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-psyco-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'e 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/kanshitsuseibokoen/pc/

Acknowledgement:
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Alex TL Lin

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Affiliations to disclose†:

None

† All financial ties (over the last year) that you may have with any business organisation with respect to the subjects mentioned during your presentation

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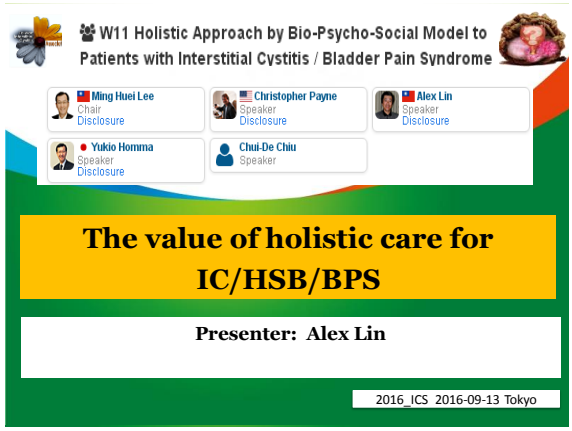
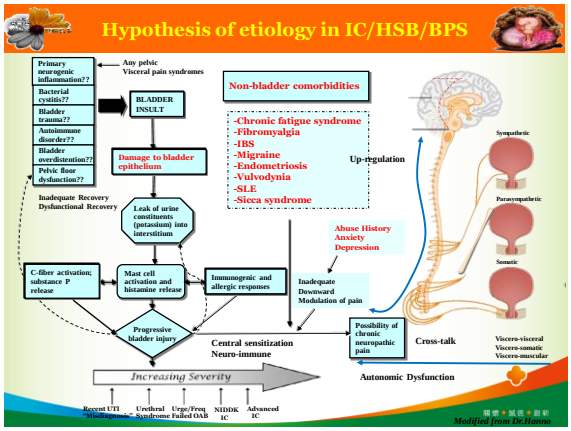
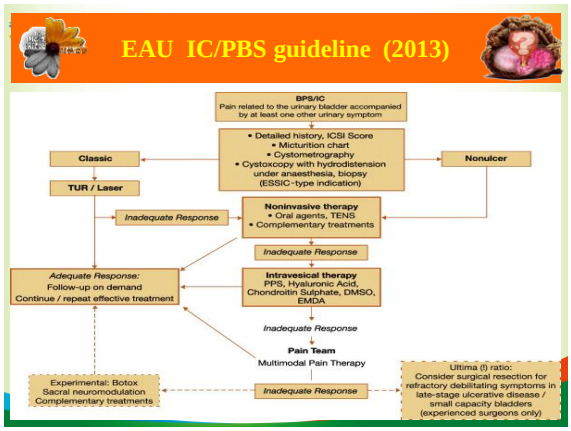
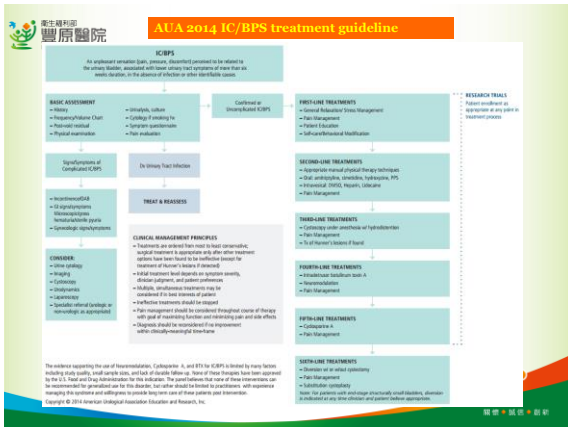
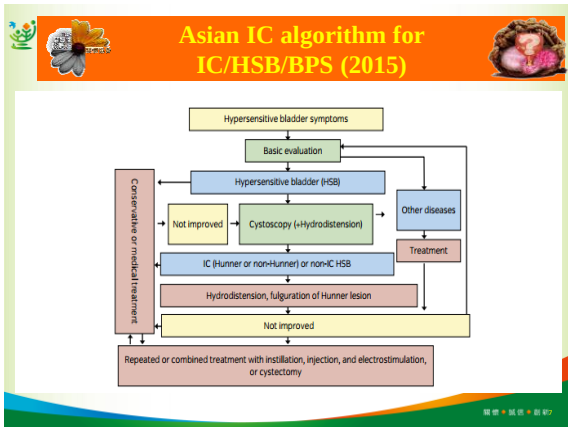
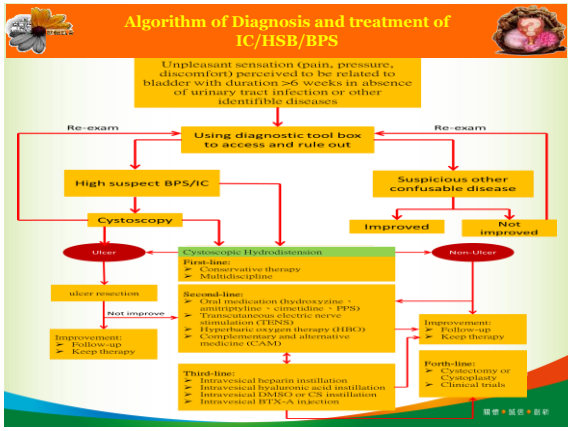


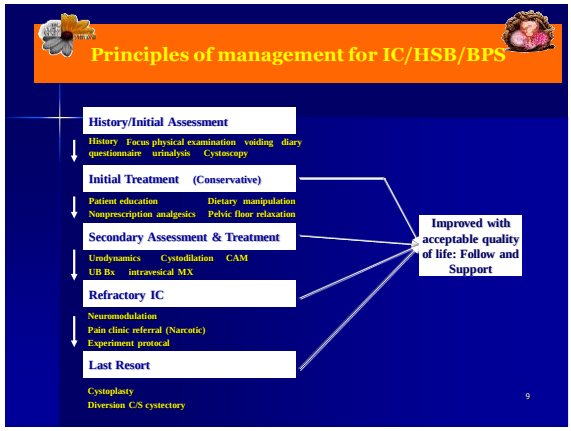









Algorithm of Diagnosis and treatment of IC/HSB/BPS
Unpleasant sensation (pain, pressure, discomfort) perceived to be related to bladder with duration >6 weeks in absence of urinary tract infection or other identifible diseases
Re-exam
Using diagnostic tool box to access and rule out
Re-exam
High suspect BPS/IC
Suspicious other confusable disease
Cystoscopy
Improved
Not improved
Ulcer
Cystoscopic Hydrodistension
Non-Ulcer
First-line:
Conservative therapy
Multidiscipline
ulcer resection
Second-line:
Oral medication (hydroxyzine + amitriptyline + cimetidine + PPS)
Transcutaneous electric nerve stimulation (TENS)
Hyperbaric oxygen therapy (HBO)
Complementary and alternative medicine (CAM)
Not improve
Improvement:
Follow-up
Keep therapy
Improvement:
Follow-up
Keep therapy
Third-line:
Intravesical heparin instillation
Intravesical hyaluronic acid instillation
Intravesical DMSO or CS instillation
Intravesical BTX-A injection
Forth-line:
Cystectomy or Cystoplasty
Clinical trials


Principles of management for IC/HSB/BPS
History/Initial Assessment
History Focus physical examination voiding diary questionnaire urinalysis Cystoscopy
Initial Treatment (Conservative)
Patient education Dietary manipulation
Nonprescription analgesics Pelvic floor relaxation
Secondary Assessment & Treatment
Urodynamics Cystodilation CAM
UB Bx intravesical MX
Refractory IC
Neuromodulation
Pain clinic referral (Narcotic)
Experiment protocal
Last Resort
Cystoplasty
Diversion C/S cystectory
Improved with acceptable quality of life: Follow and Support
9


Principles of management for IC/HSB/BPS
History/Initial Assessment
History Focus physical examination voiding diary
questionnaire urinalysis Cystoscopy
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UB Bx intravesical MX
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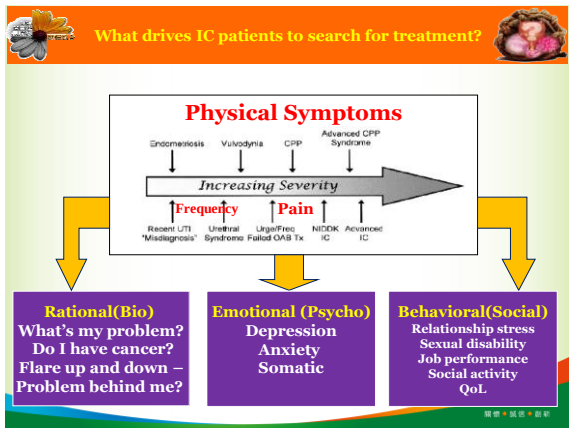
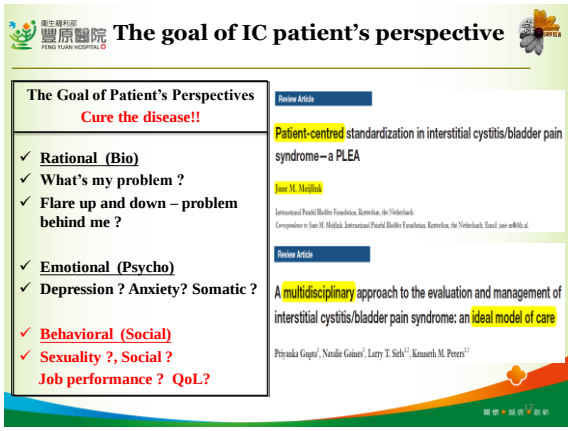
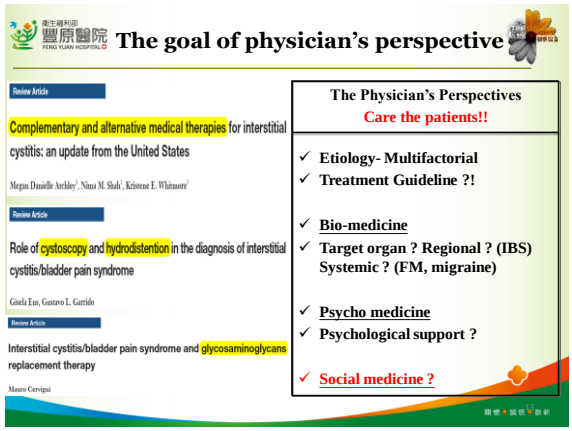
Neuromodulation
Pain clinic referral (Narcotic)
Experiment protocal
Last Resort
Cystoplasty
Diversion C/S cystectory
What's the mandatory step in the management of IC?
10


What drives IC patients to search for treatment?
Physical Symptoms
Endometriosis
Vulvodynia
CPP
Advanced CPP Syndrome
Increasing Severity
Frequency
Pain
Recent UTI "Misdiagnosis"
Urethral Syndrome
Urge/Freq Failed OAB Tx
NIDDK IC
Advanced IC
Rational(Bio)
What's my problem?
Do I have cancer?
Flare up and down – Problem behind me?
Emotional (Psycho)
Depression
Anxiety
Somatic
Behavioral(Social)
Relationship stress
Sexual disability
Job performance
Social activity
QoL


The goal of IC patient's perspective
The Goal of Patient's Perspectives
Cure the disease!!
Rational (Bio)
What's my problem ?
Flare up and down – problem behind me ?
Emotional (Psycho)
Depression ? Anxiety? Somatic ?
Behavioral (Social)
Sexuality ?, Social ?
Job performance ? QoL?
Review Article
Patient-centred standardization in interstitial cystitis/bladder pain syndrome—a PLEA
Review Article
A multidisciplinary approach to the evaluation and management of interstitial cystitis/bladder pain syndrome: an ideal model of care


The goal of physician's perspective
Review Article
Complementary and alternative medical therapies for interstitial cystitis: an update from the United States
Review Article
Role of cystoscopy and hydrodistention in the diagnosis of interstitial cystitis/bladder pain syndrome
Review Article
Interstitial cystitis/bladder pain syndrome and glycosaminoglycans replacement therapy
The Physician's Perspectives
Care the patients!!
Etiology- Multifactorial
Treatment Guideline ?!
Bio-medicine
Target organ ? Regional ? (IBS) Systemic ? (FM, migraine)
Psycho medicine
Psychological support ?
Social medicine ?

Communication is important

The Goal of Patient's Perspectives		The Physician's Perspectives
Cure the disease!!	Communication	Care the patients!!
✓ Rational (Bio)		✓ Etiology- Multifactorial
✓ What's my problem ?		✓ Treatment Guideline :
✓ Flare up and down – problem behind me ?		✓ Bio-medicine
		✓ Target organ ? Regional ? (IBS) Systemic ? (FM, migraine)
✓ Emotional (Psycho)		✓ Psycho medicine
✓ Depression ? Anxiety? Somatic ?		✓ Psychological support ?
✓ Behavioral (Social)		✓ Social medicine ?
✓ Sexuality ?, Social ? Job performance ? QoL?		

Communication is important

The Goal of Patient's Perspectives		The Physician's Perspectives
Cure the disease!!	Communication	Care the patients!!
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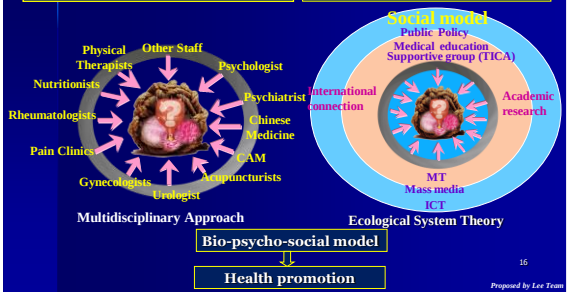
✓ Depression ? Anxiety? Somatic ?		✓ Psychological support ?
✓ Behavioral (Social)		✓ Social medicine ?
✓ Sexuality ?, Social ? Job performance ? QoL ?	Communication	

Why holistic management for IC/HSB/BPS?

- multifocal etiologies
- chronic visceral pain syndromes *(Cross talk vs. Up regulation)*
- co-morbidities
- nature histories poor described
- unpredictable treatment outcome *(Wax vs. Wane)*
- patients centered care



Bio-psycho-social model

⇩

Health promotion

16

Proposed by Lee Team

Multidisciplinary Management of IC/HSB/BPS

Treatment		Aimed effect
Pharmacotherapy		
- Peripheral pharmacotherapy	→	- peripheral physiological processes (nociceptive pain, urgency)
- Central pharmacotherapy	→	- central processes (sensation, cognition, affect)
Non-Pharmacotherapy		
- Psychotherapy & active behavior	→	- change of bodily and interpersonal behaviors sensation, cognition - active participation of patients in treatment (exercise)
- Passive physical intervention	→	- change of peripheral syndrome via physical methods (**surgical, skin penetrating**)
Others		
- Outside current medicine	→	- **CAM** - **Health care system** - culture beliefs
- Doctor- center	→	- doctor's behavior (education, training)

The Patient Perspective

Hypersensitive Bladder,
Interstitial Cystitis,
Bladder Pain Syndrome (Painful Bladder Syndrome),
Hunner Lesion

Jane Meijlink
Chairman
International Painful Bladder Foundation (IPBF)
www.painful-bladder.org

"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."

Bourque JP. Surgical management of the painful bladder. J Urol. 1951; 65:25-34.

Hypersensitive bladder, Interstitial Cystitis, Bladder Pain Syndrome, Hunner Lesion

- Pain, discomfort, pressure or some other unpleasant sensation - persistent or recurrent
- Increased urinary frequency day & night
- An urgent need to void

Hypersensitive bladder, Interstitial Cystitis, Bladder Pain Syndrome, Hunner Lesion

Leads to:

- Sleep disturbance
- Depression
- Anxiety
- Sense of helplessness and hopelessness
- But may also cause anger, irritability

Urgency, Frequency

- Constantly looking for toilets -> anxiety
- If there is a risk of no toilet then stay at home
- Leads to isolation
- Some jobs are impossible -> unemployment

Every patient is different

- Symptoms vary greatly from patient to patient
- But also from day to day in the same patient
- Symptoms may greatly increase in flares
- This means that treatment is highly individual, what works in one patient does not work in another
- Better phenotyping needed!

Impact on sexual relationships

- Both male and female patients are affected
- Leads to marital dysfunction and distress
- The health professional needs to find ways of approaching this subject since the patient may feel too embarrassed to do so.

Patients may suffer from one or multiple comorbidities

- Allergies/intolerances (which may include multiple drug intolerance)
- Chronic pain and fatigue syndromes, (e.g. fibromyalgia, chronic fatigue syndrome, temporomandibular joint disorders, migraine, vulvovaginal)
- Systemic autoimmune syndromes/diseases (e.g. systemic lupus erythematosus, Sjögren's syndrome, rheumatoid arthritis)
- Gastrointestinal and gastroesophageal disorders
- Neurological disorders

Multidisciplinary team approach is therefore essential!

So what else do patients need/want in practical terms?

Treatment:

- Treatment must be affordable and reimbursable
- It must improve quality of life
- Therefore, it must have maximum effect with minimum side effects.
- Current treatments frequently have such disabling side effects that the patient is unable to function normally.

Take home messages

1. Emotional support and empathy as well as practical support are needed from all players to help the patient learn to cope:
   - family doctor, specialist, physiotherapist, nurse, patient's family and partner, patient support group
2. Treatment is individual (= personalized medicine) and should take comorbidities into account in a multidisciplinary team approach.
3. Listen to your patients because they are the key to better understanding and better treatment of this still enigmatic disorder

Thank you!

www.painful-bladder.org

Workshop 11: ICS 2016 Tokyo

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

Biologic Approach- The differences between Hunner type IC and Non-Hunner type IC

Yukio Homma
Department of Urology
Graduate School of Medicine
The University of Tokyo

September 13, 2016

Yukio Homma

Affiliations to disclose†:

None

† All financial ties (over the last year) that you may have with any business organisation with respect to the subjects mentioned during your presentation

Funding for speaker to attend:

- ☐ Self-funded
- ☒ Institution (non-industry) funded
- ☐ Sponsored by:

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Nomenclature for IC-like Conditions

Interstitial cystitis (IC)
Painful bladder syndrome (PBS)
Bladder pain syndrome (BPS)
IC/PBS, IC/BPS, PBS/IC, BPS/IC

I will follow East Asian GL here.

Clinical Guidelines for Interstitial Cystitis and Hypersensitive Bladder Syndrome

Yukio Homma, Japan akaaki Ito, Mineo Takei, Hikaru Tomoe

Alex TL Lin, Hann-Chorng Kuo, M Taiwan g-Hwa Lu, Yao-Chi Chuang

Jeong Gu Lee, Duk Yoon Kim, Kyu-Sung Lee, Young Korea Hong

Tokyo University Kyoto City Hospital, Tamura Clinic, Harasanshin Hospital, Tokyo Women's Medical University Medical Center East

Taipei Veterans General Hospital, Buddhist Tzu Chi General Hospital, Taichung Hospital, Taipei City Hospital, Chang Gung Memorial Hospital

Korea University, DaeGu Catholic University, SungKyunKwan University, SoonChunHyang University, Cha University

Int J Urol. 16: 597-615, 2009.

Concerns/Evidence to be updated

- Inconsistency on definition with US and Europe
- Progress in understanding and management

International Journal of Urology (2016) Int J Urol. 16: 597-615, 2016. doi: 10.1111/iju.13118

Guideline

Clinical guidelines for interstitial cystitis and hypersensitive bladder updated in 2015

Yukio Homma,[1] Tomohiro Ueda,[2] Hikaru Tomoe,[3] Alex TL Lin,[4] Hann-Chorng Kuo,[5] Ming-Huei Lee,[6] Seung-June Oh,[7] Joon Chul Kim[8] and Kyu-Sung Lee[9]

[1]Department of Urology, Graduate School of Medicine, The University of Tokyo, Tokyo, [2]Department of Urology, Ueda Clinic, Kyoto, [3]Department of Urology, Tokyo Women's Medical University Medical Center East, Tokyo, Japan, [4]Department of Urology, National Yang Ming University and Taipei Veterans General Hospital, Taipei, [5]Department of Urology, Buddhist Tzu Chi General Hospital and School of Medicine, Tzu Chi University, Hualien, [6]Department of Urology, Feng-Yuan Hospital, Taichung, Taiwan, [7]Department of Urology, Seoul National University, Seoul, [8]Department of Urology, The Catholic University of Korea, Seoul, and [9]Department of Urology, Sung Kyun Kwan University School of Medicine, Seoul, Korea

Members (alphabetical order)

Japan
- Yukio Homma (The University of Tokyo)
- Hikaru Tomoe (Tokyo Women's Medical University Medical Center East)
- Tomohiro Ueda (Ueda Clinic)

Korea
- Joon Chul Kim (The Catholic University of Korea)
- Kyu-Sung Lee (Samsung Medical Center)
- Seung-June Oh (Seoul National University)

Taiwan
- Hann-Chorng Kuo (Buddhist Tzu Chi General Hospital and Tzu Chi University)
- Ming-Huei Lee (Feng-Yuan Hospital)
- Alex Tong-Long Lin (National Yang Ming University and Taipei Veteran General Hospital)

Classification/ Diagnosis of East Asian GL

	Requirement		
Diagnosis	*HSB symptoms	Confusable diseases	#Cystoscopic abnormality
Hunner type IC	Present	Absent	Hunner lesion
Non-Hunner type IC			Mucosal bleeding after distension
Hypersensitive bladder			No abnormal findings

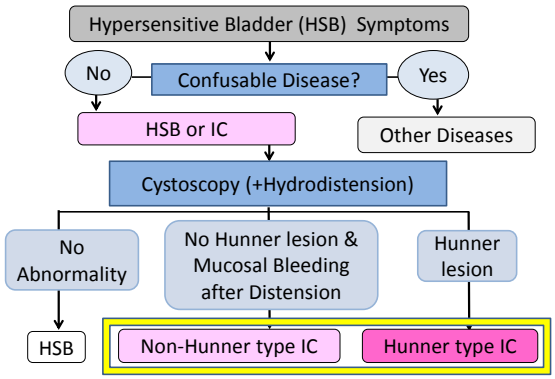
*HSB (Hypersensitive bladder) symptoms: pain, pressure or discomfort in the bladder, usually with frequency and nocturia
#cystoscopy and hydrodistension mandatory for typing

Tow Approaches to HSB or IC

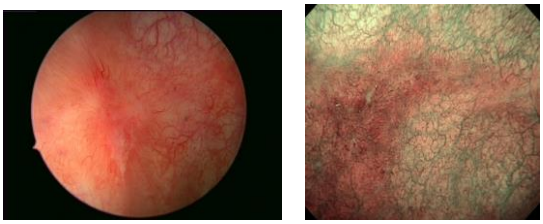
Reality: Patients complain of bladder discomfort, pain, and frequency, but we don't know why.

1. Symptomatic/ pain-centric approach
   It focuses on symptom (esp. pain) aside from reasons.
   It is patient-friendly and holistic but less analytical.

2. Biologic/ bladder-centric approach
   It presumes bladder origin or extra-bladder origin.
   It focuses on the bladder for pathophysiological research.



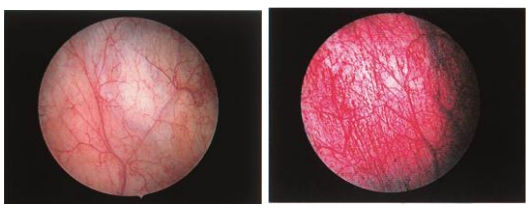
Hunner lesions



A Hunner lesion is a reddish mucosal lesion lacking in the normal capillary structure. It is often associated with converging vessels, covering fibrin clots and scars. The lesions are easily overlooked but more readily recognized by narrow-band imaging cystoscopy.

MBAD

(Mucosal Bleeding After Distension)



The apparently normal bladder mucosa (Left) undergoes intravesical mucosal bleeding during bladder emptying after distension (Right).

Definition of IC

1) Hypersensitive bladder symptoms
   (pain, pressure or discomfort in the bladder, usually with urinary frequency and nocturia)
2) Bladder pathology
   (Hunner lesion or mucosal bleeding after distension: MBAD)
3) No confusable diseases

Compatible with ICS terminology (specific diagnosis and requires confirmation by typical cystoscopic and histological features)

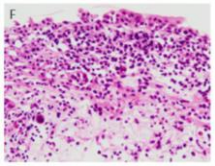
Definition of IC

1) Hypersensitive bladder symptoms
   (pain, pressure or discomfort in the bladder, usually with urinary frequency and nocturia)
2) Bladder pathology
   (Hunner lesion or mucosal bleeding after distension: MBAD)

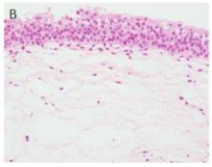
Only endoscopic pathology
How about morphological, molecular, or genetic pathology???

Histopathology of IC

HIC (Hunner type)
Severe inflammation
Epithelial denudation

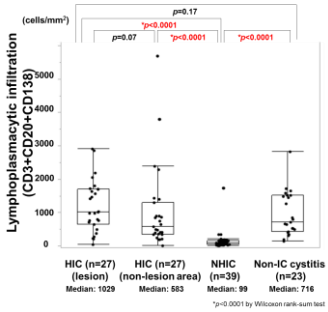


NHIC (Non-Hunner type)
Lack of inflammation
Reserved epithelium



Maeda D et al. PLoS One. PLoS One. 10: e0143316, 2015
Akiyama Y et al. Sci Rep 6: 28652, 2016

Cell Density of Lymphoplasmacytic Cells



HIC≒non-IC cystitis

＞＞NHIC

Akiyama Y et al. Sci Rep 6: 28652, 2016

Gene Expression Profile of HIC

Chronic inflammatory reactions
Ogawa T et al. J Urol 183: 1206, 2010

Immune and inflammatory responses
Gamper M et al. BMC Genomics 10: 199, 2009
Colaco M et al. J Urol 192: 1123, 2014

Antigen-mediated allergic inflammation
T-cell-mediated immune response
Tseng LH et al. Int Urogynecol J Pelvic Floor Dysfunct 21: 911, 2010

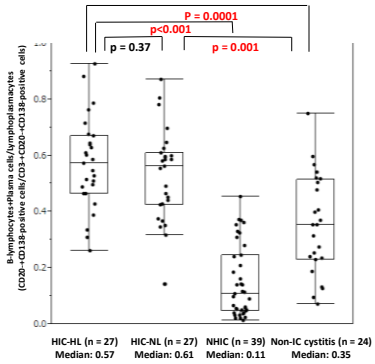
Gene Expression Profile of HIC

IL-10, IL-17A, iNOS：↑
IL-17A and NO: important role in inflammation
Logadottir Yr et al. J Urol 192: 1564. 2014

IL-12A, FGF7, CXCL1, CCL21, TNF：most dysregulated
CCL21: most relevant inflammatory mediator
Offiah I et al. Eur Urol 70: 283. 2016

Inflammation , possibly mediated by immunoreactions, in HIC

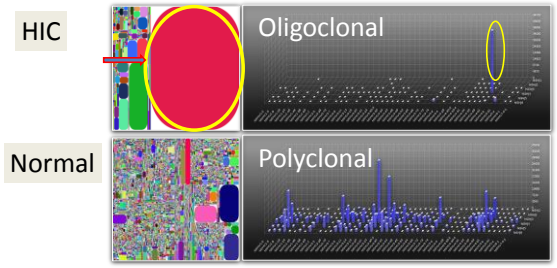
(B cells and Plasma cells) / All Lymphocytes



HIC>>
non-IC cystitis

Akiyama Y et al.
Sci Rep 6: 28652, 2016

Repertoire Analysis of Plasma Cells



Homma Y et al. Unpublished data

Sensory Activation in both HIC and NHIC

TRPA1, M2, M8, V1, V2, ASIC1, CXCL9↑ in HIC
NGF↑ in NHIC
Homma Y et al. J Urol 190: 1925, 2013

Sub-epithelial sensory hyperinnervation &
Basal urothelial NGFR staining in HIC and NHIC
Regauer S et al . J Urol in press, 2016

Hyperactivity of Sensory Nerves involved in both ICs

Summary

- We should not treat the patients as a single entity because of similar symptoms.
- We should divide them into HIC, NHIC, or HSB, and manage and investigate accordingly.
- HIC is an immuno-inflammatory disease, and IC (HSB also) is a hypersensitive disorder.

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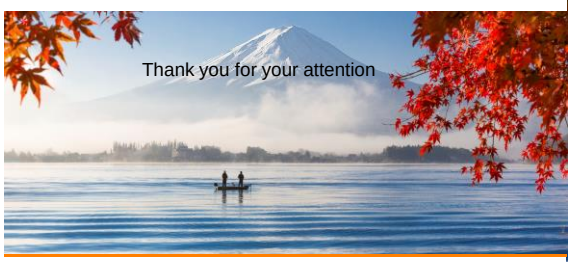


Chaired by Yukio Homma, The University of Tokyo

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

Ming Huei Lee
Chair
Disclosure

Christopher Payne
Speaker
Disclosure

Alex Lin
Speaker
Disclosure

Yukio Homma
Speaker
Disclosure

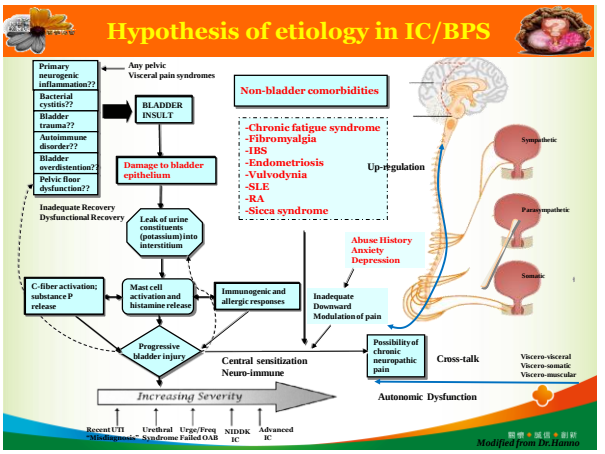
Chui-De Chiu
Speaker

Social Approach- The E-health system care of patients with IC/HSB/BPS

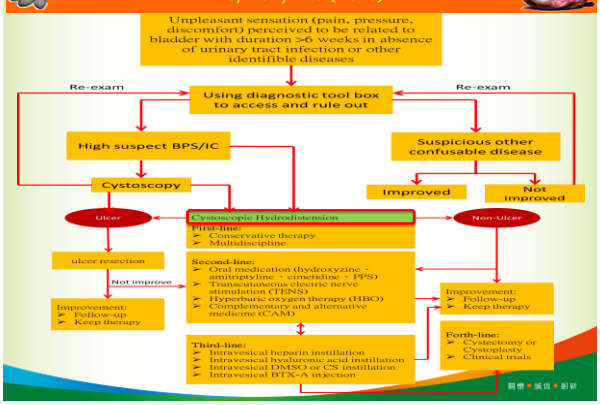
Presenter: Ming-Huei Lee
Feng-Yuan Hospital, Taichung, Taiwan

2016_ICS 2016-09-13 Tokyo

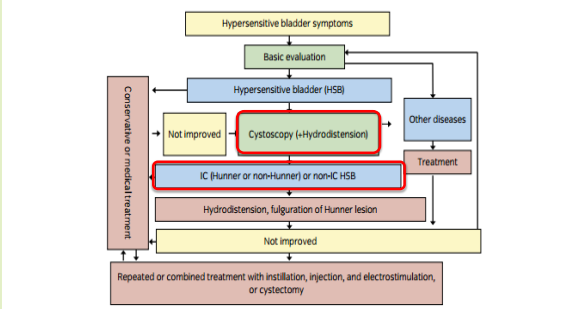
Hypothesis of etiology in IC/BPS



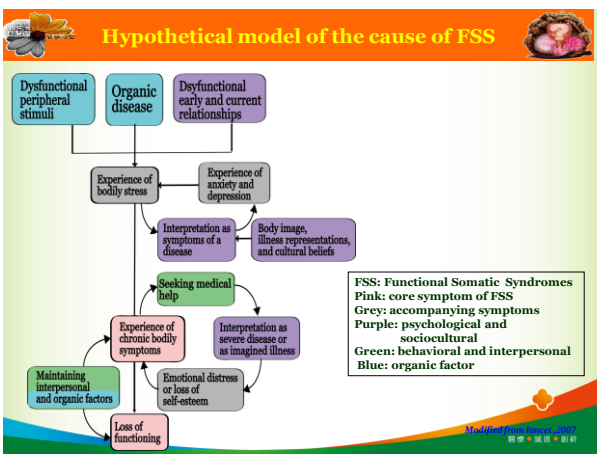
TUA-Algorithm of Diagnosis and treatment of IC/HSB/BPS (2016)



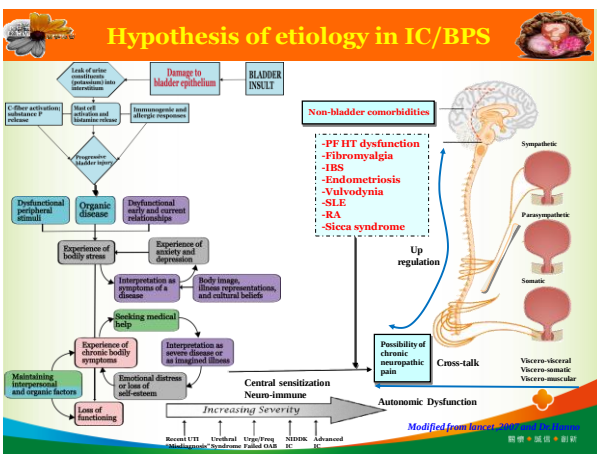
Asian IC algorithm for IC/HSB/BPS (2015)



Hypothetical model of the cause of FSS



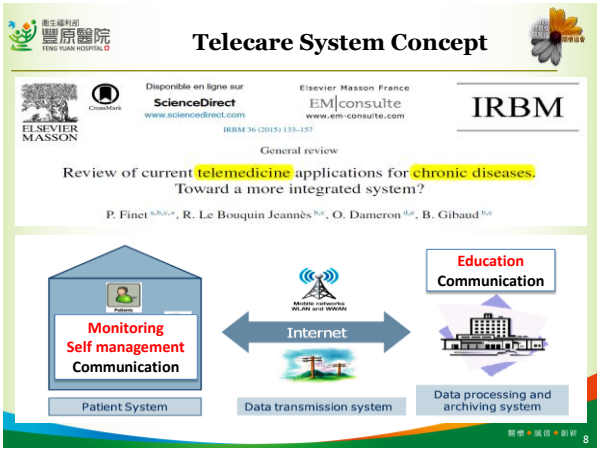
Hypothesis of etiology in IC/BPS



Gaps between IC patients and care-IC physicians

The Goal of Patient's Perspectives Cure the disease!!	Communication	The Physician's Perspectives Care the patients!!
✓ Rational (Bio) ✓ What's my problem ? ✓ Flare up and down – problem behind me ?		✓ Etiology- Multifactorial ✓ Treatment Guideline :
✓ Emotional (Psycho) ✓ Depression ? Anxiety? Somatic ?		✓ Bio-medicine ✓ Target organ ? Regional ? (IBS) Systemic ? (FM, migraine)
✓ Behavioral (Social) ✓ Sexuality ?, Social ? Job performance ? QoL ?,	Communication	✓ Psycho medicine ✓ Psychological support ? ✓ Social medicine ?

Telecare System Concept

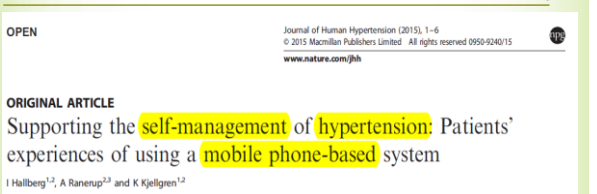


"Telecare system" may help physicians to communicate with IC patient

Interactive

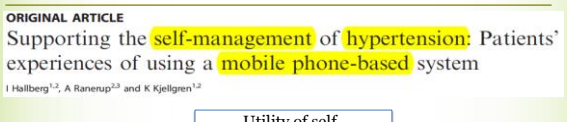
Continuing

Overview of the sub-themes in telecare system



Utility of self-management telecare system → Insights and benefits from using self-management telecare system

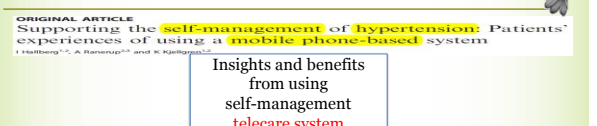
3 "E"Characteristics of telecare system



Utility of self-management telecare system

- Using mobile phone as a tool for self-reporting → Easy and relevant
- Several measuring of symptom domain → Easy to use
- Retrieving visualization of education → Easy to understand

The advantages of telecare system in chronic disease patients (IC ?)



Insights and benefits from using self-management telecare system

- Motivation of better QoL → Increase in patient's compliance to treatment
- Confirming and understanding → Awareness of factors affecting symptom flare-up
- Increasing participation → Active patient's involvement in the disease management

Reduced visits and costs of management

Advantages of telecare system in physicians with chronic disease (IC ?)

Curr Hypertens Rep (2015) 17: 21
DOI 10.1007/s11906-015-0535-3

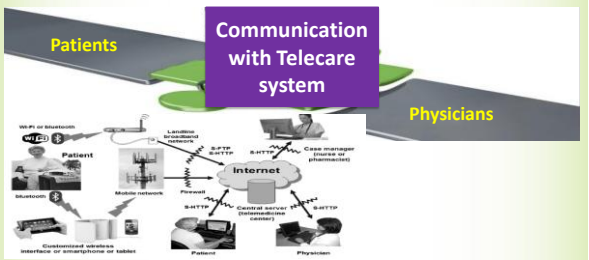
BLOOD PRESSURE MONITORING AND MANAGEMENT (J COCKCROFT, SECTION EDITOR)

The Role of Telemedicine in Hypertension Management: Focus on Blood Pressure Telemonitoring

Stefano Omboni · Rossella Ferrari

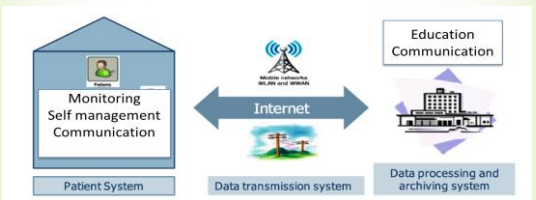
- Quick update of doctor on patient's symptom status (flare-up)
- Strict patient's monitoring and detailed medical report
- Saving of doctor's time
- Promotion of counselling between multidisciplinary specialists

Social Approach – The E-health system care of patients with IC/BPS



The effectiveness of Telecare system in caring for IC patients

Social Approach – The E-health system care of patients with IC/BPS (Web-base)



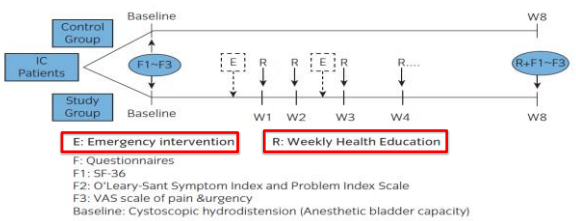
1. Development and Evaluation of an E-health System for IC patients

Social Approach - Web-base telecare system

- Aims of study

To develop and evaluate the apply of information and communication technology (ICT) to improve the quality of life, measured by SF-36、ICSI 、ICPI 、VAS for IC/BPS patients.

- Study design



F: Questionnaires
F1: SF-36
F2: O'Leary-Sant Symptom Index and Problem Index Scale
F3: VAS scale of pain &urgency
Baseline: Cystoscopic hydrodistension (Anesthetic bladder capacity)

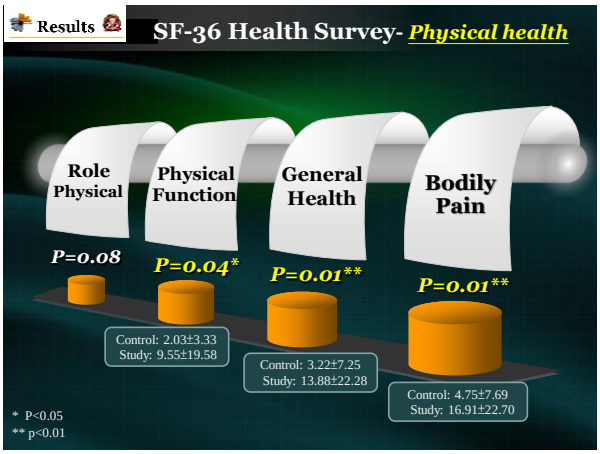
Social Approach - Education and communication function

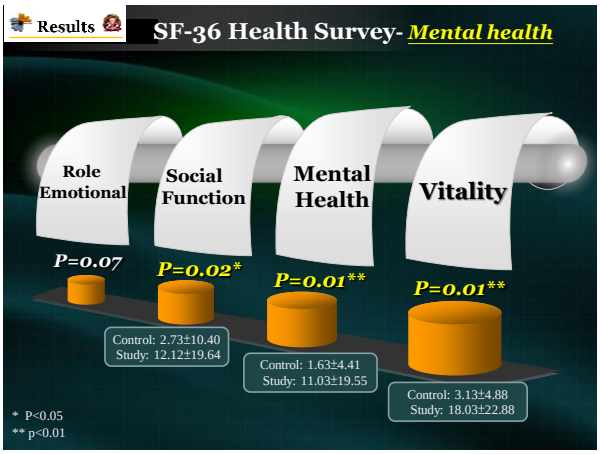
- **Education**
- **Communication**

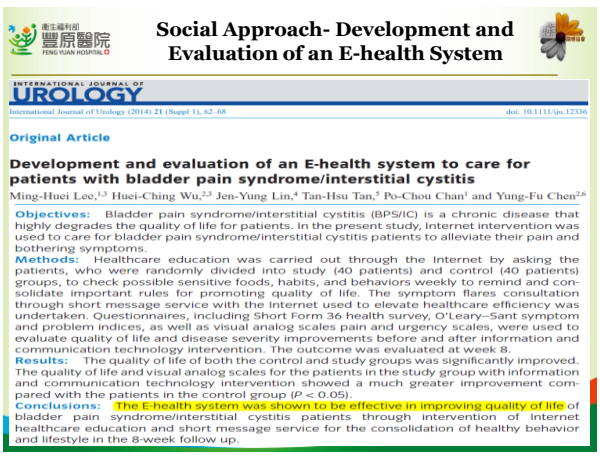
Results

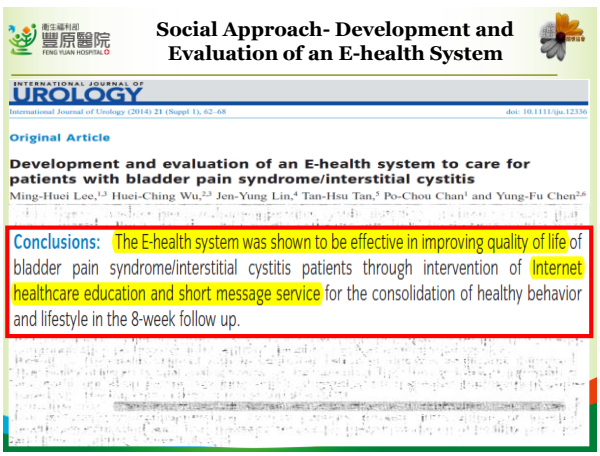
		Control (N=32)	Study (N=33)	P
Age (yr.)		49.5±8.7	46.6±9.7	0.21
Education	High school	53.1%	60.6%	0.54
	University	46.9%	39.4%	
Marry status	Marry	93.8%	81.8%	0.14
	Un-marry	6.3%	18.2%	
Capacity (ml)		649±152	607±210	0.17

	Control (N=32) Δ (M±SD)	Study (N=33) Δ (M±SD)	P value
ICSI	-2.16±4.12	-3.58±5.61	0.25
ICPI	-4.66±4.86	-2.30±6.13	0.09
VAS pain	-0.03±0.86	-1.88±3.14	<0.01
VAS urgency	-0.13±0.75	-1.85±3.03	<0.01


Results
SF-36 Health Survey- Physical health
Role Physical
Physical Function
General Health
Bodily Pain
P=0.08
P=0.04*
P=0.01**
P=0.01**
Control: 2.03±3.33
Study: 9.55±19.58
Control: 3.22±7.25
Study: 13.88±22.28
Control: 4.75±7.69
Study: 16.91±22.70
* P<0.05
** p<0.01


Results
SF-36 Health Survey- Mental health
Role Emotional
Social Function
Mental Health
Vitality
P=0.07
P=0.02*
P=0.01**
P=0.01**
Control: 2.73±10.40
Study: 12.12±19.64
Control: 1.63±4.41
Study: 11.03±19.55
Control: 3.13±4.88
Study: 18.03±22.88
* P<0.05
** p<0.01


Social Approach- Development and Evaluation of an E-health System
INTERNATIONAL JOURNAL OF UROLOGY
Original Article
Development and evaluation of an E-health system to care for patients with bladder pain syndrome/interstitial cystitis
Ming-Huei Lee,[1,3] Huei-Ching Wu,[2,3] Jen-Yung Lin,[4] Tan-Hsu Tan,[5] Po-Chou Chan[1] and Yung-Fu Chen[2,6]
Objectives: Bladder pain syndrome/interstitial cystitis (BPS/IC) is a chronic disease that highly degrades the quality of life for patients. In the present study, Internet intervention was used to care for bladder pain syndrome/interstitial cystitis patients to alleviate their pain and bothering symptoms.
Methods: Healthcare education was carried out through the Internet by asking the patients, who were randomly divided into study (40 patients) and control (40 patients) groups, to check possible sensitive foods, habits, and behaviors weekly to remind and consolidate important rules for promoting quality of life. The symptom flares consultation through short message service with the Internet used to elevate healthcare efficiency was undertaken. Questionnaires, including Short Form 36 health survey, O'Leary–Sant symptom and problem indices, as well as visual analog scales pain and urgency scales, were used to evaluate quality of life and disease severity improvements before and after information and communication technology intervention. The outcome was evaluated at week 8.
Results: The quality of life of both the control and study groups was significantly improved. The quality of life and visual analog scales for the patients in the study group with information and communication technology intervention showed a much greater improvement compared with the patients in the control group (P < 0.05).
Conclusions: The E-health system was shown to be effective in improving quality of life of bladder pain syndrome/interstitial cystitis patients through intervention of Internet healthcare education and short message service for the consolidation of healthy behavior and lifestyle in the 8-week follow up.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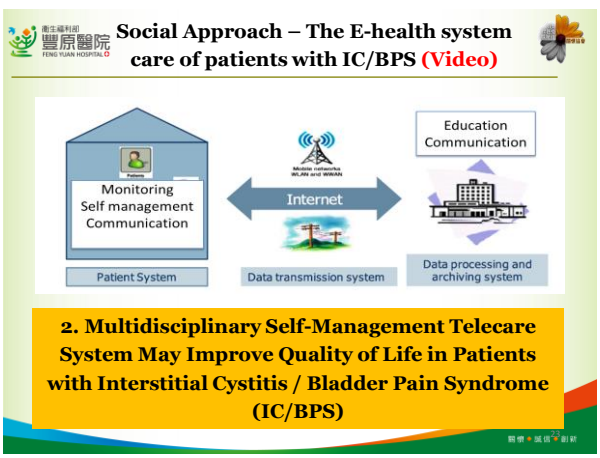
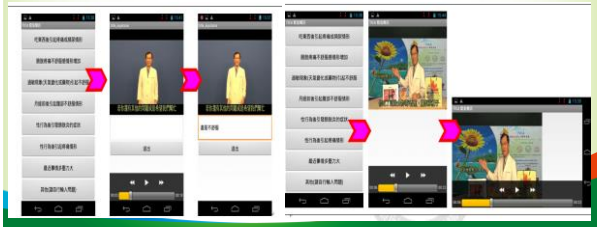

Social Approach – The E-health system care of patients with IC/BPS (Video)
Monitoring
Self management
Communication
Patient System
Internet
Data transmission system
Education
Communication
Data processing and archiving system
2. Multidisciplinary Self-Management Telecare System May Improve Quality of Life in Patients with Interstitial Cystitis / Bladder Pain Syndrome (IC/BPS)


Social Approach – Video-base telecare system design
1. J Med Internet Res. 2012 Feb 29;14(1):e37. doi: 10.2196/jmir.1998.
Do participants' preferences for mode of delivery (text, video, or both) influence the effectiveness of a Web-based physical activity intervention?
Vandelanotte C[1], Duncan MJ, Plotnikoff RC, Mummery WK.
TICA
台灣間質性膀胱炎關懷協會

Mobile Design-1

- Weekly education
- Exacerbation



Mobile Design-2

- Health questionnaire
- VAS-Pain, Urgency
- ICSI / ICPI
- Treatment outcome

Demographics

	Control (N=27)	Study (N=29)	P value
Age	46.3 ± 14.2	42.9 ± 10.4	0.31
Education			
High school	18 (66.7%)	13 (44.8%)	0.10
University	9 (33.3%)	16 (55.2%)	
Marry status			
Yes	22 (81.5%)	26 (89.7%)	0.38
No	5 (18.5%)	3 (10.3%)	
Anesthetic maximal bladder capacity	570.7 ± 218.9 ml	643.3 ± 169.2 ml	0.17

Results

	Control Group (N=27)				Video Group (N=29)				Statistics	
	Mean	SD	t	p	Mean	SD	t	p	t	p
Physical Function	9.55	19.58	2.80	0.01	28.04	26.82	5.53	<0.01	3.13	<0.01
Role Physical	25.76	48.20	3.07	<0.01	73.21	41.35	9.37	<0.01	4.13	<0.01
Body Pain	16.91	22.70	4.28	<0.01	37.86	30.11	6.65	<0.01	3.12	<0.01
General Health	13.88	22.28	3.58	<0.01	19.29	25.45	4.01	<0.01	2.89	0.02
Vitality	18.03	22.88	4.53	<0.01	18.39	16.95	2.62	<0.01	3.86	0.04
Social Function	12.12	19.64	3.55	<0.01	35.27	31.92	5.85	<0.01	3.49	<0.01
Role Emotion	32.32	3.69	4.25	<0.01	72.62	42.60	9.02	<0.01	5.42	<0.01
Mental Health	11.03	19.55	3.24	<0.01	5.71	14.42	2.10	0.05	1.21	0.057

Results

	Control Group (N=27)				Video Group (N=29)				Statistics	
	Mean	SD	t	p	Mean	SD	t	p	t	p
O'Leary Scale										
Symptom	-3.58	5.61	-1.16	0.25	-4.31	3.54	-3.52	<0.01	3.05	0.04
Problem	-2.30	6.13	-1.71	0.09	-4.48	3.53	-6.84	<0.01	3.68	0.02
VAS Scale										
Pain	-1.88	3.14	-3.21	<0.01	-0.76	3.12	-1.31	0.20	1.41	0.17
Urgency	-1.85	3.03	-3.12	<0.01	-1.95	2.91	-3.47	0.01	0.40	<0.01

- Video-based intervention outperformed the text-based intervention in consolidating good lifestyle, improving QOL, and alleviating disease symptoms

Social Approach – Placebo effect ??

Examination of the Significant Placebo Effect in the Treatment of Interstitial Cystitis/Bladder Pain Syndrome

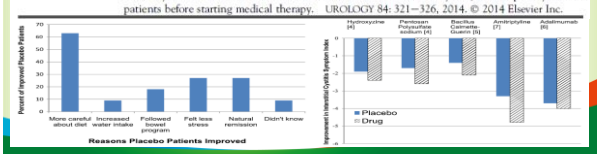
Philip C. Bosch

RESULTS

Of the 43 patients, 21 received adalimumab and 22 received placebo. Of the patients who received placebo, there was a statistically significant improvement demonstrated in the O'Leary-Sant Interstitial Cystitis Symptom and Problem Indexes of −8.1 (95% confidence interval [CI], 3.0-13.2), Interstitial Cystitis Symptom Index of −3.7 (95% CI, 0.9-6.5), Interstitial Cystitis Problem Index of −4.4 (95% CI, 2.0-6.8), and Pelvic Pain, Urgency, Frequency scale of −6.9 (95% CI, 2.8-11.0) at week 12 compared with baseline. Most of the significantly improved placebo patients felt their improvement was because they were more conscientious about following physician advice and feeling less stress while in the study.

CONCLUSION

Patients with moderate to severe interstitial cystitis/bladder pain syndrome had significant improvement after receiving only advice and support. This intervention is risk free and inexpensive. Physicians should review standard advice with all interstitial cystitis/bladder pain syndrome patients before starting medical therapy. UROLOGY 84: 321–326, 2014. © 2014 Elsevier Inc.



Social Approach – Placebo effect ??

- **Placebo Effect**

CLINICAL TRIALS

Placebo effects in interstitial cystitis/bladder pain syndrome

H. Henry Lai

Placebo effects are a major factor in randomized control trials of treatments for interstitial cystitis/bladder pain syndrome. Two studies in the past 4 years have shown greater placebo effects than are usually reported in the literature. A recent report by Bosch investigated how these placebo effects are enhanced by education and behavioural modification strategies.

Lai, H. H. *Nat. Rev. Urol.* advance online publication 12 August 2014; doi:10.1038/nrurol.2014.204

- **Patient-Physician Communication**

31

Social Approach – BPS model may come true by using telecare system

Wiecha *et al. BMC Pulmonary Medicine* (2015) 15:17
DOI 10.1186/s12890-015-0007-1

BMC Pulmonary Medicine

RESEARCH ARTICLE Open Access

Evaluation of a web-based asthma self-management system: a randomised controlled pilot trial

John M Wiecha[1*], William G Adams[2], Denis Rybin[3], Maria Rizzodepaoli[4], Jeremy Keller[5] and Jayanti M Clay[6]

- **Telecare system consist of**
  - Multidimensional
  - Educational
  - Cognitive-behavior therapy

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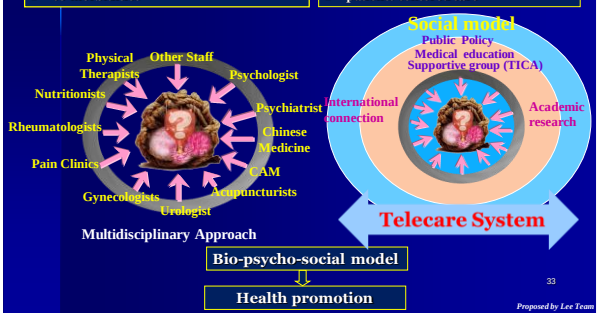
Social approach —BPS model may come true by telecare system in IC/HSB/BPS

- multifocal etiologies
- chronic visceral pain syndromes *(Cross talk vs. Up regulation)*
- co-morbidities
- nature histories poor described
- unpredictable treatment outcome *(Wax vs. Wane)*
- patients centered care



Multidisciplinary Approach

Bio-psycho-social model

⇩

Health promotion

33

Proposed by Lee Team

Take home message

- ✓ The principle of caring for IC should be focused on view of bio-psycho-social model
- ✓ The telecare has a role in multidisciplinary care of IC patients
- ✓ The telecare system was perceived as easy and relevant, easy to use, and easy to understand for IC patients
- ✓ The telecare system gave an understanding of the interplay between symptom flare-up, quality of life and increased motivation to follow treatment
- ✓ The telecare system can enhance communication between patients and physicians outside the hospital

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

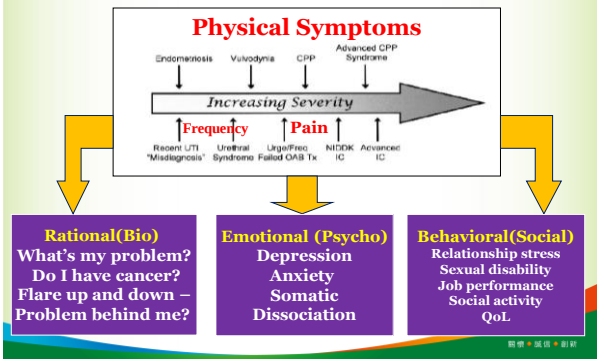
Ming Huei Lee — Chair — Disclosure
Christopher Payne — Speaker — Disclosure
Alex Lin — Speaker — Disclosure
Yukio Homma — Speaker — Disclosure
Chui-De Chiu — Speaker

Interactive Patient / Physician Forum:
Gap between patient's preference and physician's judgment

Presenter: Ming-Huei Lee
Feng-Yuan Hospital, Taichung, Taiwan

2016_ICS 2016-09-13 Tokyo

What drives IC/HSB/BPS patients to search for treatment?



What's physician's view in caring IC/HSB/BPS patients?

- **Bio medicine**
  - ✓ Etiology- Multifactorial
  - ✓ Diagnosis marker?
  - ✓ Treatment guideline!!
  - ✓ Co-morbidity
  - ✓ Chronicity-flare up and remission
  - ✓ Target organ v.s. regional v.s. systemic (Functional somatic syndrome?)
- **Psycho medicine**
  - ✓ Psychotherapy
- **Social medicine**
  - ✓ Health care system
  - ✓ Culture beliefs

The image of urinary bladder (Patient's view ? Physician view ?)

Gaps between IC/HSB/BPS patients and care-IC physicians

The Goal of Patient's Perspectives
Cure the disease!

Rational (Bio)
- ✓ What's my problem ?
- ✓ Do I have cancer?
- ✓ Flare up and down – problem behind me ?

Emotional (Psycho)
- ✓ Depression ? Anxiety? Somatic ?

Behavioral (Social)
- ✓ Sexuality ? Social ? Job performance ? QoL ?

The Physician's Perspectives
Care the patients!

Bio medicine
1. Etiology- Multifactorial
2. Diagnosis marker?
3. Treatment guideline!!
4. Co-morbidity
5. Chronicity-flare up and remission
6. Target organ v.s. regional v.s. systemic (Functional somatic syndrome?)

Psycho medicine
1. Psychotherapy

Social medicine
1. Health care system
2. Culture beliefs

Management the Gaps between IC/HSB/BPS Patients and Physicians

Patient's Perspectives
***Cure the disease!**

Bio-Rational
Psycho-Emotional
Social-Behavioral

Focus on patient

- **Organ-oriented approach**
  - Current main bodily symptoms
  - Focus on dysfunction of peripheral organs
  - Interventions aimed at peripheral physiology and restoration of organ function
- **Cognitive interpersonal approach**
  - Pattern of bodily and mental symptoms over time
  - Focus on dysfunction of central processing and context factors
  - Interventions aimed at sensations, cognitions, affects, behaviors, and restoration of overall functioning

Management the Gaps between IC/HSB/BPS Patients and Physicians

Focus on doctor
- Early recognition
- Avoidance of iatrogenic harm
- Communication skill

The Physician's Perspectives Care the patients!

Bio medicine
1. Etiology- Multifactorial
2. Diagnosis marker?
3. Treatment guideline!!
4. Co-morbidity
5. Chronicity-flare up and remission
6. Target organ v.s. regional v.s. systemic (Functional somatic syndrome?)

Psycho medicine
1. Psychotherapy

Social medicine
1. Health care system
2. Culture beliefs

Management the Gaps between IC/HSB/BPS Patients and Physicians

Focus on patient
- Organ-oriented approach
  - Current main bodily symptoms
  - Focus on dysfunction of peripheral organs
  - Interventions aimed at peripheral physiology and restoration of organ function
- Cognitive interpersonal approach
  - Pattern of bodily and mental symptoms over time
  - Focus on dysfunction of central processing and context factors
  - Interventions aimed at sensations, cognitions, affects, behaviors, and restoration of overall functioning

Patient's Perspectives "Cure the disease!"
Bio-Rational
Psycho-Emotional
Social-Behavioral

Focus on doctor
- Early recognition
- Avoidance of iatrogenic harm
- Communication skill

The Physician's Perspectives Care the patients!
Bio medicine
1. Etiology- Multifactorial
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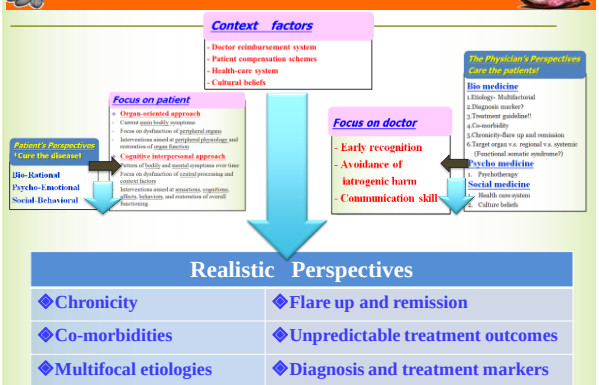
5. Chronicity-flare up and remission
6. Target organ v.s. regional v.s. systemic (Functional somatic syndrome?)

Psycho medicine
1. Psychotherapy

Social medicine
1. Health care system
2. Culture beliefs

Context factors
- Doctor reimbursement system
- Patient compensation schemes
- Health-care system
- Cultural beliefs

Management the Gaps between IC/BPS Patients and Physicians



Realistic Perspectives

◆Chronicity	◆Flare up and remission
◆Co-morbidities	◆Unpredictable treatment outcomes
◆Multifocal etiologies	◆Diagnosis and treatment markers

Interactive Patient / Physician Forum

From Japan's perspective
- IC Representative:
- Tomiko Shinozaki

Yukio Homma
Speaker Disclosure

From Western's perspective
- IC Representative:
- Jane Meijlink

Christopher Payne
Speaker Disclosure

From Taiwan's perspective
- IC Representative:
- Yu-Chen Lan

Ming Huei Lee
Speaker Disclosure

Alex Lin
Speaker Disclosure

Christopher Payne, MD

ICS 2016 TOKYO

Affiliations to disclose†:

Allergan—consultant
Astellas—consultant
Seikagaka--consultant

† All financial ties (over the last year) that you may have with any business organisation with respect to the subjects mentioned during your presentation

Funding for speaker to attend:

- ☐ Self-funded
- ☐ Institution (non-industry) funded
- ☒ Sponsored by: *ICS Board of Trustees*

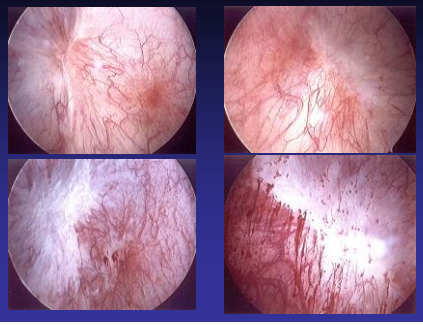
Patient Phenotyping in BPS/IC

Christopher K. Payne, MD
Emeritus Professor of Urology at Stanford
Vista Urology & Pelvic Pain Partners

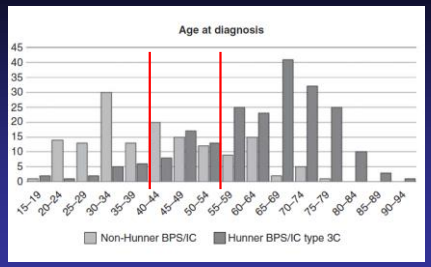
Key Messages

1. **Ulcerative IC is a disease**
2. **BPS is not a disease; it is a syndrome**
3. **Therefore, combining IC/BPS is wrong**

Ulcerative IC is a disease

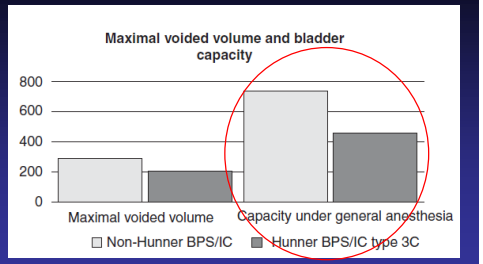


Ulcerative IC is different from BPS



Logadottir Y: Scand J Nephrol Urol 46:365, 2012

Ulcerative IC is different from BPS



Logadottir Y: Scand J Nephrol Urol 46:365, 2012

#2. BPS is a syndrome

"A syndrome is a set of medical signs and symptoms that are correlated with each other and, often, with a specific disease."

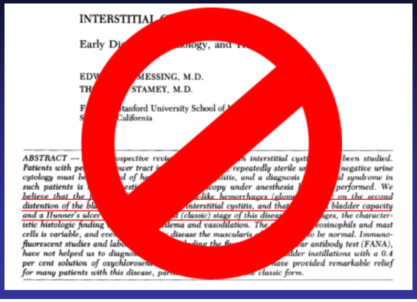
Common Syndromes

- Bladder Pain Syndrome
- Chest Pain Syndrome
- Head Pain Syndrome

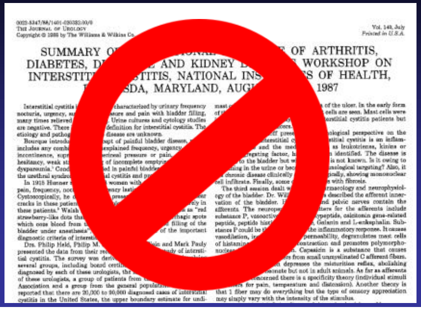
A syndrome is not a diagnosis. It is a starting point on the path to a diagnosis.

#3. IC/BPS is totally wrong

Messing & Stamey, Urology 1978



NIDDK Criteria, J Urol 1988



Review Article

The Role of Glomerulations in Bladder Pain Syndrome: A Review

Gjertrud E. Wennevik,* Jane M. Meijlink, Philip Hanno and Jørgen Nordling

From the Department of Urology (JN), University of Copenhagen (GEW), Copenhagen, Denmark, International Painful Bladder Foundation, Rotterdam, The Netherlands (JMM), and Department of Urology, University of Pennsylvania, Philadelphia, Pennsylvania (PH)

Purpose: As a diagnostic marker for bladder pain syndrome/interstitial cystitis, glomerulations were first popularized by Messing and Stamey in 1978. Later this was included in the NIDDK criteria for research and consequently used by many urologists as a default diagnostic criterion. Today the connection between glomerulations and bladder pain syndrome/interstitial cystitis is much debated

Abbreviations and Acronyms

BPS = bladder pain syndrome

ESSIC = International Society for

We found no convincing evidence . . . that glomerulation should be included in the diagnosis or phenotyping of BPS/IC.

J Urol 195:1-7; 2016

Interstitial cystitis patient accrual form

Automatic exclusions:
- <18 yrs. old
- Benign or malignant bladder tumors
- Radiation cystitis
- Tuberculous cystitis
- Bacterial cystitis
- Vaginitis
- Cyclophosphamide cystitis
- Symptomatic urethral diverticulum
- Uterine, cervical, vaginal or urethral Ca
- Active herpes
- Bladder or lower ureteral calculi
- Waking frequency <3 times in 12 hrs.
- Nocturia <2 times
- Symptoms relieved by antibiotics, urinary antiseptics, urinary analgesics (for example phenazopyridine hydrochloride)
- Duration <12 mos.
- Involuntary bladder contractions (urodynamics)
- ~~Capacity >400 cc, absence of sensory urgency~~

Automatic inclusions:
- Hunner's ulcer

Pos. factors:
- Pain on bladder filling relieved by emptying
- Pain (suprapubic, pelvic, urethral, vaginal or perineal)
- ~~Glomerulations on endoscopy~~
- ~~Decreased compliance on cystometrogram~~

J Urol 10:204-206; 1988

$10M/year Research Funding

Infection/Inflammation

Discovery of Morphological Subgroups That Correlate With Severity of Symptoms in Interstitial Cystitis: A Proposed Biopsy Classification System

Benjamin E. Leiby, J. Richard Landis,* Kathleen J. Propert, John E. Tomaszewski† and the Interstitial Cystitis Data Base Study Group
From the University of Pennsylvania School of Medicine, Philadelphia, Pennsylvania

Purpose: We identified morphologically distinct subgroups in interstitial cystitis using cluster analysis and investigated the associations between cluster membership and urinary symptoms.
Materials and Methods: Of 637 patients enrolled in the Interstitial Cystitis Data Base Study 203 (32%) provided bladder biopsies at baseline screening, representing the focus of this analysis. A cluster analysis algorithm implemented in SAS® PROC CLUSTER using standardized distances to measure the dissimilarity of each pair of patients with respect to select histopathological features was used to construct subgroups of these patients. Multivariate regression models for baseline nighttime and 24-hour voiding frequency, urinary urgency and pain were developed, incorporating indicator variables for cluster membership as predictors. Longitudinal urinary symptom profiles during 3 years of followup were also compared among the morphology clusters.
Results: Three morphology clusters were identified, corresponding to unique pathological groupings. In cluster C_2 7 patients showed multiple pathological features of parenchymal damage, including several inflammatory features. In cluster C_1 17 patients was characterized by complete denudation of the urothelium and variable edema. In cluster C_0 in 179 patients none of the pathological features were present above the specified thresholds for C_2. Cluster membership was significantly associated with baseline nighttime and 24-hour frequency ($p < 0.001$, and with urinary urgency ($p = 0.03$). These significant increases in baseline symptom severity among clusters from C_0 to C_1 to C_2 persisted throughout the 3 years of followup.
Conclusions: These results suggest an important role for histopathological features in the predictive modeling of interstitial cystitis symptoms.

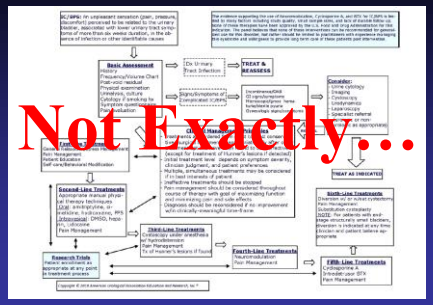
Key Words: bladder; cystitis, interstitial; biopsy; cluster analysis; urination disorders

Morphological Subgroups of IC

- 203 biopsies, 39 pathologic factors
- 3 subgroups identified by cluster analysis
  - 7 patients with multiple pathological features of parenchymal damage
  - 17 complete denudation, variable edema
  - 179 none of the pathologic features were present above the specified thresholds

Leiby BE, et. al.: J Urol 2007;177: 142-148

AUA Guidelines, J Urol 2011



Not Exactly…

Phenotyping Untangles the Puzzle

Interstitial Cystitis: a potentially curable disease

"A New Approach to Urologic Chronic Pelvic Pain Syndromes: applying oncologic principles to benign conditions"

- Diagnose and stage
- Treat to complete remission
- Consolidation therapy
- Monitor in remission

Payne CK: Curr Bladder Dysf Rep 2015

BPS cannot be treated without making a more specific diagnosis

My patient has chronic headaches. Should I follow the ANA treatment algorithm?

1. Tylenol
2. Imitrex
3. Physical therapy
4. Botox injections
5. Brain surgery

Common BPS Phenotypes

- Bladder Phenotype
- Myofascial Phenotype
- Pudendal Neuropathy Phenotype
- Systemic Pain Phenotype

Bladder Phenotype

- What we all learned—pain on bladder filling relieved by urination
- Consistently reduced volumes on diary
- Primary bladder tenderness on exam
- Pain relief with intravesical lidocaine

Myofascial Phenotype

- Often clear provocative factor
- Often other orthopedic issues
- Pain less clearly related to bladder
- Myofascial tender points > bladder, NOT only in pelvic floor
- Bladder diary shows many normal volume voids, especially overnight

Pudendal Neuropathy Phenotype

- Pain with sitting
- Specific sensory findings on exam
- Tinel sign over pudendal nerve
- Bladder symptoms less consistent and volumes not always reduced

Systemic Pain Phenotype

Do I really need to explain this?

"overlapping functional somatic syndrome including fibromyalgia, irritable bowel syndrome, chronic fatigue syndrome, chronic headache, and allergies"

- Focus treatment on central sensitization
- Look for untreated anxiety/depression
- Only when psych issues addressed should other therapy be instituted.
- Therapy aimed at restoring ADL

Five take-home points for managing IC/BPS

1. Ulcerative IC is a disease
2. BPS is not a disease; it is a syndrome
3. Don't think of IC & BPS the same way
4. IC is a potentially curable disease
5. BPS cannot be treated without making a more specific diagnosis, phenotyping

"In summary, a BioPsychoSocial model of patient care as proposed is meaningless unless it starts with a clear diagnosis (or at least a differential diagnosis). Algorithms of care are worth little for heterogeneous patient populations. Treatment must be individualized to the particular patient's disease."

ICS 2016 TOKYO

International Continence Society

46th Annual Meeting

13th - 16th September 2016

www.ics.org/2016

The Patient Perspective

Hypersensitive Bladder,
Interstitial Cystitis,
Bladder Pain Syndrome (Painful Bladder Syndrome),
Hunner Lesion

Jane Meijlink
Chairman
International Painful Bladder Foundation (IPBF)
www.painful-bladder.org

"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."

Bourque JP. Surgical management of the painful bladder. J Urol. 1951; 65:25-34.

Hypersensitive bladder, Interstitial Cystitis, Bladder Pain Syndrome, Hunner Lesion

- Pain, discomfort, pressure or some other unpleasant sensation - persistent or recurrent
- Increased urinary frequency day & night
- An urgent need to void

Hypersensitive bladder, Interstitial Cystitis, Bladder Pain Syndrome, Hunner Lesion

Leads to:

- Sleep disturbance
- Depression
- Anxiety
- Sense of helplessness and hopelessness
- But may also cause anger, irritability

Urgency, Frequency

- Constantly looking for toilets -> anxiety
- If there is a risk of no toilet then stay at home
- Leads to isolation
- Some jobs are impossible -> unemployment

Every patient is different

- Symptoms vary greatly from patient to patient
- But also from day to day in the same patient
- Symptoms may greatly increase in flares
- This means that treatment is highly individual, what works in one patient does not work in another
- Better phenotyping needed!

Impact on sexual relationships

- Both male and female patients are affected
- Leads to marital dysfunction and distress
- The health professional needs to find ways of approaching this subject since the patient may feel too embarrassed to do so.

Patients may suffer from one or multiple comorbidities

- Allergies/intolerances (which may include multiple drug intolerance)
- Chronic pain and fatigue syndromes, (e.g. fibromyalgia, chronic fatigue syndrome, temporomandibular joint disorders, migraine, vulvovaginal)
- Systemic autoimmune syndromes/diseases (e.g. systemic lupus erythematosus, Sjögren's syndrome, rheumatoid arthritis)
- Gastrointestinal and gastroesophageal disorders
- Neurological disorders

Multidisciplinary team approach is therefore essential!

So what else do patients need/want in practical terms?

Treatment:

- Treatment must be affordable and reimbursable
- It must improve quality of life
- Therefore, it must have maximum effect with minimum side effects.
- Current treatments frequently have such disabling side effects that the patient is unable to function normally.

Take home messages

1. Emotional support and empathy as well as practical support are needed from all players to help the patient learn to cope:
   - family doctor, specialist, physiotherapist, nurse, patient's family and partner, patient support group
2. Treatment is individual (= personalized medicine) and should take comorbidities into account in a multidisciplinary team approach.
3. Listen to your patients because they are the key to better understanding and better treatment of this still enigmatic disorder

Thank you!

www.painful-bladder.org

TICA
(Taiwan Interstitial Cystitis Association)

The President of TICA

Yu-Chen Lan

2016_ICS 2016-09-13 Tokyo

1

Outline

(1) • Unspeakable Pain

(2) • Evolution of TICA

(3) • TICA operation model

(4) • IC-The long and winding road

2

Unspeakable Pain

- Around my 35 years old – those uncomfortable symptoms attacked me intermittently.
- This feeling is like a knife cut my skin.

3

Evolution of TICA

- I saw lots of different clinics, included urology, gynecology,gastroenterology, and psychology. But my symptoms didn't relieve, and got worse than before.
- *I couldn't find any information relates with my symptoms during that time*, and I also had no idea what disease I got. I always worried about my symptoms, so I got panic disorder.

4

Evolution of TICA

- I met Dr. Lee. He diagnosed my disease called "interstitial cystitis" which was a really strange name for me.
- Actually, I felt happy at that moment. On the other hand, Doctor Lee told me this disease was unable to cure at this moment, it only can be controlled. Those answers let me fall into hell again!

5

Evolution of TICA

- The treatment outcome of IC didn't go well, and sometimes I loss of my faith. One day, I decided to give up all treatments when I waiting to see the doctor. Suddenly, there was a patient trying to tell me her experience about how to overcome this disease.

6

Evolution of TICA

- She encouraged me and let me become more confidence. I need to listen to the doctor, believe this disease will be controlled. The voice come into my ears, directly touched my heart.

- This power gave me the confidence to continue my following treatments. I began to interact with other patients, and shared my experiences.

7

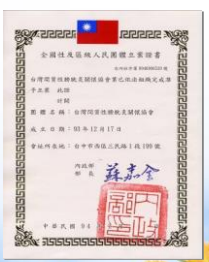
Evolution of TICA

- In 2004, there were lots of enthusiasm patients who wants to work together to establish Taiwan Interstitial Cystitis Association with Dr. Lee and other health care staff.

- In fact, the patient of interstitial cystitis has no different between normal people in appearance. As you know, this disease doesn't threat our life immediately, however, most people don't realize what interstitial cystitis is.

8

Establishment of TICA



TICA established in Dec,2004

9

Goals of TICA

TICA 間質性膀胱炎 關懷協會

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 relax and adjust to their lives, especially in the aspect of different types of pressure suchpsychology,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.

10

Promote IC public health

專家學者衛教演講 - TCS理事長 台北榮民總醫院 林登龍教授

小型聚會活動 - 骨盆底肌肉訓練 中山物理治療系 陳怡婷博士

News reports

Newspapers and magazines

IC press conference

11

The TICA support system

Outdoor recreational activities

Quarterly issue

Association website

TICA 台灣 間質性膀胱炎 關懷協會

Annual Conference activities

TICA Newsletter

Small gathering

Website of TICA

TICA Facebook

News letter publications of TICA

Inpatients Support of IC patients

Regular patients gathering (1-2/month)

TICA annual tour (once a year)

TICA annual meeting (once a year)

19

TICA Media Promotion

20

The long and winding road

–From an IC patient

The Indiana University Bloomingotn Campus
Language Education phD 2002-2006

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

Ming Huei Lee — Chair — Disclosure
Christopher Payne — Speaker — Disclosure
Alex Lin — Speaker — Disclosure
Yukio Homma — Speaker — Disclosure
Chui-De Chiu — Speaker

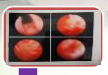
From Taiwan's perspective
- Taiwan IC Association (TICA) -

Presenter: Dr. Ming-Huei Lee
Feng-Yuan Hospital, Taichung, Taiwan

2016_ICS 2016-09-13 Tokyo

The Integration Between Multidisciplinary Care Team & TICA

- Multidisciplinary meeting
- Tele-care system (E-system)



- IC patient was admitted for cystoscopic hydrodistension

- IC multidisciplinary meeting

- Discharge and considered telecare system

2

Member of Multidisciplinary team

Urologist- *Ming-Huei Lee*

Gynecologist

Psychologist

Physical therapist

Chinese medicine

Urologist

Psychotherapist

Dietitians

Anesthesiologist

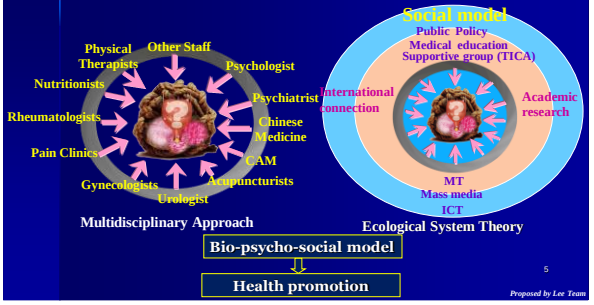
3

Multidisciplinary Management of IC/HSB/BPS

Treatment		Aimed effect
Pharmacotherapy		
- Peripheral pharmacotherapy	→	- peripheral physiological processes (nociceptive pain, urgency)
- Central pharmacotherapy	→	- central processes (sensation, cognition, affect)
Non-Pharmacotherapy		
- Psychotherapy & active behavior	→	- change of bodily and interpersonal behaviors sensation, cognition - active participation of patients in treatment (exercise)--TICA
- Passive physical intervention	→	- change of peripheral syndrome via physical methods
Others		
- Outside current medicine	→	- CAM - Health care system --TICA - culture beliefs
- Doctor- center	→	- doctor's behavior (education, training)

Why holistic management for IC?

- multifocal etiologies
- chronic visceral pain syndromes *(Cross talk vs. Up regulation)*
- co-morbidities
- nature histories poor described
- unpredictable treatment outcome *(Wax vs. Wane)*
- patients centered care



Bio-psycho-social model

⇩

Health promotion

5

Proposed by Lee Team

2011 Symbol of National Quality

2011國家品質標章證書
CERTIFICATE OF 2011 SYMBOL OF NATIONAL QUALITY
行政院衛生署台中醫院
解救「血淚的膀胱」－間質性膀胱炎B.P.S Model證
全人醫療照護團隊
有效期限：民國101年12月31日止

This is to certify that **Rescue「Bladder With Blood and Tears」- Bio-Psycho-Social Model Holistic Health Care Team of Interstitial Cystitis at Taichung Hospital, Department of Health, Executive Yuan, R.O.C.** is awarded The Symbol of National Quality in the **Featured Specialty Section, Hospital Category** by Institute for Biotechnology and Medicine Industry.
Date of Validity: Until Dec. 31st, 2012


The worldwide IC association
European
Japan
America
Society of IC of Japan (SICJ)
International Painful bladder foundation (IPBF)
Taiwan IC association (TICA)
Interstitial Cystitis Association (ICA)
Taiwan


The worldwide IC association
- What's next ?-
European
China
Japan
Korea
America
Society of IC of Japan (SICJ)
International Painful bladder foundation (IPBF)
Taiwan IC association (TICA)
Interstitial Cystitis Association (ICA)
Taiwan
Africa
Australia
South America


Wish we can cure IC/HSB/BPS!
Hope we can conquer IC/HSB/BPS!

The Long and Winding Road—A Self-Reflection of an IC Patient

- I would like to use the lyrics of the Beatles' song "The Long and Winding Road" to describe my journey as an IC patient in Taiwan.
- Just like the lyrics, IC symptoms usually lead travelers back to where they began their journey.

- When IC 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 patients are constantly struggling with different symptoms because of relapses, meaningful dialogue between patients and other people has never stopped.
- Through dialogue, IC patients can have valuable reflections as they are led to different doors during the entire process.

The First Dialogue

- 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."

Turning Point

- My impression of IC treatment did not change until I came to Taichung for work in 2006.
- Under the treatment of Dr. Lee, I changed the way I used to perceive the disease and myself as an IC 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

- 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!!!

Self-adjustment !

- 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.

The Last Dialogue

- 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.

Accept it! Be optimistic !

- 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.