

W11: Holistic Approach by Bio-Psycho-Social model to Patients with Interstitial Cystitis / Bladder Pain Syndrome

Workshop Chair: Ming-Huei Lee, Taiwan
13 September 2016 13:30 - 16:30

Start	End	Topic	Speakers
13:30	13:40	The value of holistic care for IC/HSB/BPS	Teng-Lung Lin
13:40	14:00	Biologic Approach-Possible phenotypes in IC/HSB/BPS and overlapping pain condition	Christopher Payne
14:00	14:20	Biologic Approach- The differences between Hunner and Non-Hunner types	Yukio Homma
14:20	14:40	Psychologic Approach-IC/HSB/BPS as a Medically Unexplained Syndrome: An Examination of the Role of Childhood Interpersonal Adversity	Chui-De Chiu
14:40	15:00	Social Approach- The E-health system care of patients with IC/HSB/BPS	Ming-Huei Lee
15:00	15:30	Break	None
15:30	15:35	Interactive Patient / Physician Forum: Gap between patient's preference and physician's judgement	Ming-Huei Lee
15:35	15:50	From Japan's perspective (IC Representative: Japan IC group)	Yukio Homma
15:50	16:05	From Western's perspective (IC Representative: Jane Meijlink)	Christopher Payne
16:05	16:20	From Taiwan's perspective (IC Representative: Taiwan IC Association (TICA))	Chui-De Chiu Ming-Huei Lee Teng-Lung Lin
16:20	16:30	Discussion and close remark	All

Aims of course/workshop

The purpose of this workshop is to emphasise holistic care and importance of quality of life for IC patients using bio-psycho-social model because of no curative treatment until now. In biological aspect, we focus on phenotyping about comorbid syndrome and ulcer. In psychological aspect, we recognise the assessment of somatic symptoms. In social practice, we understand the patient group support and introduce E-health system supporting health education and providing for patient self-management. Interactive forum highlight the gap between patient's preference and physician's judgement. We invite IC patients and experts from different country to have a discussion with attenders.

Learning Objectives

After this workshop participants should be able to:

1. Explain nature of possible phenotype classification including comorbid disease and ulcer
2. Recognize the psychological aspect of how to assess the childhood interpersonal adversity
3. Establish the social support from patient group and practice of self-management by using E-health system (internet & mobile)

Learning Outcomes

The IC/BPS caregivers can understand the necessity of multidisciplinary approach with bio-psycho-social model to the management of the elusive disorder

Target Audience

All members (General Practitioners, Urologists, Gynaecologists, Urogynaecologists, Nurses, Psychologists) involved with the practical care aspects of patients with interstitial cystitis

Advanced/Basic

Basic

Conditions for learning

Interactive

Suggested Learning before workshop attendance

Understand the patient's view of this disease (From each patient associations)

European: <http://www.painful-bladder.org/>

Taiwan IC Association: <http://www.twica.org.tw/ContentAspx/index.aspx>

Japan IC Association: <http://sicj.umin.jp/>

Suggested Reading

Ming-Huei Lee

1. Lee MH, Wu HC, Lin JY, Tan TH, Chan PC, Chen YF: Development and evaluation of an E-health system to care for patients with bladder pain syndrome/interstitial cystitis. *Int J Urol*. 2014 Apr;21 Suppl 1:62-8
2. I Hallberg, A Ranerup and K Kjellgren: Supporting the self-management of hypertension: Patients' experiences of using a mobile phone-based system. *Journal of Human Hypertension*. 2015 doi:10.1038/jhh.2015.37

Teng-Lung Lin

1. Fan YH, Lin AT, Lu SH, Chuang YC, Chen KK: Non-bladder conditions in female Taiwanese patients with interstitial cystitis/hypersensitive bladder syndrome. *Int J Urol*. 2014 Aug;21(8):805-9
2. Fan YH, Lin AT, Wu HM, Hong CJ, Chen KK: Psychological profile of Taiwanese interstitial cystitis patients. *Int J Urol*. 2008 May;15(5):416-8

Christopher Payne

1. Elliott CS, Payne CK: Interstitial cystitis and the overlap with overactive bladder. *Curr Urol Rep*. 2012 Oct;13(5):319-26
2. Potts JM, Payne CK: Urologic chronic pelvic pain. *Pain*. 2012 Apr;153(4):755-8

Yukio Homma

1. Homma Y, Ueda T, Tomoe H, Lin AT, Kuo HC, Lee MH, Oh SJ, Kim JC, Lee KS. Clinical guidelines for interstitial cystitis and hypersensitive bladder updated in 2015. *Int J Urol*. 2016 May 24. doi: 10.1111/iju.13118.
2. Maeda D, Akiyama Y, Morikawa T, Kunita A, Ota Y, Katoh H, Niimi A, Nomiya A, Ishikawa S, Goto A, Igawa Y, Fukayama M, Homma Y. Hunner-Type (Classic) Interstitial Cystitis: A Distinct Inflammatory Disorder Characterized by Pancystitis, with Frequent Expansion of Clonal B-Cells and Epithelial Denudation. *PLoS One*. 2015 Nov 20;10(11):e0143316

Chui-De Chiu

1. Henningsen P, Zipfel S, Herzog W: Management of functional somatic syndromes. *Lancet*. 2007 Mar 17;369(9565):946-55
2. Wright LJ, Noonan C, Ahumada S, Rodríguez MA, Buchwald D, Afari N: Psychological distress in twins with urological symptoms. *Gen Hosp Psychiatry*. 2010 May-Jun;32(3):262-7

Jane Meijlink

1. Meijlink JM. Interstitial Cystitis/Bladder Pain Syndrome: An Overview of Diagnosis and Treatment. 2016. Available online at http://www.painful-bladder.org/pdf/Diagnosis&Treatment_IPBF.pdf
2. Meijlink JM. A Patient Perspective. Chapter 28. In: *Bladder Pain Syndrome, A Guide for Clinicians*. Jørgen Nordling, Jean-Jacques Wyndaele, Joop P van de Merwe, Pierre Bouchelouche, Mauro Cervigni, Magnus Fall (Editors.) Springer 2013.p 355-363.

Ming-Huei Lee

Interstitial cystitis/Bladder Pain Syndrome (IC/BPS) is a benign, chronic syndrome highly degrading the quality of life of patients. Due to the multifocal etiologies, nature histories poor described, wax and wane picture of the disease, comorbidities, unpredictable treatment outcome, and no single therapy has found to be effective in managing the disease for most patients at present. The ultimate goal of caring the patients is taking patients quality of life. The goal could be achieved by bio- aspect approach such as bladder condition, comorbidities management, by psycho- approach such as depression, anxiety management, and by social- approach such as patients support group Taiwan interstitial Cystitis Association (TICA), and E- health system.

The activity of patients supporting group have three main goals:

- Educational Goal : Through the aid of doctors and nurse, we would like to provide workshops about medicine and nursing care. We would also like to offer correct knowledge about IC prevention, self-caring, and treatment.
- Supportive Goal : Through the help of TICA, we would like to help IC patients and their family relaxes and adjusts to their lives, especially in the aspect of different types of pressure such as psychology, emotion, family, and social environment.
- Self-help Goal : We integrate experience sharing and emotional assistance to engage patients in mutual concern and encouragement. Finally, IC patients can establish positive perspective of life and can be more able to solve relevant problems

The E-health system based on textual education was developed for effectively changing the lifestyles of patients and managing patient diseases. The video-based m-health system with content of health education and consultation of emergent outbreak presented by the physician to alleviate the symptoms of patients and to improve their quality of life will be discussed. The better effectiveness of video-based intervention suggests that patient's trust in physician or better physician-patient relationship can improve O'Leary symptoms and problems scales, VAS urgency score. Moreover, the higher QOL improvement manifested in 5 SF-36 constructs (physical function, role physical, body pain, general health, vitality, social function and role emotion) was observed.

The BPS model, moving beyond physical aspects and providing tools for reflection the quality and management of the IC/BPS patients, would have more benefits and efficiency than biomedical model that we familiar with and in general practice at present

time. BPS, though more complexity and time consuming, should be a more humanistic and individualized approach to IC/BPS patients.

Take home message

The text-based and video-based intervention is effective in improving the QOL and alleviation disease symptoms for IC/BPS patients. The patients supporting group reinforce the patient compliance in performing the social aspect of IC/BPS care.

Teng-Lung Alex Lin

Patients with Interstitial Cystitis / Bladder Pain Syndrome (IC/BPS) comprise a diverse heterogeneous group with various different clinical phenotypes. These several phenotypes were divided into two main parts, one is the overlapping and/or confusable disease, which we call "comorbidity", and the other is Hunner / Non-Hunner lesion.

There are several comorbid diseases, which we do not understand as the cause, effect, or reciprocal causation, related to IC/BPS in recent studies, including functional somatic syndrome (fibromyalgia, irritable bowel syndrome, chronic fatigue syndrome, and migraine), psychological problem (depression, anxiety, emotional catastrophizing, personality, and childhood interpersonal adversity), pelvic floor dysfunction (hypertonic pelvic floor, dyspareunia, and muscle spasm), and confusable disease (overactive bladder, endometriosis, and autoimmune disease).

The other main phenotype is Hunner / Non-Hunner lesion. IC/BPS patients with Hunner's lesion seem older and more severe urological symptoms than without Hunner's lesion. There are also increased inflammatory processes in patients with Hunner's lesion. In the aspect of non-bladder syndrome, there is the similar prevalence of comorbid diseases between patients with and without Hunner's lesion. Moreover, central sensitization could be found in some IC/BPS patients due to chronic pain and/or relationship to autonomic dysfunction.

So it's difficult to manage IC/BPS patients with traditional approach. AUA guideline also suggested that multimodal and multidisciplinary approach is available for treatment of patients with IC/BPS. Holistic approach by Bio-Psycho-Social model to patients with IC/BPS is recommended.

In biological approach, we could identify IC/BPS patients if there is Hunner's lesion and / or functional somatic syndrome. Moreover, some overlapping confusable disease (ex. Overactive bladder, endometriosis, and autoimmune) could be considered to identify and treat. In psychological approach, we could exam the mood status and the role of childhood interpersonal adversity. In social aspect, good patient-physician communication and supportive group are important in improvement of quality of life because flare-up / remission and chronicity are the characteristics of IC/BPS.

Take-home message

IC/BPS care providers should understand the value and importance of holistic care by bio-psycho-social model in IC/BPS patients.

Christopher Payne

In recent clinical trials, treatment of IC/BPS has been generally unsatisfactory. Cyclosporine A had a low success rate for patients without Hunner lesions. Moreover, intravesical therapies almost were of poor-quality (level evidence 4 and 5). A minority of patients with IC/BPS have evidence of bladder pathology, such as Hunner's lesion with decrease bladder capacity during cystoscopic hydrodistension under general anesthesia. However, the majority of IC/BPS patients have little or no inflammation in bladder biopsy. Recent study revealed that gene expression in bladder tissue from patients with IC/BPS who had normal bladder capacity (Mostly without hunner's lesion) do not significantly differ from that in healthy participants.

Treatments focused mainly on bladder-centric, especially IC/BPS patients without Hunner's lesion, seem to have poor response. It's appropriate to consider that IC/BPS without Hunner's lesion as a complex phenotype of neuromuscular-psychosocial disorder. IC/BPS patients reported express of the overlapping functional somatic syndrome including fibromyalgia, irritable bowel syndrome, chronic fatigue syndrome, chronic headache, and allergies. Moreover, a twin study demonstrated that 127 patients with chronic fatigue syndrome showed significantly higher prevalence of other functional somatic syndrome including IC/BPS compared to nonfatigued co-twin. Treatment of IC/BPS with functional somatic syndrome should be emphasized on recovering social function, such as ability to work, exercise, or sexual function rather than attempts to cure the all symptoms.

Take-home message

A multidisciplinary approach focused on individualized therapy for IC/BPS patients with functional somatic syndrome are warranted to improve quality of life.

Yukio Homma

We are here, because we are all engaged in interstitial cystitis (IC) and IC-like conditions (IC&ICLC). The patients are embarrassed by pain in the bladder and frequent urination, and medical care providers are overwhelmed by the complaints by frustrated patients. We may take approach to IC&ICLC in either way, symptomatic/ pain-centric or biologic/ bladder-centric, although both approaches should come together in practice.

When you follow the symptomatic/ pain-centric approach, IC&ICLC is a pain syndrome. This approach appears to be patient-oriented, but may fail to reach the realistic resolution. Biologic/ bladder-centric approach should focus on the pathology of the urinary bladder, which we presume hurts. In this regard, IC&ICLC should be classified into three categories; 1) Hunner type IC (ulcer type IC) with Hunner lesions, 2) non-Hunner type IC (non-ulcer type IC) with mucosal bleeding after distension (MBAD) in the absence of Hunner lesions, or 3) hypersensitive bladder (HSB) without the bladder pathologies mentioned above. MBAD is an obvious abnormal endoscopic abnormality reflecting some bladder pathology, although its convincing evidence for phenotyping of IC is lacking.

We have been working with bladder specimens of IC&ICLC patients after differentiating these three classes. Our study using DNA microarray analysis and quantitative real-time polymerase chain reaction revealed over expression of genes related to immune and inflammatory responses, including T-helper type 1 related chemokines, and cytokines such as CXCR3 binding chemokines and TNFSF14 in Hunner type IC. Another study showed increased expression of the genes involved in pronociceptive inflammatory reactions in Hunner type IC including TRPV1, 2 and 4, ASIC1, NGF and CXCL9, and TRPM2. On the pathology slides, we observed wide-spread epithelial denudation, and substantial plasmacytic infiltration expansion with light-chain-restricted B-cells in Hunner type IC. These changes were not found in non-Hunner type IC, HSB, or control subjects. Thus we postulate that Hunner type IC is a kind of pancystitis associated with hyperactive nociceptive sensation and strong inflammatory reactions. The inflammation may be initiated and/or exaggerated by clonal B-cell expansion producing antibody to specific antigen. We have found distinct biological abnormality in the bladder of non-Hunner type IC that is not detected in Hunner type IC (under investigation), while could not detect any biological abnormalities in HSB so far.

We should not regard IC&ICLC patients as a single entity because of similar symptomatology but treat them differently. The guidelines of interstitial cystitis and hypersensitive bladder follow this concept by proposing a concept "hypersensitive bladder" to refer to a bladder condition with hypersensitive bladder symptoms (discomfort, pressure or pain in the bladder usually associated with urinary frequency and nocturia) and no obvious pathology.

Take-home message

We should take bladder-centric approach and treat patients differently based on three categories; 1) Hunner type IC with Hunner lesions, 2) non-Hunner type IC with mucosal bleeding after distension (MBAD) in the absence of Hunner lesions, or 3) hypersensitive bladder (HSB) in the absence of Hunner lesion or MBAD.

Chui-De Chiu

Several psychosocial deficits have been reported for women with IC/BPS. Recent study identified mental disorders such as depression or panic disorder, in 23% of IC/BPS cases compared to 3% of female controls. Patients with IC/BPS reported higher use of medications for anxiety, depression, or stress compared to healthy participants.

Moreover, IC/BPS patients reported higher prevalence of overlapping comorbid diseases regard as functional somatic syndrome, ex fibromyalgia, irritable bowel syndrome, and chronic fatigue syndrome. Some studies regarded IC/BPS with comorbid disease as one of functional somatic syndrome. There are several predisposing, precipitating, and maintaining factors for functional somatic syndrome. In terms of predisposing factors, no clear pattern of genetic influences has been identified, nevertheless there is a genetic survey which revealed that panic disorder with bladder symptoms may be genetically different from panic disorder without bladder symptom.

Childhood experience of organically unexplained symptoms, which are not restricted to sexual or emotional abuse, parental ill health, and increased parental illness behaviour for bodily symptoms in the child increase the risk of functional somatic syndrome later in life. Personality factors, such as cognitive styles, might affect the maladaptive illness behaviour in functional somatic syndrome.

When IC/BPS patients have experience of bodily stress, they interpreted as symptom of disease and finally have experience of anxiety and depression. When the disease is chronicity and flare-up, emotional distress may happen with loss of functioning. The management of IC/BPS using by multidisciplinary treatments need to focus on organ-oriented approach, cognitive interpersonal approach, and primary physician. In organ-oriented approach, we need to focus on dysfunction of bladder and restoration of organ function. In cognitive interpersonal approach, interventions aimed at sensations, cognitions, affects, behaviours, and restoration of overall functioning were needed. In physician aspect, we need to focus on early recognition, patient-physician communication skill, and avoidance of iatrogenic harm.

Take-home message

The management of IC/BPS using by multidisciplinary treatments need to focus on organ-oriented approach, cognitive interpersonal approach, and primary physician.

Additional Resources

The voice from patient's representative from each organizations

Jane Meijlink, the chairman of International Painful Bladder Foundation

"We have all met, at one time or another, patients who suffer chronically from their bladder; and we mean the ones who are distressed, not only periodically but constantly, having to urinate often, at all moments of the day and of the night, and suffering pains every time they void. We all know how these miserable patients are unhappy, and how those distressing bladder symptoms get finally to influence their general state of health, physically at first, and mentally after a while." From Bourque JP. Surgical management of the painful bladder. J Urol. 1951; 65:25-34.

Chronic, persistent or recurrent pain, discomfort, pressure or fullness in the bladder, together with urgency and frequency, can cause not only physical disability, but also depression, anxiety, sleep disturbances and above all a sense of helplessness. It can transform a normal, cheerful person into a depressed, anxious recluse who is tired all the time, unable to cope and who feels stigmatised by having this embarrassing bladder disease. The impact on the patient, and particularly the psycho-emotional impact, is often greatly underestimated and misunderstood.

This situation may be exacerbated by the fact that some patients may have spent years going from doctor to doctor, trying to get a diagnosis, and may have been repeatedly told that nothing can be found, that it is all in the mind. This means that patients who have been through a long period of no diagnosis are very fragile and need a great deal of support and understanding. These patients are now constantly afraid of rejection by any health professional and feel that nobody believes them.

IC is not simply pain, pressure or discomfort: it is also a frequent need to void day and night and often an urgent need to void. This means that patients are constantly looking for toilets, plan all outings around available toilets, and if they think that there is a risk of not finding a toilet when they urgently need it, they stay at home. And there are plenty of patients who scarcely leave their home because of this and consequently become very isolated.

Every patient is different. Some patients have severe pain, other simply unpleasant discomfort. Frequency, day and night, varies hugely from one patient to another and from one day to another in the same patient. Urgency in IC patients is a compelling and overwhelming need to urinate due to pain or other unpleasant sensation in the bladder reaching an intolerable level. All the symptoms can greatly increase during so-called flares.

An important impact of IC is the effect on sexual relationships for both male and female patients, leading to marital dysfunction and distress. The health professional needs to find ways of broaching this subject since the patient may feel too embarrassed to do so.

Multiple comorbidities may add to the burden on the patient, who may be suffering from several different pain syndromes, severe chronic fatigue – mental, physical, hypersensitivities or allergies including multiple chemical and drug intolerance, fibromyalgia or systemic autoimmune diseases such as Sjögren's syndrome, Lupus or rheumatoid arthritis. This means that a multidisciplinary approach is essential, but urologists themselves need to be aware of signs and symptoms that may indicate the presence of comorbidities and the need for referral.

Emotional support and empathy as well as practical support are needed from all players: the family doctor, the specialist, the physiotherapist, the patient's family and partner and the support group.

Taiwan IC Association (TICA):

"The Long and Winding Road—A Self-Reflection of an IC Patient in Taiwan". I would like to use the lyrics of the Beatles' song "The Long and Winding Road" to describe my journey as an IC/BPS patient in Taiwan. Just like the lyrics, IC/BPS symptoms usually lead travellers back to where they began their journey. When IC/BPS patients start feeling better and think that they have made some progress, they are suddenly back where they started without having learned much. While IC/BPS patients are constantly struggling with different symptoms because of relapses, meaningful dialogue between patients and other people has never stopped. Through dialogue, IC/BPS patients can have valuable reflections as they are led to different doors during the entire process.

The first dialogue occurred during my interactions with various clinicians—it started in 1991 when I was a college sophomore. However, the things that I got were the waste of time on transportation, waiting for medical treatment under uneven medical service, or just the diagnosis "psychological overreaction." My impression of IC/BPS treatment did not change until I came to

Taichung for work in 2006. Under the treatment of Dr. Ming-Huei Lee, I changed the way I used to perceive the disease and myself as an IC/BPS patient.

First, the doctor-patient relationship is more equal. Urologists in the hospital inform patients about the latest developments in research and treatment methodology through different channels—Such as during the diagnosis or via the Taiwan Interstitial Cystitis Association newsletters. Second, patients in the hospital can see medical doctors who are more proactive in dealing with IC symptoms. Nurses here are more active by offering relevant information and suggestions. With different treatment and a better understanding of IC, I have become more willing to accept and tolerate various IC symptoms.

The second dialogue is related to how I have been dealing with IC and my case history suggests that human beings are still unable to fully understand many diseases and totally cure them. During the first eight years of my case, I started to lose my confidence after trying a variety of medicines and the therapy of Chinese acupuncture.

But I never quit!!!

When I started to understand this condition (i.e. IC) more, I realized that nowadays clinicians still have nothing to do with many diseases with the modern equipment. What IC patients can do right now is to know more about themselves, to adjust their lifestyle, and to try some alternative methods. Try a constant conversation with myself. Through it, I gradually understand who I am and what I am. Many IC patients are impatient and I belong to that group. In addition, IC patients need to take the treatment with medicine regularly, to follow a better lifestyle, and to pay attention on their nutrition.

I have been changing my lifestyle and many of my concepts. I try my best to lead a regular life. I do not stay up late, drink, or smoke. Put it another way—IC might be a blessing in disguise because it has made me follow a healthy lifestyle. I exercise regularly, trying to make myself healthier and happier. I am not going to sit there and do nothing. Finally, I have taken a more positive attitude and accepted the fact that I am an IC patient. Many patients with other chronic diseases might be more unfortunate than IC patients.

Many patients with other chronic diseases might be more unfortunate than IC patients. In other words, IC patients might need to be willing to receive long-term treatment and accept it with an optimistic attitude. Perhaps what we IC patients should do now is to accept our lives as imperfect.

Japan IC association:

<http://hp.kanshin-hiroba.jp/kanshitsuiseiboken/pc/>

Acknowledgement:

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