

The New Paradigm for Treating IC

Do You Know Your Phenotype?

by Jill Heidi Osborne MA

A New Approach To Urologic Chronic Pelvic Pain Syndromes: Applying Oncologic Principles To 'Benign' Conditions *by Christopher K. Payne*

When an oncologist makes a diagnosis of cancer, they don't just say "cancer" or "breast cancer." They offer a very detailed description of the cancer including where it is located, if it's estrogen or progesterone sensitive and more. The name and details of the cancer allow the clinician and the patient to understand the biology, treatment options and prognosis very early in the process.

For the bladder or prostate pain patient, however, this information is not as clear cut. Dr. Payne says *"we remain at a level where the diagnosis conveys almost no useful information."* He suggests that the IC community adopt an oncological approach to patient care, with clear, intentional steps that provide for a more accurate diagnosis, targeted treatments and a thorough evaluation of those treatments with the goal of achieving a cure. Yes, you read that correctly, Dr. Payne believes that complete remission if not cure is possible for many patients.

In this trailblazing article, Dr. Payne begins with an honest discussion about the frustration that urologists struggle with when caring for a challenging patient population like IC. For the physician who says *"There is no hope"* to his patients, Dr. Payne wrote *"Negative expectations have been shown to increase pain intensity and have opposite effect on brain*

activation when compared to positive expectations." He writes that there is good reason to be optimistic. Infection is no longer considered a root cause of IC or chronic prostatitis. Other than in Hunner's lesions, inflammation is rarely found. There's growing acceptance that urologic pain is the result of a few syndromes that can cause similar symptoms, such as pelvic floor dysfunction. Simply put, we've come a long way in understanding why past therapies were ineffective and how current, targeted therapies have the potential of achieving complete symptom remission, aka a "cure." It begins with an accurate diagnosis.

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Diagnosis

Dr. Payne argues for increased specificity in the diagnosis. He suggested five variants or phenotypes:



Dr. Christopher K. Payne

#1 - IC: Hunner's lesions - A small subset of patients who have deep, inflammatory lesions on their bladder wall.

#2 - BPS: Bladder Wall Phenotype - Patient symptoms often start with a UTI or other bladder insult. Frequency and urgency can occur throughout the day and night. Pain increases as the bladder fills with urine and is reduced on emptying. These patients usually find that their pain decreases when an anesthetic, aka lidocaine, is instilled into the bladder.

#3 - BPS: Pelvic Floor / Myofascial Pain Phenotype - These patients often have a history of sports or orthopedic injuries. Upon examination, they have pelvic floor tension and the presence of trigger points in their pelvis, abdomen, back and hips that trigger severe symptoms when touched. They may have less diet sensitivity, normal or larger voids, may sleep more comfortably when their muscles are relaxed. Bladder instillation of lidocaine is NOT generally helpful.

#4 - BPS: Pudendal Neuralgia - These patients have muscle tension found in the pelvic floor phenotype above that is squeezing or pressing on nerves. This causes severe pain when sitting, *"sensory abnormalities in the pudendal distribution"* and a positive Tinel's sign (tingling or pins and needles when the nerve is tapped gently).

#5 - Multiple Pain Disorders/ Functional Somatic Syndrome - These patients have multiple pain disorders (i.e. IBS, vulvodynia, etc.). Dr. Payne wrote *"Their prognosis is inherently different and the invasive treatments that may be appropriate for pelvic pain phenotypes could actually make things worse...Clinicians should proceed much more cautiously."*

Thus, using this system, a typical patient might be diagnosed as:

- Bladder wall predominant
- Pelvic floor predominant
- Pudendal neuralgia secondary

Staging

Staging is a way of understanding the severity of a condition. In the case of Hunner's lesions, Dr. Payne proposes that ulcerative IC be more fully described, using the examples:

- ulcerative IC, normal bladder capacity, complete remission lasting

16 months.

- ulcerative IC, contracted bladder, complete remission but early relapse
- ulcerative IC, end stage bladder, partial remission

Bladder pain syndrome, however, can be bit more arbitrary to describe. He suggests using bladder capacity as an objective measurement. Bladder diaries can also be helpful and provide valuable insight about treatment response. Thus, this might be described as:

- bps - bladder predominant with a reduced capacity of 4oz
- bps - mixed bladder & pelvic floor - with severe pain - 9oz capacity.

By indicating both source and status, treatments can then be best staged for the condition of each unique patient.

Treatment

Dr. Payne differs from the AUA Guidelines which suggest starting at Step One, conservative therapies, and then moving up the list. Rather, he suggests that the treatment plan be developed based upon the phenotype presented. If lesions are present, then lesion treatment would be an early goal. (The AUA does suggest this.) If pelvic floor tension is present, then physical therapy would be suggested and so forth.

Other types of complementary therapy could also be suggested, such as self-care, diet modification, oral medications, bladder instillations, physical therapies, surgery and so forth but just as the progress of chemotherapy is measured so should progress with bladder pain therapies. Effective therapies should be continued while ineffective therapies are discarded so that the patient does not struggle with unnecessary side effects and polypharmacy over time.

Most importantly, if a patient is non-responsive to treatment, then the diagnosis should be revisited and, if necessary, additional testing performed.

Followup

In cancer care, the oncologist strictly monitors patient progress. In IC, not so much. Doctors tend to rely on a patient's general sense of satisfaction rather than objective data. Dr. Payne encourages the use of both a symptom survey (i.e. the O'Leary Sant Survey) and a bladder diary to directly and consistently track patient progress. If the patient shows no response to that treatment, it would be discontinued. If symptoms begin to improve, then that medication would be continued or perhaps adjusted until sufficient progress has been made. If symptoms resolve or return to normal, Dr. Payne offered *"the patient has taken a great step toward a cure."* He also reminds us that relapses can occur during times of stress and that the previous treatment plan can be again utilized.

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Looking for a Cure

The majority of the top IC & pelvic pain clinics in the USA, Canada and around the world are knowledgeable and informed about the clear distinctions that Dr. Payne discussed in this article. It is the smaller regional and local clinicians who are likely uninformed about the new research and findings in urologic chronic pelvic pain. There are still some clinicians who identify Hunner's lesions via hydrodistention but provide no treatment for them. Similarly, there are clinicians who are unaware of the growing role of the pelvic floor in bladder symptoms and pain. And, sadly, there are many doctors who are simply discouraging, with statements like "There is no cure" or "You will always be in pain."

Dr. Payne makes an encouraging and compelling case for the future treatment of all "urologic chronic pelvic pain patients." For the patients reading this, take some time to think about your possible phenotype. Have your ulcers been treated? Could they have recurred? Have you begun pelvic floor therapy if your physician found tight muscles? Are you following the diet if you have bladder wall driven discomfort?

Perhaps the most important question for patients to consider is "How are you evaluating your progress with treatments?" Near the end of my first year with IC, I did a 90 day voiding diary that taught me that I actually had some good days even though I thought they were mostly bad. It showed me when I started to respond to some treatments though the change was very subtle. My frequency was the first to respond with a slow but steady improvement from 25 times per day to 22, then 18, then 15 over several months. I could not deny that good things were happening and that played a huge role in my outlook on life. Had I not been doing that diary, I might have stopped the therapy that was actually starting to work for me.

About: Dr. Christopher Payne is one of the best female pelvic pain practitioners on the west coast, if not the world. He practiced at Stanford University for more than two decades before departing

to open a clinic (Vista Urology) dedicated to pelvic pain with his wife Dr.

Jeannette Potts. Learn more at their website: <http://www.vistaurology.com>

Source: Payne C. A New Approach To Urologic Chronic Pelvic Pain Syndromes: Applying Oncologic Principles To 'Benign' Conditions. Current Bladder Dysfunct Rep. Topical Collection on Pelvic Pain. March 2015

Myofascial Pelvic Pain by Rhonda Kotarinos

The bladder, prostate and pelvic pain movement owe a tremendous debt of gratitude to physical therapist Rhonda Kotarinos who, in the early 1990's, was the first physical therapist in the USA to explore the role pelvic floor dysfunction in pelvic pain patients. Her early studies demonstrated that the treatment of painful trigger points in the pelvic floor muscles with myofascial release therapy improved both muscle function and pelvic pain. Twenty two years later, she continues to advocate for the proper assessment and treatment of trigger points and muscle dysfunction in the pelvis.

"Individuals who frequently experience more stress and anxiety have an increased predisposition to develop trigger points, which can lead to myofascial pain syndrome."

—Rhonda Kotarinos

In her latest article "Myofascial Pelvic Pain: Rationale and Treatment", she shares what is known today about trigger points, their potential causes and risk factors

and how they are treated. It's an excellent resource to share with clinicians who may underestimate or ignore the potential role of the pelvic floor musculature in pelvic pain.

Known more commonly as a muscle knot, a "myofascial trigger point is a hyperirritable area within skeletal muscle that is associated with a palpable hypersensitive nodule with a taut bud that when provoked, produces pain," Ms. Kotarinos shared. This extended muscle contraction compresses blood vessels and reduces blood flow to the surrounding tissues. Produced by muscles at work (i.e. in contraction), lactic acid then becomes trapped in the muscle where it provokes a variety of inflammatory mediators.

Common causes include repetitive muscle overuse, muscle overload and repetitive minor muscle trauma. A career with limited access to a rest-room (i.e. teachers, physicians, assembly line workers, drivers, etc) may cause someone to "hold" it for long periods of time by contracting their pelvic floor. Patients who struggle with pain may tighten muscles in a "guarding reflex." Coughing, diarrhea, constipation and even sex could overuse muscles and cause trigger point development. Traumatic events, such as childbirth, pelvic surgery and sexual abuse, can trigger muscle dysfunction. Even minor events, such as riding a bicycle, horseback riding, the use of sexual toys and tampon insertion, could play a role.

Unfortunately, once present, trigger points are easily activated. Ms. Kotarinos shared "Individuals who frequently experience more stress and anxiety have an increased predisposition to develop trigger points, which can lead to myofascial pain syndrome."

Interestingly, nerve studies have shown that these patients may have "an imbalance between the excitatory and inhibitory impulses in the descending system of the corticospinal tract" explaining why emotional stress can increase pain sensation.

Trigger points in the levator ani muscle can refer pain to the vagina, rectum, bladder, uterus or coccyx area. Men with pain at the tip of, or along the shaft of, the penis (and

scrotum) may have trigger points in the urogenital diaphragm while women may have pain at the entrance to the urethra, the labia and perineum.

Trigger points in muscles outside of the pelvis (i.e. the abdominal wall) can also trigger bladder discomfort, including bladder spasm, urinary frequency, retention and incontinence. Women who struggle with pain during their periods may have trigger points in the lower rectus abdominis. Abdominal muscle knots have also been linked to constipation and diarrhea symptoms. Ms. Kotarinos points out that scars can also become trigger points and, in one study, the management of an appendectomy scar increased bladder capacity and relieved frequency and urgency. Trigger points can be a persistent source of localized pain that transitions into a regional pain syndrome and, for some, central sensitization.

Treatment is centered around the treatment and resolution of the trigger point and restoration proper muscle tone in the area. Various medications may also be necessary to address pain such as NSAID's or narcotic medication. Antidepressants and neuroleptic medications may help with chronic pain though have not been found effective for trigger point pain. Muscle relaxants may be somewhat helpful. Single or multiple injections of Botox for myofascial pelvic pain have modest results in research studies. Trigger points can also be aggressively managed with injection or dry needling.

Perhaps the most compelling reason to explore and treat pelvic floor dysfunction are the two clinical trials that found that manual physical therapy had the highest success in resolving symptoms of all therapies tested for urologic chronic pelvic pain (interstitial cystitis, chronic prostatitis). It outperformed all therapies.

About: Rhonda Kotarinos continues to work with men and women struggling with pelvic pain. Kotarinos Physical Therapy is located in Oakbrook Terrace, Illinois. Learn more about her practice at: www.rhondakotarinos.com

Source: Kotarinos R. Myofascial Pelvic Pain: Rationale and Treatment. Current Bladder Dysfunct Rep. Topical Collection on Pelvic Pain. March 2015

In The Beginning, There Were Hunner's Ulcers

About one hundred years ago, Dr. Guy Hunner was the first to look inside the bladder of patients struggling with bladder pain where he found profoundly inflamed, deep lesions in the bladder wall that came to be known as Hunner's ulcers/lesions. For decades, the presence of these lesions were considered the hallmark of "interstitial cystitis" but slowly the definition of "IC" was broadened to include patients with much smaller and non-inflammatory glomerulations on the bladder wall and even patients with a normal bladder wall who struggled with frequency and urgency. IC eventually became an umbrella term for most bladder pain conditions.

The downside of this "one term fits all" approach to bladder pain was in research for new treatments. Most IC researchers today will agree that studies have been less than productive because a wide variety of patients were included. Would a Hunner's lesion or pelvic floor patient respond favorably in a trial for Elmiron, a bladder wall coating? Certainly not consistently.

It was the European IC research community, led by Drs. Fall and Peeker, who boldly suggested a new approach. They ONLY diagnose someone with interstitial cystitis if they have Hunner's lesions. Patients with all the symptoms but without lesions are diagnosed with "Bladder Pain Syndrome (BPS)." Performing a hydrodistention with cystoscopy is now a required diagnostic test for all patients in Europe. Fall and Peeker wrote "The earlier such lesions are identified, the shorter the period the patient has to suffer from excruciating symptoms."

The American IC research and clinical community agreed that Hunner's lesions are found in only about 5% of patients but would they go so far as to diagnose patients without lesions as having bladder pain syndrome instead? Discussions and debates ensued resulting in the designation of Interstitial Cystitis/Bladder Pain Syndrome (IC/BPS) in

the AUA Guidelines. A compelling reason against the change was the cost of requiring a hydrodistention for a diagnosis. Many doubt that American health insurance companies would pay for the test so early in the diagnostic process.

In this most recent article, Fall and Peeker make a compelling case for furthering the divide, suggesting that "Hunner's lesions" represent a completely different disease.

Hunner's lesions are very unique. They generally have a reddened mucosal area with small blood vessels radiating towards a central and quite fragile lesion or scar like area. As the bladder is filled, deep ruptures occur which ooze blood in a "waterfall" effect. This level of bleeding is not seen in the typical bladder pain syndrome patient.

During the hydrodistention, another characteristic sign emerges, edema and swelling at the site of the ulcer which, for the expert urologist, helps identify the areas of intense inflammation. It's important to note that patients without Hunner's often do not show edema.

Patients with Hunner's lesion may have a reduced or worsening bladder capacity showing the long term, destructive effects of inflammation. The authors wrote "classic IC can produce a progressive reduction in anesthetic bladder capacity over time. This is all but unheard of in bladder pain syndrome."

When biopsied, tissue from Hunner's lesions present unique pathological findings including urothelial detachment, vacuolization, perineurial cell infiltrates, neutrophil and eosinophils granulocyte, lymphocytes and plasma cell infiltrates often involving deeper layers of the bladder wall. The authors note that a "unique mast cell response compromising two distinct mast cell populations" is also found in lesion biopsies. Mast cell degranulation is often observed which the authors suggest is the result of "repeated trauma by bladder filling and stretch of the areas of inflammatory involvement." This, too, does not occur in the typical non-Hunner bladder pain patient.

Genetic studies have also found that patients with Hunner lesion

have an up regulation of genes associated with inflammation that were not observed in the non-ulcer patient.

The authors suggest, based upon the lack of pathological distinction, that the bladder might not be the driving force in bladder pain syndrome. This supports growing evidence that pelvic floor dysfunction may be the root cause of the urinary frequency, urgency and pain for many patients.

Ultimately, Fall and Peeker say that the identification or exclusion of Hunner's lesions be the central goal of diagnosis and that their treatment (i.e. fulguration, laser or injection of steroid) be the first line of therapy. Several research studies have demonstrated that treatment of the ulcerated areas that can provide "good to excellent effect in up to 90% of patients."

Magnus and Fall make a compelling case for Hunner's lesions as a separate and distinct entity known as interstitial cystitis. Patients without lesions would fall into a more generic category of bladder pain syndrome or urologic chronic pelvic pain syndrome where they, in conjunction with their medical care providers, must try to discover the origin of their pain (i.e. the bladder wall vs. the pelvic floor).

Source: Fall M, Peeker R. Classic Interstitial Cystitis: Unrelated To BPS Current Bladder Dysfunct Rep. Topical Collection on Pelvic Pain. March 2015

Male Pelvic Pain Syndrome: Escaping the Snare of Prostatocentric Thinking

by Jeanette Potts

For the millions of men who have been diagnosed with chronic prostatitis, been given prescription after prescription with no relief and struggled with urologists who have few answers, Dr. Jeanette Potts not only feels your pain and frustration, she also rages against a machine obsessed with and apparently unwilling to look beyond the prostate. In "Male Pelvic Pain Syndrome: Escaping



Dr. Jeanette Potts

the Snare of Prostatocentric Thinking," she says "We need to understand that men with pelvic or perineal discomfort and lower urinary tract symptoms (LUTS) may have something other than prostatitis. It has been demonstrated over and over again that very few men with these symptoms have a prostatic malady, much less an infection."

In 1993, when the National Institutes of Health created a four point classification system for prostatitis, category three was labelled "non bacterial prostatitis/chronic pelvic pain syndrome" to state that the symptoms could come from outside of the prostate. Yet, despite the clear declaration that bacteria is not present, men with genital, perineal and pelvic pain are often prescribed ineffective antibiotics. Dr. Potts wrote "Tragically, antibiotics are not even prescribed 'empirically, as most patients receiving antibiotic therapy today have never had a positive urinalysis, a positive urine culture, or fever. Such misuse of antibiotics should be an embarrassment to the urological community." She continued "Today, I believe our patients suffer a far greater risk of developing a resistant bacterial infection as a result of the overuse and abuse of antibiotics."

She suggests that the term "chronic prostatitis/chronic pelvic pain syndrome (CP/CPPS)" is not only mis-

leading but perpetuates the perception that it is related to the prostate. She also disagrees with the use of the term "urologic chronic pelvic pain syndrome" because it, too, suggests that the urinary tract is the source of the problem. She believes that a better descriptor is "pelvic floor tension myalgia," because of the consistent muscular dysfunction found in multiple research studies as well as positive results from physical therapy studies.

One key challenge is the lack of interest shown by the American Urological Association in creating basic guidelines for male pelvic pain. Without a set of standards that would correct the names used, as well as diagnostic and treatment guidelines, she believes that men are being victimized by "a biased and irresponsible use of nomenclature... (which) has obstructed progress in research."

About: Dr. Potts has dedicated her career to the treatment of male pelvic pain. If anyone could lead an AUA panel, it would be she and, frankly, it's beyond due. She is a co-founder Vista Urology and Pelvic Pain Partners, located in San Jose, CA. Learn more at their website: <http://www.vistaurology.com>

Source: Potts J. Male Pelvic Pain Syndrome: Escaping the Snare of Prostatocentric Thinking Current Bladder Dysfunct Rep. Topical Collection on Pelvic Pain. March 2015