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		Introduction	Philip Hanno
		Overview of female BPS/ IC and patient story	Peter Dwyer
		BPS ICI 2021 update	Philip Hanno
		Role of Continence physiotherapist	Ali Harding
		Bladder instillations and the continence nurse	Kristina Cvach
		Panel discussion	Philip Hanno Peter Dwyer Ali Harding

Aims of Workshop

Interstitial Cystitis/Bladder Pain Syndrome (IC/BPS) is a challenging condition to treat.

For the majority of patients this involves a stepwise approach. Multidisciplinary care including input from the continence nurse, physiotherapist and clinician allows for flexibility in conservative treatments options. This includes patient education, dietary modification, oral treatments, neuromodulation and pelvic floor muscle targeted treatments as well as bladder specific therapies such as bladder instillations and surgery. This workshop includes the chair of the bladder pain syndrome ICI chapter, Phil Hanno, Professor of Urology and clinicians from Melbourne with a long experience of treating women with IC.

Learning Objectives

History of IC/BPS

Relationship of Hunner Lesion Disease to IC/BPS

Diagnosis and Treatment

role of continence nurse in managing IC/BPS

role of physical therapist in managing IC/BPS

Target Audience

Urology, Urogynaecology and Female & Functional Urology, Conservative Management

Advanced/Basic

Advanced

Suggested Learning before Workshop Attendance

International Consultation on Incontinence 2017 chapter on IC/BPS

Cvach K, Rosamilia A. Transl Androl Urol. 2015 Dec;4(6):629-37. Review of intravesical therapies for bladder pain syndrome/interstitial cystitis.

Overview and clinical features of IC/BPS – Peter Dwyer

Skene in 1887 was the first to describe the condition of IC stating “when the disease has destroyed the mucous membrane partly or wholly and extended to the muscular parieties, we have what is known as interstitial cystitis.” However it was not until 1915 (1) and 1918 publications of Guy Hunner in the Journal of the American Medical Association titled “A rare type of bladder ulcer” was this condition truly described with a description of macroscopic and microscopic bladder pathology, nomenclature and classification, possible aetiology and symptoms, diagnosis and treatment.

This clarity of description was made possible by the use of a primitive cystoscope pioneered by his mentor Howard Kelly at John Hopkins Hospital, which was little more than a cylinder introduced into the bladder with natural light illumination in the knee chest position to distend the bladder with air to allow visualization.

“The crucial test in cystoscopy is the finding of a small abrasion on the mucosa surface which, if not bleeding on discovery, will easily bleed on being touched.” “Occasionally the distention of the bladder by air as the patient assumes the knee-breast posture causes this area to split and a tiny stream of blood flows to the vertex”. “The ulcer is usually found in the vertex or free portion of the bladder.”

The symptoms of IC described by Hunner over 100 years ago still defines the disease today. “The chief symptom associated with this type of ulcer is pain. Associated with this pain, the other symptoms of cystitis occur in varying degree namely frequency day and night, strangury, burning and smarting.”

Chronic pelvic pain (CPP) of moderate to severe intensity of greater than 6 months duration affects 1 in 5 women aged over 20 years. Over half of women with CPP have urinary frequency and urgency. Also women with an overactive bladder have

frequency urgency with or without urge incontinence. In women with IC the chief symptoms are bladder pain and frequency so there is overlap in symptoms between these conditions. Cystoscopy may not be diagnostic in all cases of IC with petechial bleeding present after cystodistension and Hunner's ulcers, but is necessary to exclude others causes including malignancy, calculi, foreign bodies etc.

Medical treatments and surgery for IC have been disappointing with effectiveness frequently little better than placebo. So treatment is multimodal with psychological therapies of counseling, behavioral, physical physiotherapy, neuromodulation, and medication.

Of utmost importance is the patient should be given a clear explanation of the condition and treatments, so they can feel empowered to influence and control the symptoms themselves. A positive attitude of self help and outcome is important as most patients have at least partial resolution over time.

Bonica said in 1990 that "the aetiology of chronic pelvic pain syndrome is unknown, but is a result of a complex, poorly understood, abnormal physiological interaction between noxious stimuli, both visceral and somatic; actual dysfunction with the nervous system itself; and adverse interplay with psychological, family and social relationships and interactions." Still true today.

References.

1. Hunner GL: A Rare Type of Bladder Ulcer in Women; Report of Cases. Boston Med Surg J 172; 660 (1915)

Principles of Management – Philip Hanno

Where possible, decisions on the treatment of interstitial cystitis/bladder pain syndrome (IC/BPS) and Hunner lesion disease (HLD) should be evidence based. Unfortunately, high level evidence of efficacy is lacking for many common treatments, either because such studies have not been done, failed to differentiate patients with HLD from IC/BPS and/or failed to demonstrate efficacy vs placebo.

We should be guided by patient perceived and driven outcomes. Newer symptom scores are based on this principle and the US Food and Drug Administration in the United States is asking pharmaceutical companies to develop more patient reported outcome measurements as a requirement for successful future drug development.

Many patients prefer noninvasive therapies. It would seem reasonable to start with physical therapy and/or oral or intravesical therapies as per patient preference if conservative non-medical fail to result in significant symptom amelioration. Use of surgical therapies should be approached with some caution. Patient education is critical in developing a personalized treatment algorithm that can be modified based on their ongoing quality of life.

Two major constructions may provide the foundation for the basic principles of management. The first is early diagnosis of HLD through local cystoscopy or cystoscopy under sedation with bladder distention. This changes the treatment algorithm and provides an initial surgical option through direct treatment of the lesion that yields generally reliable good clinical results, albeit not permanent.

The second is the natural history of interstitial cystitis/bladder pain syndrome. Up to one half of all patients may exhibit symptom improvement with time, with or without regular follow-up and receiving a new treatment. Symptom duration is associated with more severe symptoms only in limited populations. Symptom duration is not associated with risk for chronic overlapping pain comorbidities or mental health comorbidities. To the extent we can prevent catastrophizing we can expect less long-term pain symptoms.

As no single treatment works well over time for the majority of patients, the treatment approach should be tailored to the specific symptoms of each patient and a multidisciplinary approach may be required.

Time tends to be the ally of the patient and the provider. It does not make sense to throw a wide variety of treatments at the patient immediately upon determining the diagnosis. There is no long-term advantage, and one loses the benefit of the often-salutary natural history of the disorder, prone to symptoms waxing and waning. Follow conservative principles, allay patient anxiety and catastrophizing, and begin a specific intervention, adding to it if necessary or substituting another therapy if it is ineffective.

Treatment strategies should proceed from conservative to less conservative in most patients. Of course, symptom severity, clinician judgment, and patient preference will play key roles in the decision as to where in the algorithm to begin therapy. In the rare instance when an end-stage small, fibrotic bladder has been confirmed and the patient's quality of life suggests a positive risk-benefit ratio for major surgery, reconstructive surgery can be considered early in the algorithm. Pain management should be continually assessed in all patients.

Bladder instillations and the continence nurse - Dr Kristina Cvach

Bladder instillations are an important part of the multimodal therapy used to manage patients with Bladder Pain Syndrome/Interstitial Cystitis (BPS/IC). The American Urological Association places bladder instillations as second line treatment in their treatment algorithm. The advantages of bladder instillations are that the treatment is delivered directly to the bladder, minimising potential side-effects however with instrumentation of the bladder comes the risk of urinary tract infection and a flare in the patient's pain. Whilst the pathogenesis of BPS/IC is not well-understood it is thought that the agents used in bladder instillation therapy may reduce inflammation, provide some analgesic effect, facilitate detrusor relaxation, replenish a possibly defective glycosaminoglycan (GAG) layer or provide some anti-bacterial effect. A number of agents have been studied although much of the published literature is based on studies with small sample sizes, with poor methodology using non-validated outcome measures and not differentiating between those patients with non-Hunner lesions (BPS) and those with Hunner lesions (IC). A number of instillation therapies are outlined.

The Continence Nurse Specialist is a highly-specialised professional with postgraduate qualifications in continence assessment and care. They provide both clinical care and education to patients with BPS/IC. I asked some of my colleagues what they saw was their role in the care of patients with BPS/IC and they identified that their most important role was to validate the patients experience both in terms of the journey they have been on in achieving a diagnosis and the symptoms they were currently experiencing. The one-on-one care provided during the course of bladder instillation therapy, which often occurs over many weeks, allows the development of a trusting relationship between the nurse and patient, helping to alleviate anxiety and providing a direct point of contact with the hospital or clinic if the patient experiences any side-effects of the treatment.

Role of Continence physiotherapist - Ali Harding

Physiotherapy plays an important role in the management and treatment of BPS/IC. This condition commonly presents as part of the overlapping chronic pain conditions. As clinicians, it is our responsibility to have a deeper understanding of the potential underlying mechanisms of BPS and how treatment may be tailored to address these.

Physiotherapy is recommended as a first line management approach in the AUA pathway. It is an accessible and conservative treatment option and will often form part of the multi-modal and multidisciplinary team.

Whilst evidence is limited, a number of small scale studies have shown a relationship between pelvic floor myofascial pain and those with BPS/IC (1,2,3). This provides a basis for pelvic floor dysfunction to be addressed. Furthermore, there is a well recognised relationship between voiding mechanics and pelvic floor function. As our understanding develops, differential phenotyping may further improve our understanding on which patients will benefit more from physiotherapy intervention.

Physiotherapy will involve a thorough assessment, and aim to identify potential underlying neurophysiological mechanisms. It is commonly accepted that both peripherally sensitising factors and more centrally mediated mechanisms may be at play. Physiotherapy provides a unique role for ongoing evaluation to identify these potential factors and address them with specifically targeted therapies.

As well as addressing pelvic floor muscle function, pelvic floor physiotherapy may aim to optimise bladder health, address patient perceptions and beliefs around their condition, and help to explain these potential underlying neurophysiological mechanisms. Conservative neuromodulatory treatment techniques may also be utilised. There are many tools available to us, and treatment choice will depend on patient symptom severity, depth of understanding of their condition, patient preference and appropriate assessment and clinical reasoning to identify the most beneficial treatment for the individual at the time.

Patient centred care is paramount and needs to be provided under the biopsychosocial model. The treating team need to utilise an empathic and informed model of care to strive for the best outcomes in this challenging patient cohort.

1. Petrikovets A, Veizi IE, Hijaz A, Mahajan ST, Daneshgari F, Buffington CAT, McCabe P, Chelimsky T. Comparison of Voiding Dysfunction Phenotypes in Women with Interstitial Cystitis/Bladder Pain and Myofascial Pelvic Pain: Results from the ICEPAC Trial. *Urology*. 2019 Apr;126:54-58. doi: 10.1016/j.urology.2019.01.015. Epub 2019 Jan 22. PMID: 30682465; PMCID: PMC6443427.
2. Weiss JM. Pelvic floor myofascial trigger points: manual therapy for interstitial cystitis and the urgency-frequency syndrome. *J Urol*. 2001 Dec;166(6):2226-31. doi: 10.1016/s0022-5347(05)65539-5. PMID: 11696740.
3. Peters KM, Carrico DJ, Kalinowski SE, Ibrahim IA, Diokno AC. Prevalence of pelvic floor dysfunction in patients with interstitial cystitis. *Urology*. 2007 Jul;70(1):16-8. doi: 10.1016/j.urology.2007.02.067. PMID: 17656199.