GLOBAL INTERSTITIAL CYSTITIS, BLADDER PAIN SOCIETY

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GIBS News Letter

Supplement

PILLAR TO POST.... Multiple Clinicians; BEFORE ... A correct DIAGNOSIS... A successful TREATMENT - TIME FOR AN UPDATE

For quite some time now, I have been constantly struggling to find the right title for this newsletter. Continuous brainstorming, more than 15 times of video reviews and reading through different articles did not help me to find a suitable title. And finally, this morning when I was reading through an article on the diagnostic tools for Interstitial Cystitis/ Bladder pain Syndrome, the suitable title hit my imaginations and, I started writing the newsletter.

Dr. Roger R. Dmochowski, Professor Urology, Gynecology and Surgery at Vanderbelt University, Nashville, USA, in his talk during the Global Interstitial Cystitis Bladder Pain Society (GIBS), 2021 meeting have focused on the latest updates in the field of IC/BPS diagnosis, treatment modality, symptoms and many more other important aspects with many more insightful thoughts on IC/BPS. He shared his views on the same, as well as pointing out the dos and don'ts during the conditions of suffering IC/BPS and updated the delegates about where we stand with IC/BPS in the current time frame. Dr. Roger emphasized on the work done by him and Dr. Lindsay Mccarron together as a team for a wonderful ground breaking work in IC/BPS.

As per Dr. Roger, it is still a challenge to understand the diagnosis of IC/BPS, the cause of the condition and, the evaluation of the best management or treatment modality. It is very challenging especially if the patient has fixed pain syndrome. There has been a continuous evolution in the definition of the condition. As per the early data findings from 1990's which were cited by the NIDDK were too restrictive and considered too many exclusion criteria, however the International Continence Society (ICS) tagged it as Painful Bladder

Syndrome (with a focus on the pain condition as the prime criteria) a condition involving suprapubic pain with bladder filling which is considered to be improved by bladder emptying, Urinary symptoms includes urinary frequency and urgency with nocturia which is considered to occur in the absence of an identifiable pathology. It is known that many of the urologic conditions there are overlapping syndromes and conditions that contribute painful bladder syndrome or interstitial cystitis.

One of such condition is Overactive Bladder dry which is a very much common condition, however pelvic pain without urinary dysfunction associated with conditions such as endometriosis or fibromyalgia are also few amongst such overlapping conditions and then IC/BPS which obviously has been known to overlap with the Overactive Bladder Dry Syndrome, and Pelvic pain with no LUTS as well. Such overlapping conditions confuse the diagnosis and misdiagnosis occurs.

Coming to the definition of diagnosis of IC/BPS, the term Painful Bladder Syndrome was considered to be much more directive to the condition. It is predominantly a condition impacting the female population who are in the middle decades of their age. Now a days there has been increasing recognition in childhood voiding dysfunction contribution to the lower urinary tract symptoms. There isa persistence with some of these symptoms into adulthood and therefore, many patients are actually transitional urology patients who had experienced some of the symptoms and continue to experience the same in their adulthood too. It is known that occasional pain syndrome generally occurs after pelvic surgery, especially hysterectomy. It is also known, that with some patients there is a very strong historical relationship with urinary tract infection and many of these patients have constellation of other morphologic conditions such as migraine headache, fibromyalgia and irritable bowel syndrome. Some patients with painful bladder syndrome also exhibit onset of certain things such as reflex sympathetic dystrophy. Around 30% concordance between all of the other syndromes being present and painful bladder syndrome is being noticed. A significant short-term variability is being noted when the natural history of the condition is being evaluated. For many patients the long-term course is best defined in terms that we use for multiple sclerosis, relapsing, remitting. It is known that exacerbations and certain external irritants certainly contribute to the occurrence of the syndrome including history of urinary tract infection or current urinary tract infections, food ingestions, stress a significant contributor to the cause of this syndrome along with menstrual association was also noticed to be a prominent contributor in some of the young women. Dr. Roger considered it to be important to focus upon the goal of the evaluation and as per him the goal has to be reasonable. He feels, in terms of the relationship of the symptoms to the lower urinary tract symptoms. It is important to exclude the excludable conditions such as neurogenic disease, other functional disorders as there are fair chance of clouding the diagnosis. He also mentioned the navailability of definitive diagnosis and many urologists make suppositions based upon confluence of symptoms that constitute the IC/BPS. Hence, definitive diagnosis is a challenge as there is a lack of either an objective criterion that helps in specific diagnosis and generally it is the elements from multiple areas that is being used to make the final diagnosis. Dr. Roger also suggested a large group of differential diagnosis. Carcinoma in situ, is one such condition, which is although a very problematic issue and is very unusual in IC/BPS population. However, it must be considered especially when there is hematuria. There are patients with reflex neurogenic disease from multiple sclerosis that predominantly affect the pelvic organ. Also, prior toxin exposure is one more criterion that must be considered as, most of the reported IC/BPS cases exhibited an associated condition of radiation-induced cystitis from prior treatment of a gynecologic malignancy. Variety of other conditions such as anatomic lesion too must be considered, i.e. urethral diverticulum which are associated with painful voiding and voiding dysfunction capable to mimic IC/BPS.

A clear history – A crucial challenge... What is to be done as a part of Evaluation???

Solutions may be found from a critical history with all the information including the comorbidities and co-presenting conditions, which requires a confluent management with a multi-disciplinary evaluation. Focused physical examination of the Pelvic floor and pelvic region in case of women to determine the reproducibility of pain and palpation of the pelvic musculature, digital rectal examination in cases of male is a must, urinalysis and urine culture must be viewed along with all the guideline documents as being the other critical elements for the absolute components of the diagnostic schema. It is important that the individual knows his condition cannot be cured but care

givers are attempting to improve and ameliorate the condition with various interventions and modulations.

Other measures to be taken...

Symptom indices such as visual analogue scores, are heavily relied upon as it is an important aspect to determine the baseline of the gravity of the symptoms and helpful in the assessment of the progression of the symptoms. The next that may be focused upon is the voiding logs to establish baseline impact in cases where the individuals have significant voiding dysfunction. A way has been found from the primary use of cystoscopy and urodynamics, although there are conditions and circumstances where both of these techniques are applied. Many times, cystoscopy is reserved for the time of anesthetic hydrodistension to help determine morphologic issues in the bladder as well. Symptom scores are not specific, as they do allow quantification of baseline evaluation but also post-therapeutic baseline evaluation. The voiding diary is utilized as a time volume chart. Different arguments on the length of the diary are being noticed, to which the solution was 1-day voiding diary is considered to be the absolute minimum as the patient concordance with 3-day voiding diary was found to be difficult. During this, conditions of polyuria was important to be excluded. The voiding diary maintenance is a method for functional voiding assistance.

How about the role of Cystoscopy and Hydrodistension???

It has been clearly mentioned by Dr. Roger, that these are not the diagnostic tools, but definitely capable to impart therapeutic benefit also helps in occasional visualization of some malicious lesions and some ulcer dependent diseases. As per Dr. Roger, if a hunner ulcer is diagnosed using cystoscopy and hydrodistension, then he may render some benefit by focal therapy to those ulcerogenic lesions by focusing his therapy precisely on those lesions. Though a cystoscopy reveals glomerulations, however glomerulations are not specific to IC/BPS and may be seen associated with other conditions after cystoscopy. Also, cystoscopy revealing hunner positive conditions is a sub-component of IC/BPS. Only about 10 – 20% of the patient demonstrate the hunner ulcers during the course of IC/BPS condition.

There are caveats with cystoscopy and hydrodistension. Anesthetic hydrodistension gives an idea of the daily functional reserve, DE functionalization and helps in recognition of a cadre of elderly women, who possess very small bladder capacity. Such patients often benefited from urinary diversion. The appearance of hunner's ulcer on cystoscopy allows directive local therapy with thermo-therapeutic intervention. Dr. Roger recommends electrocautery may be used in such conditions, however some use laser therapy.

Role of Biopsy in IC/BPS

Biopsy is not recommended in this condition due to poor pathologic correlation with IC/BPS. Also, it is from the evidence of biopsy of some individuals that they have an ischemic or a noxic component to thebladder much as observed in patients with myocardial disease and there has been an increasing role of the potential for hypoxia especially in certain sub-groups including the individuals with bladder DE

functionalization with markedly small bladders in the elderly group. It has been thought that may be predominantly or significantly driven by vascular insufficiency at the time of evaluation of the condition.

Different Treatment and Management Modality Ulcers are generally seen in older patients and are a different path of physiology, associated with bladder capacity impact and exhibits increased inflammation on biopsy which is benefited by thermotherapy.

A long-term therapy for the condition must have a flexible algorithm, with individualized treatment modality, unique approach for each individual due to unique presentation of each individual in their condition and the excellent assessment of the patient's symptoms must be performed as the most bothersome concern are critical to underscore a reasonable ongoing treatment algorithm. It has been also seen that the evidence basis for the treatment is improving, however still lacks when level one evidence and the paucity of that is considered.

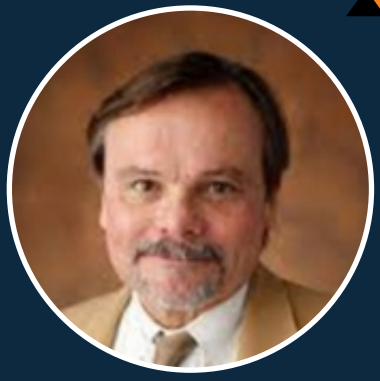
It has been noted that there's no single unified approach but a simple therapeutic regimen to be followed. There are basic principles of the therapy that should be considered. Sequential therapy is often needed in the condition and combination therapy as a corner stone may be utilized. Other therapies include pharmacotherapy, behavioral therapy, cognitive therapy is also important. In conditions of flare, therapy must be planned for directed therapy to improve flare related symptoms. It must also be understood that there is a high degree of emotional overlay with this condition. Often anger and hostility is observed towards the care provider due to the chronicity of the condition and perceived lack of motivation from the patient's end due to prior negative experience from the health care and lack of interest or lack of concern regarding the severity of the condition towards

the patient's syndrome. Also, it is very important to be cognizant of stress exacerbations as management of stress in conditions of IC/BPS is extremely critical in such individuals. The availability of in-clinic supports such as nurse practitioners, physiotherapists who work and interact with patients and such individuals, and behavioral psychologists, play a vital role to help such stressful situations of individuals suffering from the syndrome. Such methods of management are aimed at providing a holistic multidisciplinary approach by providing mental support, physiotherapeutic evaluation, rheumatology in conditions of fibromyalgia, pain management, gynecologic consultation, urologic consultation and gastrointestinal consultation.

Cognitive behavioral intervention is too a very crucial for the management of behavioral aspect of patients suffering from IC/BPS and is very much supported by Dr. Mccarron. Functional disorders are driven by patient's responsiveness and cognitive behavioral intervention was found to be the single aspect that benefit patients with this syndrome to the maximum. Conservative therapy includes restriction of accelerants of symptomatology, following a restricted diet is crucial, bladder retraining and adjunctive therapies are few more such as stress reduction and physical exercise. Dietary considerations must be individualized, as there may be unique irritants for unique individuals.

Complementary therapy has these days become a more focused area of interest in the management of IC/BPS. Mucosal rehabilitants such as chondroitin and glucosamine have gained substantial interest, however sufficient data is unavailable on this. Data regarding Hyaluronic acid is found to be building of its potential benefits in a small number of patients with IC/BPS. Asper Dr. Roger, once the invasive therapies are being considered, hydrodistension may be repeated once on an annual basis, multimodal oral therapy, multimodal intravesical therapy and finally salvage therapy are inclusive of very rare palliative diversion. The development of alternative pharmacotherapies is also noted in the current trend of treatment and management modality. Neuromodulation has gained some importance as it is found to benefit some individuals suffering with the syndrome. Bladder replacement must be rarely considered. There are a variety of immunologic investigational therapies, but one thing is not to be forgotten that those are immunologic investigational therapies with no assured findings as yet. Latest data findings have also focused on Leukotriene Receptor Blockade therapy, Gabapentin has also shown some of the benefits in the conditions of IC/BPS, Systemic steroids have also been reported with some benefits in some individuals, Cyclosporine A remains a consideration for the condition and is also being reported with some benefits and exists in guideline recommendations. Finally sacral nerve stimulation, which is not yet approved for painful bladder syndrome, however may help individuals with urgency, frequency and improve patient quality of life. Sacral nerve stimulation will not help to resolve conditions of pain though, but has been reported to exhibit benefits in individuals and some percutaneous trials.

Hence a lot of effort for improvement in the systematic delivery of intervention has been noticed. With surgical intervention, bladder replacement or augmentation therapy is highly not recommended in the population with this syndrome, as recurrent conditions are developed in the remnant bladder. Hence, with treatment and management modality the future seems to be bright and with lots of developmental hopes associated with treatment and management of painful bladder syndrome.



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The Blog is written by Dr. Sapna Biswas [Scientific Writer - GIBS] while it was presented by me at GIBS 2021 6th Annual Conference on IC/BPS.

- Prof. Dr. Roger Dmochowski

GLOBAL INTERSTITIAL CYSTITIS, BLADDER PAIN SOCIETY

EDUCATE, IDENTIFY, TREAT

Fighting the Fire in Bladder

GIBS 2022

7th Annual Congress on IC/BPS

27th & 28th August 2022

'Save a Bladder - Save a Family'

It is immense pleasure to state that GIBS 2022 is a grand success through offline & online with its "Theme: Save a Bladder - Save a Family"

The aim of the GIBS is to disseminate the knowledge of IC to spread awareness about the science behind it. A short video on GIBS milestones was discussed. All these years, it took us great hard work and dedication to reach the place where we are today. As it is rightly said, "Nothing comes easy; it takes dedication and hard work".

This year's meeting received over 350 zoom registrations from all over the globe, making it as 281 participants on Day 1 and 286 participants on Day 2.

And we had 120 plus participants for physical conference, involving our Foreign Delegates from Bangladesh, Russia, Hungary, & Nepal.

The journey has taken a tremendous peak! GIBS is determined to disseminate the evolving science of IC/BPS in all the seven continents, hopefully by the end of next year, in order to reach out to all those patients suffering from this disease and their physicians.

The planning for the further GIBS events & the 8th GIBS (2023) Annual congress has already started coining the Theme: Compassion and Care for Bladder Flare which will be held on 26th & 27th August 2023

Information about the other details would follow through emails, as the program evolves through the various planning stages.

Looking forward to another exciting year full of educational activities on the subject of IC/ BPS.

Announcing

GIBS 2023

8th Annual Congress on IC/BPS

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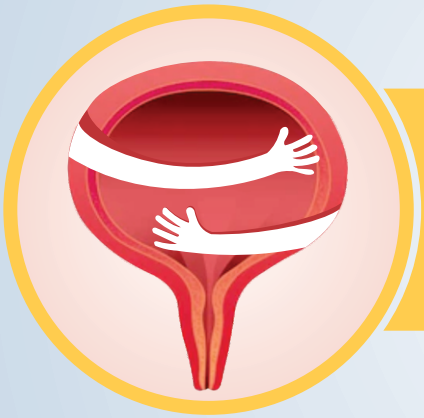
26th & 27th August 2023



Compassion & Care For Bladder Flare

SCIENTIFIC BONANZA

from GLOBAL HORIZON

Will be back with more info soon

For more information kindly visit : www.gibsociety.com

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