

Interstitial Cystitis Linked with Female Sexual Dysfunction, Plus a Review of Causes and Treatments

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Friday, 16 January 2009
Last Updated Tuesday, 19 May 2009

Interstitial Cystitis (IC), also called Painful Bladder Syndrome (PBS), is linked to dyspareunia (pain with intercourse) and is thought of as contributing to long term female sexual dysfunction. Interstitial cystitis is the most therapeutically frustrating condition of the urinary tract.

Patients describe IC/PBS as pelvic pain, pressure, or discomfort related to the bladder, typically associated with a persistent urge to void, or urinary frequency, without the presence of infection or other medical reason. We also know that the prevalence of IC/PBS is underestimated and we are just getting a grasp on the magnitude of compromised mental health and quality of life it causes.

It's hard to judge, but it appears to impact 30-300 per 100,000 population; however, this statistic may grossly underestimate the frequency of the disorder given the variability of how IC/PBS is diagnosed, characterized and identified.

One problem is that IC/PBS is frequently confused with endometriosis, recurrent urinary tract infections, overactive bladder, irritable bowel syndrome, generalized vulvodynia, and vestibulodynia. The female to male ratio of people diagnosed with interstitial cystitis is approximately 10:1.

IC/PBS and sexual dysfunction

Recent reports of IC/PBS have now started including the problem of pain with intercourse and that, often, is on the list of symptoms woman share with their gynecologist or other health care provider.

The inclusion of dyspareunia, secondary to underlying bladder issues, has not traditionally been recognized, and to date has not been widely addressed in studies. In fact, pelvic pain of bladder origin continues to be widely diagnosed as a gynecologic issue, often as endometriosis, generalized vulvodynia, or vestibulodynia. While these entities individually may be a source of dyspareunia, they also may co-exist with IC/PBS. Pelvic floor dysfunction, a condition of spasm of the pelvic floor muscle, is a common source of sexual pain during or after sexual relations. Pelvic floor dysfunction accompanies IC/PBS in 75 percent of patients.

In one medical study of women with IC/PBS, 94 percent reported varying degrees of lower abdominal, urethral, lower back, and vestibular or vaginal pain. Seventy-five percent of women with IC/PBS claim that sex makes their urinary and pain symptoms worse. Over time, the dyspareunia associated with IC/PBS becomes chronic, and threatens libido, arousal, and orgasm.

Findings of one study showed that women with urinary incontinence/lower urinary tract symptoms demonstrated greater levels of sexual dysfunction. In a British study, members of an IC/PBS support group, 30 percent of respondents indicated that IC/PBS made a considerable impact on their sexual relationships. Sexual dysfunction was identified as one of the strongest predictors of poorer quality of life in women with refractory (unresponsive to treatment) IC/PBS.

It is possible that recurrent episodes of dyspareunia initiate a fear of pain that may lead to reflex hypertonicity of pelvic floor muscles. This increases dyspareunia and mechanical trauma to the vestibular mucosa or urethra. The repeated instances of pain result in a chronic pain condition, with an associated alteration in sexual function.

IC/PBS and sexual dysfunction often coexist. Medical treatments should focus on the multiple components of this pain syndrome, including reducing local inflammation and decreasing neuropathic pain. Physical therapy should be used to address concurrent pelvic floor dysfunction. Cognitive-behavior therapy and sex therapy should address the psychosexual distress that accompanies IC/PBS. All in all, headway can be made.

What causes it?

The cause of interstitial cystitis is still a basic mystery, which has resulted in debate as to what characterizes the disorder. It has become clear that IC is a condition with many possible causes. The components of this illness act in combination to cause the symptoms of IC.

It is likely that structure of the bladder, neurologic, immunologic, genetic, infectious, environmental, dietary, and psychological factors all play a role in IC. The most commonly accepted assumption focuses on an abnormality of bladder mucosa. Normally the lining of the bladder is protected by a layer of mucosa, called the glycosaminoglycan (GAG) layer, which prevents penetration by toxic substances. If the bladder is subject to repeated injury, the GAG layer

can become damaged and more permeable.

This increased permeability permits potassium to leak through the bladder lining and causes irritation of the underlying nerves resulting in pain and inflammation. Then certain cells are activated which leads to the release of histamine and other inflammatory agents that cause increasing pain and tissue damage. Thus, there is further breaking down of the GAG layer leading to a vicious cycle of pain and inflammation.

It also appears that IC/PBS is similar to other chronic pain syndromes, such as generalized vulvodynia. There is a chemical we call "Substance P" ("P" stands for "pain") that is found in high concentration in the bladder mucosa and urine of women with IC/PBS. Substance P stimulates a chain of events which leads to more and more inflammation in the bladder and that perpetuates the pain cycle.

There are several validated questionnaires that can be useful in diagnosis of IC/PBS. In addition, these questionnaires can quantify the severity of IC/PBS and its impact on sexual function. The Pelvic Pain and Urgency/Frequency scale (PUF) is a short, self assessment questionnaire that combines a symptom score and a bother score. The symptom score includes assessment of daytime and nighttime urinary frequency, urinary urgency, pain with sexual activity and location of pelvic pain. The "bother" score quantifies the degree of discomfort related to the variable comprising the symptom score.

The PUF scale has been validated in a large multicenter study, including both urologic and gynecologic patients with chronic pelvic pain. Women without IC/PBS generally have PUF scores less than 4. A score of 12-15 is suggestive of IC/PBS whereas a score greater than 15 is associated with a very strongly likelihood of having IC/PBS. In a study of 334 patients with IC/PBS and 48 controls, 84% of women with PUF scores greater than 15 had a positive potassium sensitivity test. While degree of discomfort is thoroughly assessed and quantified in the PUF questionnaire, "bother" related to sexual issues is limited to only one question directly relating to dyspareunia.

The "Leary-Sant Symptom and Problem Index can differentiate interstitial cystitis versus other urinary disorders. The OSSOI may be used as a screening tool for interstitial cystitis, but appears to be most helpful in gauging changes in clinical state over time. The OSSOI does not independently have high enough sensitivity and specificity to warrant its use as the sole diagnostic tool.

Another multidimensional self-report questionnaire that may be used in a woman with IC/PBS to assess the impact on her function is the Female Sexual Distress Scale (FSDS). The FSDS is a self report screening tool shown to be a valid and reliable measure for assessing sexually related personal distress in women.(16) Twelve items comprise the FSDS that relates feelings such as distressed, unhappy, guilty, frustrated, stress, inferior, worried, inadequate, regrets, embarrassed, dissatisfied and angry during the past thirty days concerning sexuality. Each item is scored never = 0; rarely = 1; occasionally = 2; frequently = 3; always = 4. Women with high distress associated with their sexual health problem, such as sexual pain, will have high scores compared to the maximum distress score of 48. Longitudinal scores are useful to assess improvement or worsening of the distress over time.

A diagnostic procedure called the potassium sensitivity test (PST) also is useful in the diagnosis of IC/PBS. Initially, sterile saline is instilled through a catheter in an empty bladder. The patient then rates her sensations of urinary frequency and pain. The bladder is then emptied and a solution containing potassium is then instilled. Again, the patient rates her symptoms. If she experiences increased pain with the potassium solution this is a positive test and is highly suggestive, but not diagnostic for IC/PBS. A positive PST has been observed in 78% of women with symptoms of IC/PBS but is positive in only 4% of healthy controls(13).

Cystoscopy with hydrodistention is a useful diagnostic tool but is not required when making the diagnosis of IC/PBS. A cystoscopy with hydrodistention may be done under anesthesia to confirm a diagnosis of IC. This involves stretching the bladder with fluid, allowing your physician to see changes that are typical of IC. Some of these changes include the presence of glomerulations (pinpoint hemorrhages that occur on the bladder wall, and are seen in 95 percent of IC patients), or Hunner's ulcers , which may be present in a small minority.

The Treatments

A range of therapeutic interventions, including pharmacologic solutions, are recommended for the management of IC/PBS. Initial treatment should include patient education and behavior modification. Voiding diaries examine frequency, volume of voided urine, time of urination, and associated symptoms and may help to identify foods and behaviors that cause an exacerbation of symptoms.

With the complexity of interstitial cystitis, a multifaceted medical treatment regimen is recommended in targeting various pathophysiologic (The functional changes associated with or resulting from disease or injury) aspects of the disorder. Current pharmacologic treatment recommendations include several concurrent treatments, each addressing different disease mechanisms. In addition, there is evidence that early recognition and treatment of IC/PBS leads to a more rapid relief of symptoms.

Medication to restore the protective barrier between bladder and urine which counteract dysfunctional epithelium include Elmiron® (PPS) or intravesical (within the bladder) heparin (with or without Lidocaine). To date, PPS is the only oral medication approved by United States Food and Drug Administration for use in the treatment of patients with IC/PBS. More recently, oral PPS has been used in combination with intravesical instillation of PPS and this combination was shown to be a safe and effective therapeutic option.

Secondly, inhibition of mast cell activation is achieved by the use of hydroxyzine (Atarax). And thirdly, amitriptyline (Elavil), nortriptyline (Pamelor), or other tricyclic antidepressant is recommended to treat the neuropathic pain component of IC/PBS. Several treatments used to treat IC/PBS symptoms, such as antidepressants may exacerbate (make more severe) female sexual dysfunction. Gabapentin and pregabalin are anticonvulsants that may be used to decrease the neuropathic pain component of IC/PBS.

A recently published study tested whether patients with IC/PBS treated with an intravesical therapeutic solution of lidocaine, heparin, and sodium bicarbonate experienced an alteration in the quality and frequency of dyspareunia. Sexually active patients with interstitial cystitis were treated with an intravesical therapeutic solution three times a week for three weeks.

Follow up occurred three weeks later with the administration of the Objective Rating of Improvement of Symptom scale. Sixty-five percent of the patients reported improvement greater than 50%. There was significantly less nocturia (urinating during the night), more voided volume of urine, and improvement of score on the PUF scale. More than half of the patients reported resolution of dyspareunia. The study concluded that intravesical therapy combinations of lidocaine, heparin, and sodium bicarbonate for the treatment of interstitial cystitis provided relief of voiding symptoms, pain, and dyspareunia.

As with other chronic regional pain syndromes, a multidisciplinary approach to the treatment of IC/PBS is necessary. Pelvic floor physical therapy or biofeedback can be used to address the pelvic floor muscle dysfunction that frequently accompanies IC/PBS. Some patients may benefit from cognitive behavior therapy and sex therapy to treat concurrent anxiety, depression and sexual dysfunction. Additional therapies include sacral neuromodulation (neuromodulation is defined as the therapeutic alteration of activity in the central, peripheral or autonomic nervous systems, electrically or pharmacologically by means of implanted devices) and Botulism toxin type A injections and hydrodistention may be useful in some patients.