Treating Interstitial Cystitis/Bladder Pain Syndrome as a Chronic Disease

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The management of interstitial cystitis/bladder pain syndrome (IC/BPS) is both frustrating and difficult. The etiology is uncertain and there is no definitive treatment. Consequently, both patients and doctors tend to be unhappy and unsatisfied with the quality of care. The American Urological Association (AUA) provides a guideline for the diagnosis and treatment of IC/BPS. Recommended first-line treatments include patient education, self-care practices, behavior modifications, and stress management. Management of IC/BPS may be also improved if both patients and doctors treat this condition as a chronic disease. This article reviews the AUA first-line treatments for IC/BPS and considers the benefits of treating this condition as a chronic disease.

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Key Words
Interstitial cystitis • Bladder pain syndrome • Chronic disease • Autoimmune diseases

Interstitial cystitis/bladder pain syndrome (IC/BPS) is a chronic, debilitating bladder disease. IC/BPS symptoms result in poor quality of life with sleep dysfunction, sexual dysfunction, depression, anxiety, and stress. Stress increases symptoms of pain and urgency in patients with IC/BPS. Family relationships and responsibilities were adversely affected in 70% of IC/BPS patients according to one survey. Employment is difficult or impossible in 84% of IC patients. Many patients have persistent symptoms despite a variety of treatments. Narcotics are the most commonly prescribed class of medications for this condition. The direct cost of medical care for an IC patient is more than $11,000 per year. In 2011, the American Urological Association (AUA) provided guidelines for the diagnosis and treatment of IC/BPS. The recommendation is that IC/BPS is best managed through the use of a logical algorithm. Treatment strategies should proceed using the more conservative therapies first. The first-line treatments should be performed on all patients and include patient education, self-care practices, behavior modifications, stress management, and coping techniques. However, the AUA guidelines offer limited explanation or references.
Like arthritis, diabetes, and heart disease, IC/BPS is a long-lasting condition that can be controlled but not cured. Chronic diseases such as these are among the most common and costly health problems, but they are also the most preventable and effectively treated diseases. In 2005, 133 million Americans (almost one out of every two adults) had at least one chronic disease. Chronic diseases are the leading cause of death and disability in the United States, accounting for 70% of all deaths. Aside from causing physical suffering, chronic diseases place an enormous economic burden on our society. They account for $3 of every $4 spent on health care. With an aging population, the incidence of chronic diseases will continue to rise. Because of the enormous human suffering and societal costs, much time and money has recently been expended on research, education, and pharmaceutical development for most chronic diseases. The human suffering and societal costs of IC/BPS warrant a similar standard of care.

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AUA Guideline Statements
Treatments that may be offered are divided into the first-, second-, third-, fourth-, fifth-, and sixth-line groups based on the balance between potential benefits to the patient, potential severity of adverse events and the reversibility of the treatment.

First-Line Treatments
Patient Education.
Patients should be educated about normal bladder function, what is known and not known about IC/BPS, the benefits versus risks/burdens of the available treatment alternatives, the fact that no single treatment has been found effective for the majority of patients, and the fact that acceptable symptom control may require trials of multiple therapeutic options (including combination therapy) before it is achieved.

This statement makes clear that IC/BPS warrants a great deal of patient education. Still, patients with IC/BPS reported having the greatest need while being least satisfied with the level of support and information they currently receive. These patients were unaware of many self-help options (including combination therapy) before it is achieved.

Generally, fluid intake increases frequency of urination. IC/BPS patients naturally limit fluid intake to decrease pelvic discomfort and urinary frequency. However, adequate and sustained water intake dilutes irritants and toxins in the urine. Adequate fluid intake flushes the bladder and may help prevent urinary tract infections. Adequate hydration reduces constipation, which can also exacerbate the symptoms of IC/BPS.

What is known or not known about IC/BPS and the benefits versus risks and burdens of available medical treatment is beyond the capacity of this article. A review of the evidence-based medical treatment of IC/BPS is available elsewhere.

To maintain a working relationship, patient and physician expectations must be realistic and therapies mutually agreed upon. Patients need to be aware that no single treatment may be effective, and multiple therapeutic trials may be necessary for acceptable symptom control.

Self-care Practices and Behavior Modifications.
Patients should be made aware of specific behaviors that may improve or worsen IC/BPS symptoms. These therapies are usually risk free and inexpensive. Application of either hot or cold packs to the suprapubic or perineal area or taking a warm sitz bath may relieve IC/BPS discomfort. Restricting consumption of coffee, citrus products, chocolate, alcohol, and spicy foods is a commonly used IC/BPS self-care strategy. Elimination diets help determine which foods or fluids affect each individual patient. Behavior modification therapy includes pelvic floor muscle relaxation by placing knees against the chest, reclining with spread legs, or squatting. For patients in whom urinary
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frequency predominates instead of pain, keeping voiding diaries, controlling fluid intake, and pelvic floor exercises can increase voiding intervals.\textsuperscript{18,19} Carrico and colleagues\textsuperscript{20} had IC/BPS patients watch a guided imagery compact disc that focused on bladder healing, pelvic floor muscle relaxation, and quieting nerves involved in IC/BPS with improvement in symptoms. Behaviors that may worsen symptoms include pelvic floor muscle exercises, sexual intercourse, and wearing tight fitting clothing.

Over-the-counter medications for the treatment of IC/BPS have not been adequately studied in randomized, placebo-controlled studies. The bioflavonoid quercetin, in an open-label study, showed that most IC/BPS patients had some improvement in outcome measures.\textsuperscript{21} Calcium glycerophosphate reduces titratable acids in foods and prevented food-related flares in IC/BPS.\textsuperscript{22} Phenazopyridine hydrochloride is a urinary analgesic that can be helpful for the short-term management of an IC/BPS flare.\textsuperscript{16}

**Stress Management Practices and Improving Coping Techniques.** Stress is the most significant flare factor for IC/BPS symptoms.\textsuperscript{23} Stress reduction management aids in diminution of severe symptoms and is a preventive measure for patients in remission. Higher stress levels were related to greater urgency and pain in IC/BPS patients.\textsuperscript{24} Behavior modification techniques such as exercise, bathing, meditation, shortening work hours, creating a nonstressful environment at home, or joining educational programs and patient support groups help to maintain a reduced stress level.\textsuperscript{20,25}

Patients should be encouraged to learn positive coping techniques to lessen the inconveniences of daily activity. Clinical interventions that encourage patients to take an active role in managing their lives and make adjustments to the disease may improve their quality of life.\textsuperscript{23} Research on other chronic pain disorders demonstrates a relationship between coping abilities and the extent of depression and functional disability.\textsuperscript{26} Catastrophic thinking is a negative coping strategy in which one believes the worst may happen and the result will not be tolerable. Patients who catastrophize feel helpless and obsess about their conditions. Greater catastrophizing by IC/BPS patients was associated with depression, greater pain, and poorer social functioning.\textsuperscript{27} Patients with chronic pain who avoid catastrophizing appear to be more functional.\textsuperscript{26}

Venting is another negative coping strategy that focuses attention on personal distress and expresses negative emotions. Venting about IC/BPS symptoms prolonged depressive symptoms and was related to higher levels of distress.\textsuperscript{27} Seeking emotional social support is a positive coping strategy that is associated with better health in chronically ill patients.\textsuperscript{28} This includes support from spouses, family, friends, IC/BPS support groups, and professionals in the health care field. Patients with IC/BPS who sought emotional support, talked about their feelings, and solicited empathy from others saw some benefits, especially during an IC/BPS flare.\textsuperscript{29} Patients with IC/BPS who sought advice or information from others had decreased feelings of isolation, increased sense of control, and fewer depressive symptoms.\textsuperscript{27}

Treating IC/BPS as a Chronic Disease

Despite the AUA guidelines, the current medical model still focuses on the treatment of the disease rather than its prevention. This is clearly not the entire answer. Although the clinical approach to medicine is important, it is not always complete. It is imperative that we consider both the social and environmental factors of chronic diseases for a more thorough understanding of their causes as well as methods to treat and prevent them. Historical evidence supports the contention that social issues most profoundly impact the health of a society. Better living conditions, a clean environment, proper nutrition and hygiene, and a safe work environment are key determinants of the health of a nation. Social stress, family environment, and

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McKinlay reports a story told by his friend Irving Zola:

A physician is standing on the shore of a river, and hears the cries of a drowning man. He quickly jumps in to save the man, and he drags him to shore and applies artificial respiration. Just when he begins to breathe, another man cries for help. So he jumps in again and drags the next man to shore and applies artificial respiration. Just when that man begins to breathe, there is another cry for help. This happens again and again and again.

This is the story of how a physician explains the current practice of medicine. The physician concludes, "I am so busy jumping in, I have no time to see who the hell is upstream pushing them all in." This story is significant for IC/BPS in more ways than one. First, physicians are too preoccupied with addressing acute problems, rather than investigating the cause, exacerbating factors, or prevention of the disease. Past medical practice is to take the “downstream approach” of treating people after they become sick, rather than the “upstream” approach of focusing on environmental and social causes or contributing factors of disease. Second, this is an issue that physicians, or even the medical field, cannot address alone. The health care industry and the US government must use their expertise and money to drive research, education, and pharmaceutical development to prevent, treat, and cure IC/BPS.

Autoimmunity is one of the proposed causes of IC/BPS. Like autoimmune diseases, IC/BPS affects more women than men. Stress worsens both conditions. There is a clinical concordance of IC/BPS with other established autoimmune diseases. The incidence of autoimmune diseases has been increasing in the United States. This suggests environmental factors are at play, as genes do not change in such a short period of time. Environmental exposures play a role in triggering autoimmune processes, such as how gluten ingestion causes autoimmune celiac disease. Yamada reported that 80% of young IC/BPS patients have complications of allergic disease. Allergies are caused by environmental exposure to compounds such as mold, pollen, and an ever increasing number of industrial chemicals. Shorter and colleagues reported that 90% of patients with IC/BPS reported exacerbations of symptoms following ingestion of specific foods. Lifestyles are changing with more consumption of processed food. If IC/BPS is indeed an autoimmune disease, understanding the environmental factors that trigger and exacerbate the disease will be important for treatment and prevention.

Physicians need to take a different approach when caring for IC/BPS patients. They must view IC/BPS as a chronic disease requiring a long-term health care plan. They must view themselves as “healers” instead of physicians or surgeons. Validation of the disease is important to patients as many have lived with IC/BPS symptoms for years. Patients are reassured to learn that they are not the only persons with these symptoms, that they are experiencing a well-described syndrome, and that the disease is not life threatening. Physicians need to be aware of the social and environmental factors that exacerbate this disease. Both medical and social treatment options should be utilized in their care. IC/BPS advice concerning diet, bowel function, sexual activity, and stress reduction must be part of standard care. Physician advice and support combined with patient lifestyle changes can have a significant positive effect on quality of life for IC/BPS sufferers.

Conclusions
The AUA guideline for the diagnosis and treatment of IC/BPS identifies a management strategy. First-line treatments should be performed on all patients and includes patient education, self-care practices, behavior modifications, stress management, and coping techniques. This management strategy is important as the past medical model of trial and error of various drug regimens for the treatment of IC/BPS was inadequate. However, physicians need to go a step further in the care of IC/BPS patients. Strategic management should include treating IC/BPS as a chronic disease, recognizing all the components of this disease, appreciating the social and environmental factors that cause and exacerbate IC/BPS, and offering both medical

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The authors report no real or apparent conflicts of interest.

References
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MAIN POINTS

- Interstitial cystitis/bladder pain syndrome (IC/BPS) is a chronic, debilitating bladder disease that results in poor quality of life with sleep dysfunction, sexual dysfunction, depression, anxiety, and stress.

- In 2011, the American Urological Association (AUA) provided guidelines for the diagnosis and treatment of IC/BPS. The following first-line treatments are recommended for all patients: patient education, self-care practices, behavior modifications, stress management, and coping techniques.

- Despite the AUA guidelines, the current medical model still focuses on the treatment of the disease rather than its prevention, which only addresses part of the problem. It is imperative that the medical community consider both the social and environmental factors of chronic diseases for a more thorough understanding of their causes as well as methods to treat and prevent them.

- Physician advice and support combined with patient lifestyle changes can have a significant positive effect on quality of life for those with IC/BPS.