

Clinical Characteristic Picture and Impact of Symptoms on Quality of Life of Interstitial Cystitis Patients in Taiwan

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Objective: No clinical characteristic picture and impact of symptoms on quality of life (QOL) of interstitial cystitis (IC) patients in Taiwan had been reported. This paper is intended to provide preliminary descriptive results of IC research in Taiwan.

Methods: A total of 319 patients, based on National Institute of Arthritis, Diabetes, Digestive and Kidney Diseases (NIDDK) criteria, were enrolled in the study from February 2004 through March 2006. Evaluation data included baseline demographic information, patient and family medical history, dietary effects, pregnancy data, sexual relationships with symptoms, and impact of symptoms on quality of life. The main responsibility of the hospitals discussed was patient care and data collection. Taichung Hospital presents the results.

Results: The Interstitial Cystitis Database (ICDB) patients were predominantly female, that is, 86% of the total, with an average enrollment age of 46. The analysis of various symptoms indicates the following distribution: (i) 94% frequency; (ii) 80% pain; (iii) 53% nocturia; (iv) 43% urgency; and (v) 10% associated incontinence. Approximately 83% reported pain over the bladder while in full stage, and 74% reported pain relief after voiding. The predominant characteristic of pain was full sensation (54%) with the predominant position on low abdominal area (52%). Moreover, 80% reported sleeping disturbance due to disease, and 66% reported difficulty in performing daily work.

Conclusions: Interstitial cystitis patients in Taiwan have lower economic status but lower impact on QOL than Western patients. However, the sexual-related pain and sleeping disorder were higher than previously thought and deserve our attention. Accordingly, this research provides a foundation for further investigations of baseline associations and longitudinal trends.

Key words epidemiology, interstitial cystitis, quality of life

1. INTRODUCTION

The clinical presentation of interstitial cystitis (IC) varies greatly. Until now, there are no globally accepted, objective diagnostic tests to aid in diagnosis, nor are there any validated, generally accepted symptom indices or any questionnaires that could be used in epidemiological studies.

The first epidemiologic study of IC was reported by Oravisto in 1975.¹ Since then several sporadic reports have been conducted with different prevalences from 17/100 000 to 500/100 000.^{2–5} Contradictory findings exist among these few available reports. Several reasons can explain such a discrepancy. One of the main reasons is the lack of a uniform definition of interstitial cystitis.^{6,7} The only recognized definition of interstitial cystitis was made by the National Institute of Arthritis, Diabetes, Digestive and Kidney Diseases (NIDDK), which included and excluded different criteria in order to have a uniform definition at a workshop in 1987.⁸ The purpose of the NIDDK definition was to establish universal criteria in order to compare clinical data among different research

studies. However, as interstitial cystitis was better understood, more clinicians (e.g. urologists, gynecologists and family practitioners) started to diagnose and treat interstitial cystitis according to their own interpretation. Many interstitial cystitis specialists have pointed out that the NIDDK criteria are intended for research purposes only and that they are too restrictive for clinical applications.⁷

From their experience with the NIDDK-sponsored collaborative multicenter study of interstitial cystitis called the Interstitial Cystitis Database (ICDB), Hanno et al. pointed out that more than 60% of the interstitial cystitis patients were under-diagnosed.⁹ The ICDB showed

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that of the 71% of subjects described by the researchers as definitely or very likely to have IC, only 32% met NIDDK criteria for those who had had complete evaluation and only 40% for those who had had partial evaluation.

It is impossible to have accurate epidemiologic data of interstitial cystitis unless definite criteria are made. However, no clinical characteristic picture of IC in the Asian area has been reported. Could there be ethnic disparity in the nature and clinical presentation of IC patients? It is our opinion that data of clinical presentation with baseline demographic information may be the first step in order to approach the issue. By using questionnaire data obtained from IC patients in three hospitals in Taiwan, we collected the demographic information, patient and family medical history, dietary effects on symptoms, previous history, pregnancy, sexual-related pain and impact of symptoms of quality of life (QOL). Herein, we report our initial descriptive data of interstitial cystitis patients recruited at three different hospitals in Taiwan.

2. METHODS

2.1. Study population

This is a hospital and urologist based study. The patients in the study diagnosed with interstitial cystitis were based on NIDDK criteria. The patients were enrolled to the study from three hospitals located in northern, middle and southeastern parts of Taiwan. The patients were recruited from February 2004 through March 2006. There are three researchers in the present study, including Ming-Huei Lee, Alex Tong-Long Lin and Hann-Chorng Kuo. They were all responsible for the enrollment of patients. The data were analyzed and documented by Ming-Huei Lee. The patients in the study were diagnosed based on the cystoscopic findings deemed as the major criteria. The clinical symptoms were evaluated and presented. The criteria were mostly adherent to the NIDDK criteria, except that the patient age was not limited to 18 years or older and the symptom duration was not necessarily longer than 9 months.

2.2. Symptom assessment for IC

The questionnaires included demographic, patient medical history, family medical history, dietary effects, past history, pregnancy history, and sexual relationship. They were designed according to the statements offered from patients with interstitial cystitis and were modified from previous studies by Koziol et al.¹⁰ and O'Leary preliminary IC symptom index.¹¹ Researchers in the study considered that different characteristics of patients with interstitial cystitis (e.g. pain perceived as throbbing) might reflect different subgroups of interstitial cystitis. Therefore, we developed the questionnaires mentioned above on the basis of these characteristics. The questionnaire was designed for self-administration to avoid the bias of interviewers and/or the judgment of physician or nurses.

2.3. Quality of life for IC

Quality of life (QOL) was assessed using questions from a validated QOL questionnaire. The questionnaire was directed at psychosocial aspects of interstitial cystitis, which can predict whether the lack of physical wellbeing will adversely affect personal functioning, that is, the performance or capacity to perform the kinds of tasks that most healthy people do in daily life (such as physical activities and mobility) and role functioning (such as employment).

3. RESULTS

3.1. Demographics

A total of 319 patients with a mean age of 46 years were enrolled in the study. The age at symptom onset was 38 years. The interval between the onset of symptoms and the diagnosis was 8 years. The female to male ratio was 86–14%. Seventy-seven percent of the patients were married, and 55% had education higher than junior high school. Employees and housewives comprised around 70% in our study group. Patients with a yearly income below NT\$400 000 (US\$12 000) comprised 71%. (The annual average GNP of Taiwan in 2003 was around US\$ 12 000.) (Table 1) Forty-four percent of the patients indicated that they felt stress pressure from their life.

3.2. Symptom severity and duration

The onset of first symptom occurred at the age of 37.6 years (ranging from 18 to 81 years). The duration of urgency/frequency was 62 months (ranging from 9 to 396 months). The duration of pain was 46 months (ranging from 9 to 492 months). The average daily voiding frequency was 16 times (ranging from 9 to 50 times), including 3.7 times (ranging from 1 to 18 times) during sleeping time. While 94% had frequency and complaint, 80% suffered from pain, 53% had nocturia, 10% associated with incontinence. Forty-seven percent of the IC patients in the study complained that their symptoms were persistent in nature. Eighty-three percent of the pain with a full urinary bladder was the prominent pain characteristic followed by 74% of pain relief after voiding. Forty-five percent reported pain when their urinary bladders were not full. Forty percent had burning pain during voiding. Fifty-four percent of the IC patients in the

TABLE 1. Basic demographic data of patients among Koziol, ICDB and Taiwan groups

	Koziol (1994)	ICDB (1995)	Taiwan (2005)
Sample size	565	424	319
Age (years)	53.0	44.3	45.8
Age at symptom onset	–	32.2	37.6
Female (%)	94.0	92.0	86.0
Marital status (%)	–	68.4	77.0
≥High school education (%)	–	56.0	55.0
Employed (%)	–	62.0	70.0
Annual income <GNP (%)	–	31.0	71.0

ICDB, Interstitial Cystitis Database.

TABLE 2. Location and type of pain among Koziol, ICDB and Taiwan groups

Koziol (1994)		ICDB (1995)		Taiwan (2005)	
Vaginal area	60.8%	Low abdomen	80.4%	Low abdomen	52%
Across lower abdomen	56.7%	Urethra	73.8%	Suprapubic	23%
Above pubic bone	53.2%	Low back	65.7%	Vagina	22%
Groin area	34.3%	Vaginal area (♀)	51.5%	Left low abdomen	14%
Across lower back	30.2%	Perineum (♂)	46.9%	Right low abdomen	12%
Right lower abdomen	19.2%	Others	27.7%	Left flank	11%
Left lower abdomen	16.7%	Rectum	24.7%	Right flank	10%
Right back under rib cage	6.5%			Inguinal	9%
Left back under rib cage	6.0%			Low back	8%

Type of pain			
ICDB (1995)		Taiwan (2005)	
Dull, aching	59.8%	Fullness	54%
Heaviness, fullness	58.1%	Soreness	32%
Spasms	54.8%	Sharp	22%
Soreness	48.3%	Hot stabbing	21%
Sharp	38.6%	Spasms	11%
Hot, stabbing	35.9%	Throbbing pulsating	4%
Throbbing, pulsating	31.5%	Dull aching	8%
		Others	3%

ICDB, Interstitial Cystitis Database.

TABLE 3. Factors aggravate symptoms in Taiwan group

Stress	44%	Beer	14%	URI	3%
UTI	31%	Red Wine	13%	Antibiotics	3%
Tea	29%	Whisky	13%	Strawberry	3%
Coffee	25%	Others	10%	C/S	1%
Orange	16%	Pepper	12%	Pelvic operation	1%
STD	15%	Chocolate	6%	Smoking	1%
Pineapple	15%	Banana	5%		
Walking	15%	Asparagus	5%		
Milk	15%	Sweeter	4%		

C/S, cesarean section; STD, sexual-transmitted disease; URI, upper-respiratory infection; UTI, urinary tract infection.

study complained the type of pain was a full sensation, followed by 32% of soreness, 22% of sharp, 21% of stabbing, 11% of spasms, 8% of dull, and 4% of throbbing. Fifty-two percent of patients pointed to the pain at the lower abdomen area, 23% at suprapubic, 22% at vagina, 14% at left low abdomen, 12% at right low abdomen, 11% at left flank area, 10% at right flank area, 9% at inguinal area, and 8% at low back area (Table 2).

3.3. Factors that aggravate symptoms

The factors that aggravated interstitial cystitis symptoms were screened. Among the factors, 44% of the patients indicated that stress was the factor most frequently encountered, followed by 31% of urinary tract infection. Beverages such as tea and coffee were the most frequent fluid that would aggravate IC symptoms. Oranges and pineapple were the most noted fruit that made IC symptoms worse (Table 3).

3.4. Patient and family medical history

The most associated diseases were recurrent urinary tract infection (28%), migraine headache (24%),

neurodermatitis (21%), and hay fever/allergic rhinitis (20%). The family history of the IC patients in this study were hypertension (18%), diabetes mellitus (14%), hay fever/allergic rhinitis (11%), heart disease (18%), urinary stone (10%), migraine headache (7%), neurodermatitis (7%) (Table 4). Thirteen percent of female patients had the history of hysterectomy and 15% had tube ligation. The average of doctor visitation was 3.2 doctors (1–37) and traditional doctor 1.3 doctors (0–10) before diagnosis. Eleven percent had a history of anti-depression or anti-anxiety drug intake. Five percent had an allergic drug intake. The average number of the children from married patients discussed was 1.9 persons. Sixty percent of these children were normally delivered. Thirteen percent of the female group discussed in the present study had a history of D/C, 7% had abortion experience, and 1% had ectopic pregnancy history. Twenty percent experienced worse symptoms during pregnancy with 53% happening in the third stage of pregnancy.

3.5. Sexual life and menstrual cycle

Forty-two percent of the female patients had no pain during or after sexual intercourse, while 34% experienced occasional pain and 24% had frequent pain. The location of post-sexual pain was lower abdomen (29%), vagina (30%), and back (3%). Twenty-nine percent of the female patients experienced flare-up symptoms related to their menstrual cycle. Twenty-six percent had frequency flare-up related to menstrual cycle, with 66% before menstrual cycle, 26% during menstrual cycle, and 8% after menstrual cycle. Fourteen percent of the female patients experienced flare up of pain related to the menstrual cycle, with 73% before, 17% during, and 10% after menstrual cycle.

TABLE 4. Patient and family history in Taiwan group

	Patient (%)	Family (%)		Patient (%)	Family (%)		Patient (%)	Family (%)
Recurrent UTI	28	4	Dry eye	8	2.0	Urolithiasis	5.0	10
Migraine headaches	24	7	HIVD	7	3.0	Heart disease	3.0	10
Neurodermatitis	21	7	Hypertension	6	18.0	Asthma	3.0	5
Hay fever/allergic rhinitis	20	11	Endometriosis	6	1.0	Fibromyalgia	3.0	1
Extremities Numbness/sting	12	1	Incontinence	6	2.0	DM	2.0	14
Frequent defecation	12	2	BS	6	1.0	RA	1.0	3
Arthralgia	11	6	Food allergy	6	3.0	SLE	1.0	1
Depression	10	4	Thyroid disease	6	6.0	Regional enteritis	0.3	0
Drug allergy	8	3	URI	5	0.9	TB	0	0

DM, diabetic mellitus; HIVD, herniated intervertebral disc; IBS, irritable bowel syndrome; RA, rheumatoid arthritis; SLE, systemic lupus erythematosus; TB, tuberculosis bacillus; URI, upper-respiratory infection.

TABLE 5. Activity (not difficult) of QOL between Koziol and Taiwan groups life

Activity (not difficult)	Koziol (1991)	Taiwan (2005)
Family relationships and responsibilities (%)	30.3	76
Relation of partner (%)	–	65
Short travel (%)	24.0	42
Working at position for which you are qualified (%)	21.1	34
Sleep (%)	11.6	20
Long travel (%)	5.7	17

3.6. Impact of IC on quality of life

The most frequently encountered problems indicated from the studied group were long travel (83%) and sleep (80%), working at position which patients were qualified to do (66%), short travel (58%), partner relationship (35%), family relationships and responsibilities (24%) (Table 5).

4. DISCUSSION

Comparing our data with the data analyzed in some large-scale research outside Taiwan, we have the following findings:

4.1. Basic information of the patients

The average age in the present study is the same as the age shown in ICDB, but is younger than that offered in the studies of Koziol et al.¹² This suggests that the average age of IC patients through clinical diagnosis has become younger with the increasing awareness of this disease in the field of medicine. Our patients reported that their first symptom occurred at the age of 38, but they did not get diagnosed until the age of 46. Thus, there is a difference of 8 years and it suggests that IC is not a disease that can be diagnosed at the early stage. Compared with the difference of 4–7 years documented in the studies outside Taiwan, the difference of 8 years in the present study implies that the understanding of IC in Taiwan is still not sufficient. In addition, the duration of frequency and urgency symptoms is longer than that of pain symptoms (i.e. 62 months vs. 46 months). It might imply that the initial symptom of IC patients includes frequency and

urgency, accompanied by the symptom of pain. Suffering from pain is then the biggest factor that causes IC patients to become serious about clinical and medical assistance. Some research studies have found that patients who suffer from early symptoms are younger than patients who suffer from typical IC patients. Variability and progression is commonly seen in interstitial cystitis. Because typical symptoms such as frequency, urgency, pain, and nocturia might not occur simultaneously, the biggest challenge that clinicians encounter is how to diagnose the disease at the early stage and how to treat patients appropriately.

4.1.1. Reasons for the increase in male patients

We can tell the difference between chronic prostatitis and interstitial cystitis more precisely at present day.. In the early days, many IC male patients might be fairly likely to be diagnosed with chronic prostatitis. As some researchers suggest, if patients suffer from symptoms such as urgency/frequency, nocturia and are diagnosed with prostatitis, chronic pelvic pain, or recurrent bacterial cystitis, clinicians should consider the possibility of interstitial cystitis.¹³ Likewise, if patients with the symptoms of urinary infection, gynecologic pain, or prostatitis show no sign of improvement after they receive medical or surgical treatment, clinicians should take into account interstitial cystitis as well.

Interstitial cystitis may be under diagnosed. It should deserve further investigation since the treatment modality between chronic prostatitis and interstitial cystitis in men was different.

4.1.2. Marital status

The data from Taiwan and other countries show that 70% of the IC patients are married. It should be pointed out that the disease status of IC patients will influence not only patients themselves but also their families. The economic burden from the IC patient and their family should not be ignored.

4.1.3. Education status

Forty-six percent to 61% of the patients in the study have a degree with or higher than senior high diploma. It shows that there are no correlations between the disease and patients' academic degrees.

4.1.4. Socioeconomic status

The average yearly income of 62% of Taiwanese patients is lower than the national per capita income of Taiwan in 2003. Nevertheless, only 31% of IC patients in the countries of North America have an average yearly income that is lower than their national per capita income. It suggests that IC patients in Taiwan are in a lower social class, but it should be pointed out that 34% of the IC patients discussed in the present study were housewives. Their incomes were conservatively calculated, which led to a striking difference between the average annual income and the national per capita income. Another reason was that our medical insurance system covered all the medical expenses. Patients could undergo the diagnosis procedure, without paying much money. Even the low economic status could get the service. However, low socioeconomic status of the IC patients was noted in one study.¹⁴ The socioeconomic status of IC patients should deserve further study.

4.1.5. Different painful positions

The lower abdomen is the most frequently painful area as seen in other studies (Table 2). The vagina area is also a common area. Pelvic floor is also a commonly painful area. Accordingly, IC influences the entire low pelvic area.

4.1.6. Types of pain

Full sensation of pain and soreness are two of the pains that are most commonly seen in IC patients as seen in other studies (Table 2). It suggests that IC is a chronic and progressive disease. Except for acute pain caused by a grave recurrence of IC, most of the pains are chronic dull pain, which is the reason why many IC patients do not appeal for medical support at the initial stage

4.2. Analysis of patients' and family members' diseases

4.2.1. Medical history of IC patients

Recurrent urinary tract infection, migraine, and allergic rhinitis fall into the first three symptoms in the medical history of IC patients. Accordingly, there is some correlation between allergy and IC, a relationship that we still cannot fully understand. This is why mast cells play a key role in the treatment of IC patients. The reason that recurrent urinary tract infection comprised a higher portion in our study than in the studies conducted outside Taiwan, might be due to the fact that the diagnosis of urinary tract disease is not based on urinalysis but on the symptoms described by patients themselves. However, before IC patients are being diagnosed, they might already suffer from recurrent urinary tract infection as well. When a patient presents with symptoms of pain, urgency, frequency and urine analysis showed pyuria, the diagnosis of IC should be suspected not ignored.

4.2.2. Medical history of family members

Diabetes is second place in the family history as seen in ICDB study. It may mean that the performance of certain diabetes genes of every other generation merits further investigation. Allergies have the tendency to be

hereditary and such diseases are commonly seen among IC patients and their family members. Many studies outside Taiwan have pointed out that there are several twin siblings among IC patients.¹⁵ The present study shows that there were some cases of twin sisters in Taiwan. As a consequence, the genes of IC can be our future research direction. The reason why high blood pressure was first place in our research should be further investigated.

4.3. The impact of ic on QOL

Interstitial cystitis patients in Taiwan could endure the impact of IC on the quality of life more than patients in other countries. It may indicate that Taiwanese IC patients have not had a sufficient understanding of this disease, so they have a higher degree of endurance of the disease. We can also analyze the phenomenon with the conclusion that the seriousness of IC among our patients was not so high that their quality of life was not influenced considerably. However, previous studies in patients diagnosed with IC demonstrated an impact on quality of life in low socioeconomic status and equivalent to that of rheumatoid arthritis and end stage renal disease.¹⁶ Further studies that include psychological evaluation should be performed in low socioeconomic individuals to better establish the impact of IC in these populations.¹⁶

4.3.1. Pitfalls of the study

The first pitfall of this research is that the questionnaire was not standardized, but modified from other studies. The second pitfall is that the questionnaire was not truly a study of epidemiologic prevalence because it was drawn from other research papers in order to understand the condition of IC patients among three hospitals in Taiwan. The third is that the study population may not represent the true epidemiologic data of IC in Taiwan. However, the physicians of the three hospitals had devoted their efforts to the diagnosis and care of IC patients. We believed our study could represent most of the clinical characteristic picture of IC in Taiwan.

We think that further research on the epidemiology of IC in Taiwan is needed to better define prevalence and incidence rates and to identify potential risk factors so that we may more effectively prevent and treat this chronic disabling condition.

Our findings are compatible with those of the empirical studies discussed above. With regard to feature of the patient's history, our findings confirm those of Ito et al. (2000),¹⁷ recurrent UTI and a history of allergy of some kind was reported in 28 and 19% of cases, respectively, compared to 28 and 20% in our study. This finding suggested that medical history of IC patients in Taiwan is similar to that in Japan.

Our study is different from the study conducted by Choe et al. (2011)¹⁸ with regard to the study method. All of our patients were diagnosed based on the physician-assigned diagnoses with cystoscopic finding treated as the major criteria, complemented by the symptoms, including frequency and pain, noted in the NIDDK criteria. However, the method of Choe et al. was performed by telephone

interview using O'Leary-Sant IC Symptom and Problem (OLS) index. Therefore, it may be unsuitable to compare the two patient groups.

5. CONCLUSION

Interstitial cystitis patients in Taiwan have lower economic status but lower impact on QOL than Western patients. However, the sexual-related pain and sleeping disorder were higher than previously thought and deserve our attention for improving QOL of the patients. In order to know if there is any difference of characteristic between the IC patients in Taiwan and in other countries, further research on epidemiology should be conducted. This is what we should strive to achieve in the future.

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Disclosure

The authors have no conflicts of interest.

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