. However, many times immediate, durable or complete resolution of symptoms is not achieved. For this reason IC/BPS is one of the most challenging as well as frustrating conditions for patient and physician to treat in the urological field.

Since there is virtually no standardization for this syndrome/disease, it is important to evaluate current beliefs among practicing urologist for the etiology, diagnosis and treatment of this syndrome/disease to establish the most common practices in the community.

Materials and Methods

Under institutional review board exemption approval a web link to a 19-item survey was emailed to urologists across the United States (see Appendix). Surveys were sent via the ACOS (American College of Osteopathic Surgeons) and AUA membership email lists. All responses were recorded anonymously and completion was voluntary. No compensation was provided to complete the survey.

Results

Epidemiology

Surveys were sent via the AUA membership list to 936 members, of whom 20 opted out. Of those surveys 54 bounced back. Surveys were also emailed to 100 members of ACOS. Thus, 962 surveys were sent and received.

The survey was completed by 95 urologists (10.1%) between December 2012 and January 2013. Of respondents 92% practiced general urology, 3% practiced female urology and 5% were trained in another urological discipline. Median time in practice was 15 years and 56% of respondents had been in practice for 15 years or more. Of the respondents 43% practiced in a community setting while 32% practiced in an urban setting, 10% practiced in academia and 7% practiced in a rural area. Of the urologists 64% managed IC themselves and 23% managed it in their practice while only 10% referred cases to a practitioner elsewhere. The number of newly diagnosed cases of IC/BPS annually ranged from 0 to 200 per urologist (average 23). Most respondents diagnosed between 5 and 10 cases per year.

Etiology

Of the respondents 47% believed that the etiology of IC is still unknown while 35%, 5% and 2% believed it to be of organic, psychogenic and infectious origin, respectively. The remaining 11% of respondents cited autoimmune/immune mediated, inflammatory and multifactorial factors as contributing to IC.

Diagnosis

Most urologists used multiple diagnostic modalities. The most commonly used diagnostic method was cystoscopy plus hydrodistention with 70% of respondents having used this as part of the workup. Of those who performed cystoscopy petechiae, hemorrhages, ulcers and/or glomerulations were the criteria for IC as well as the subjective feeling of pain with filling and/or relief with emptying following hydrodistention. Of the urologists 65% qualified and quantified symptoms through validated questionnaires, including PUF (Pelvic Pain and Urgency/Frequency Scale), and the O'Leary-Sant Symptom and Problem Indexes or using general findings of pain, urgency and frequency without a specific questionnaire. Other diagnostic tools used included bladder biopsy by 24% of respondents, anesthetic bladder challenge by 14%, potassium sensitivity test by 10% and urine studies/biomarkers by 4%. Ultimately, 54% of respondents diagnosed IC/BPS by exclusion and only 37% followed guidelines for IC established by AUA or NIH (National Institutes of Health). Figure 1 shows a summary of diagnostic choices. [F1]

Treatment

The treatment of IC/BPS is variable and most respondents reported administering multiple therapies. Of the respondents 94% included oral medication as part of treatment for IC and almost all chose more than 1 medication. Figure 2 [F2] shows a breakdown of the oral medications.

Intravesical therapy was performed by 77% of urologists, of which the most common were DMSO and lidocaine at 61% each, followed by PPS at 32%. Other instillations were