Patient information: Diagnosis of interstitial cystitis/bladder pain syndrome (Beyond the Basics)

INTRODUCTION

Interstitial cystitis/bladder pain syndrome (IC/BPS) is a group of symptoms, including mild to severe bladder pain and an urgent and/or frequent need to urinate. The disorder can affect women and men but is more common in women. It can be difficult to diagnose and treat because the underlying cause is not well understood.

The symptoms and diagnosis of IC/BPS will be discussed here. Treatment of this disorder is reviewed separately. (See "Patient information: Treatment of interstitial cystitis/bladder pain syndrome (Beyond the Basics)".)

DEFINITIONS

The definition of interstitial cystitis/bladder pain syndrome (IC/BPS) has evolved over the years, and will probably continue to change as the cause is better understood. The American Urological Association (AUA) defines IC/BPS 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 of other identifiable causes.

It is difficult to know for sure how many people are affected by IC/BPS, but research indicates that IC/BPS symptoms occur in about 2 percent of women. However, many fewer than that are diagnosed with the disorder, perhaps because it is unrecognized.

PAINFUL BLADDER CAUSES

Little is known about the cause of interstitial cystitis/bladder pain syndrome (IC/BPS). Many studies have shown that patients with this disorder have abnormalities in the lining of the bladder. However, it is not known if these bladder abnormalities are the cause of symptoms or if the abnormalities develop as a result of some unknown underlying disorder that also causes painful bladder symptoms.

It is likely that the nerves in the bladder become highly sensitive to pain and pressure as IC/BPS develops. Nerves outside the bladder, including nerves of the abdomen, pelvis, and hips, and legs, may also become more sensitive.

One or more events may lead to the symptoms of IC/BPS, including:

- Urinary tract infection
- An episode of vaginitis or prostatitis (eg, an infection of the vagina or a bacterial infection of the prostate)
- Bladder, pelvic, back, or other type of surgery
- Trauma (eg, fall onto the tailbone [coccyx] or car accident)

However, in many people, there is no clear explanation for why or how the symptoms of IC/BPS first began.

PAINFUL BLADDER SYMPTOMS

The symptoms of interstitial cystitis/bladder pain syndrome (IC/BPS) can vary from one person to another and from one episode to another. All patients with IC/BPS have bladder pain that is relieved at least partially by urinating. Symptoms usually include a frequent and urgent need to urinate during the day and/or night. Most, although not all, people with IC/BPS do not have urinary leakage (incontinence). Most people describe pain in the suprapubic area (in the lower abdomen, above the pubic bone) or urethral area (figure 1). The severity of pain ranges from mild burning to severe and debilitating pelvic pain.

Most people describe symptoms that begin gradually, with worsening discomfort, urgency, and frequency over a period of months. A smaller subset of patients describes symptoms that are severe from the beginning. When symptoms of IC/BPS begin suddenly, some patients are able to name the exact date on which symptoms began. (See 'Painful bladder causes' above.)

Some people with IC/BPS also have other types of chronic pain, such as irritable bowel syndrome, painful menstrual periods, endometriosis, vulvar pain (vulvodynia), fibromyalgia, or prostatitis. IC/BPS symptoms are sometimes at their worst during times when other pain symptoms are also at their worst. (See "Patient information: Irritable bowel syndrome (Beyond the Basics)" and "Patient information: Endometriosis (Beyond the Basics)" and "Patient information: Fibromyalgia (Beyond the Basics)".)

Symptoms may vary from one day to the next. Worsening of IC/BPS symptoms may occur after consuming certain foods or drinks (eg, coffee, alcoholic drinks, spicy foods), during the luteal phase of the menstrual cycle (14 to 28 days after the first day of the last period), during stressful times, or after activities such as exercise, sexual intercourse, or being seated for long periods of time (eg, during a plane trip).

A person with severe disease may have to urinate several times per hour, which can seriously disrupt daily activities and sleep. As a result of these symptoms, home and work life are often disrupted, interest in sex may be minimal, and the person may have difficulty coping with chronic pain and fatigue. In surveys, 50 percent of patients reported being unable to work full-time, 75 percent described pain with intercourse, 70 percent reported sleep disturbance, and 90 percent reported that IC/BPS affected their daily activities [1].

PAINFUL BLADDER EVALUATION
The diagnosis of interstitial cystitis/bladder pain syndrome (IC/BPS) is based upon a person's symptoms and examination. A careful medical history, physical examination, and sometimes laboratory testing are needed to confirm the diagnosis and also to be sure that another condition (e.g., bladder infection or kidney stone) is not the cause of symptoms. There is no single test that can definitively diagnose IC/BPS. (See "Patient information: Urinary tract infections in adolescents and adults (Beyond the Basics)" and "Patient information: Kidney stones in adults (Beyond the Basics)".)

Physical examination — The physical examination usually includes a complete pelvic examination with a brief rectal exam. Often, patients with IC/BPS have tenderness in the lower abdomen, hips, and buttocks. Women often have tenderness in the vagina and around the bladder, and men may have tenderness in the scrotum and penis. For this reason, being examined can be uncomfortable.

If an examination is too uncomfortable, some healthcare providers will recommend that the patient begin a course of treatment for IC/BPS without further testing. If improvement is not seen, it may be necessary to perform more testing to confirm the diagnosis.

Some providers will measure the amount of urine remaining in the bladder after the patient urinates; this is called a post-void residual. This measurement can be done by inserting a small catheter into the bladder or by using ultrasound. While it is normal to have some urine in the bladder after voiding, having a large amount of urine is not normal. Urinary retention is the medical term for retaining urine in the bladder, and is not typical of IC/BPS.

Laboratory tests — Most clinicians will perform a urine test to ensure that a person's symptoms are not related to another condition, such as a kidney stone or bladder infection. If a urinary tract infection is discovered, the person will be treated with antibiotics. If blood is detected in the urine, further urine and/or diagnostic testing (e.g., cystoscopy) may be recommended. (See "Patient information: Urinary tract infections in adolescents and adults (Beyond the Basics)" and "Patient information: Blood in the urine (hematuria) in adults (Beyond the Basics)".)

Cystoscopy — Cystoscopy is a test that allows a doctor to examine the inside of the bladder. Cystoscopy is not required to diagnose IC/BPS, but may be recommended in certain situations. Cystoscopy can be done in the office, after a numbing gel is applied inside the urethra. It can also be done in an operating room while a patient is under anesthesia, sometimes in combination with other procedures.

To perform cystoscopy, a physician inserts a thin telescope with a camera through the urethra and into the bladder. The physician examines the inside (lining) of the bladder to determine if there are any abnormalities. A person with IC/BPS may have either a normal or abnormal-appearing bladder. If an abnormality is seen, further testing may be recommended.

PAINFUL BLADDER TREATMENT
A topic review that discusses the treatment of interstitial cystitis/bladder pain syndrome (IC/BPS) is available separately. (See "Patient information: Treatment of interstitial cystitis/bladder pain syndrome (Beyond the Basics).")

WHERE TO GET MORE INFORMATION

Your healthcare provider is the best source of information for questions and concerns related to your medical problem.

This article will be updated as needed on our web site (www.uptodate.com/patients). Related topics for patients, as well as selected articles written for healthcare professionals, are also available. Some of the most relevant are listed below.

Patient level information — UpToDate offers two types of patient education materials.

The Basics — The Basics patient education pieces answer the four or five key questions a patient might have about a given condition. These articles are best for patients who want a general overview and who prefer short, easy-to-read materials.

Patient information: Bladder pain syndrome (interstitial cystitis) (The Basics)
Patient information: Dyspareunia (painful sex) (The Basics)
Patient information: Vulvar pain (The Basics)

Beyond the Basics — Beyond the Basics patient education pieces are longer, more sophisticated, and more detailed. These articles are best for patients who want in-depth information and are comfortable with some medical jargon.

Patient information: Treatment of interstitial cystitis/bladder pain syndrome (Beyond the Basics)
Patient information: Irritable bowel syndrome (Beyond the Basics)
Patient information: Endometriosis (Beyond the Basics)
Patient information: Fibromyalgia (Beyond the Basics)
Patient information: Urinary tract infections in adolescents and adults (Beyond the Basics)
Patient information: Kidney stones in adults (Beyond the Basics)
Patient information: Blood in the urine (hematuria) in adults (Beyond the Basics)

Professional level information — Professional level articles are designed to keep doctors and other health professionals up-to-date on the latest medical findings. These articles are thorough, long, and complex, and they contain multiple references to the research on which they are based. Professional level articles are best for people who are comfortable with a lot of medical terminology and who want to read the same materials their doctors are reading.

Causes of chronic pelvic pain in women
Pathogenesis, clinical features, and diagnosis of interstitial cystitis/bladder pain syndrome
Management of interstitial cystitis/bladder pain syndrome
Acute uncomplicated cystitis and pyelonephritis in women
The following organizations also provide reliable health information [1-5]:

- National Library of Medicine
  (www.nlm.nih.gov/medlineplus/healthtopics.html)
- National Institute of Diabetes and Digestive and Kidney Diseases
  (http://kidney.niddk.nih.gov/kudiseases/pubs/interstitialcystitis/)
- Interstitial Cystitis Association
  (http://www.ichelp.org/)
- Interstitial Cystitis Network
  (www.ic-network.com)
- European Society for the Study of Interstitial Cystitis
  (www.essic.eu)
- United States Department of Health and Human Services
  (womenshealth.gov/publications/our-publications/fact-sheet/interstitial-cystitis.cfm)
- International Painful Bladder Foundation
  (www.painful-bladder.org/index.html)

Literature review current through: Oct 2013. | This topic last updated: Jul 11, 2013.