



WOMEN'S HEALTH & REPRODUCTIVE NUTRITION REPORT

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Interstitial Cystitis: Overview*

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From: *Alternative Therapies in Women's Health*. 2001;3(5):36–39. (reprinted with permission)

Interstitial cystitis (IC), a chronic inflammatory condition of the bladder, is characterized by pelvic/perineal pain, urinary urgency and frequency in the absence of bacterial infection or other identifiable causes. The etiology of IC is unknown and there is no cure. For many years IC was dismissed as a “hysterical female condition”; as late as 1985, *Campbell's Urology* described IC as “a disease that...may represent the end stage of a bladder that has been made irritable by emotional disturbance... A pathway for the discharge of unconscious hatreds.”¹ The text finally has been revised and attitudes are changing slowly.

Epidemiology

There are an estimated 700,000 cases of IC in the United States, with projections running as high as several million; 90% of IC patients are female. IC can occur at any age, including childhood and adolescence (25% of patients are <30). The prevalence

of IC in the United States is three-fold greater than that reported in Europe.² Recently, the National Institutes of Health allocated \$7.5 million to be used for epidemiologic studies of IC.

Symptoms and Causes

Pain, urinary frequency and urgency are the paramount symptoms of IC. Dyspareunia can be so severe that many women abstain from all sexual activity. Bladder and suprapubic pain and pressure can range from mild to severe and may be accompanied by urinary frequency (as often as 60 times a day). Patients also may report urethral, vaginal or rectal pain, and lower back and thigh pain. These symptoms can disrupt every aspect of patients' personal and professional lives, resulting in sleep deprivation, depression, and in some cases, suicide. Many patients are unable to work fulltime, thus limiting their access to affordable health insurance. Others may be unable to work at all. Some have pain so severe it prevents them from riding in a car or even leaving their homes. The quality of life of IC patients has been documented to be worse than that of women undergoing dialysis for end-stage renal disease.³ IC can be associated with other chronic conditions such as fibromyalgia, vulvodynia, migraines, allergic reactions and gastrointestinal problems.⁴

The etiology of IC remains unknown but a number of theories are being investigated including: a defect in the bladder lining allowing substances in the

urine to damage the bladder wall; an immunologic/autoimmune response; an allergic reaction; an unidentified bacterium, fungus or virus; and a neurogenic inflammatory response.⁵ A familial or genetic component also is being investigated.

Diagnosis

No IC-specific urinary marker has yet been identified but two factors are under investigation: a glycoprotein (GP51) and an anti-proliferative factor.^{6,7} Also, a rhamnase/lactulose blood assay to test for bladder permeability (thought to be correlated with IC) is being studied.⁸

Cystoscopy with hydrodistension performed under general or regional anesthesia is considered the “gold standard” for confirmation of diagnosis and is therapeutic as well in some patients. Office cystoscopy may be too painful for IC patients and may not distend the bladder sufficiently to reveal the signs of IC: pinpoint hemorrhages or glomerulations (present in 90% of patients) and Hunner's ulcers (present in 5–10% of patients). Up to 10% of IC patients may show no signs of glomerulations or Hunner's ulcers with cystoscopy under general anesthesia.⁹ A potassium chloride sensitivity test has been proposed as a possible diagnostic tool for IC. The test consists of instilling a solution of potassium chloride into the bladder via urinary catheter and measuring pain response. A positive pain response may indicate a defect in the glycosaminoglycans (GAG) lining, which may be diagnostic

of IC. However, this painful test compounds an already painful condition. A recent study reports only 60% accuracy with this test.¹⁰

Conventional Treatment

A recent report from the Interstitial Cystitis Database, established in 1993, reported that of 581 women in the database, 105 (18%) were receiving no treatment.¹¹ An astounding 183 different treatments for urinary symptoms were prescribed by physicians. The most common physician-prescribed treatments for women at baseline were cystoscopy/hydrodistension (32.9%), amitriptyline (16.9%), phenazopyridine (14.3%), special diet (9.3%), intravesical heparin (9.1%), hyoscamine (7.1%), oxybutynin (5.9%), oral pentosan polysulfate sodium (5.5%), propoxyphene plus acetaminophen (4.8%) and urinary antiseptic combinations (4.5%). The authors point out that current pentosan polysulfate sodium is probably much higher; the drug was approved by the FDA in 1996, after most women had entered the database. Although this report was recently published, data in this paper date from 1990–1995; the IC Database has been concluded for several years.

The researchers note that there is a paucity of good, placebo-controlled, randomized clinical trials of therapies and clearly, there is no consensus on treatment.

Oral medications. The only oral medication approved specifically for IC is pentosan polysulfate sodium. *Interstitial cystitis cont'd on page 2*

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cifically for IC, pentosan polysulfate sodium, is a glycosaminoglycan-like material thought to help restore the bladder surface.¹² In double-blind, placebo-controlled trials, 38% of the patients treated with pentosan polysulfate sodium for three months reported improvement of their IC symptoms. In open-label trials, 61% of the patients reported improvement.¹² Low-dose tricyclic antidepressants (10-75 mg qhs) have been used both for their analgesic and anticholinergic effects that can help decrease urinary frequency.¹³ Selective serotonin reuptake inhibitors (SSRIs) also are used, but no research has been conducted on SSRIs. The most widely used antihistamine to treat IC is hydroxyzine, which inhibits mast cell degranulation, thought to play a part in some IC symptoms. It also has sedative and anxiolytic effects.¹⁴ Pain medications include anticonvulsants such as gabapentin or carbamazepine, and short- or long-acting narcotics. Other oral medications used in the treatment of IC include: antispasmodics (methenamine), anticholinergics (tolterodine tartrate, oxybutynin, hyoscyamine), H2 blockers (cimetidine, ranitidine), urinary alkalinizing agents (sodium citrate, potassium citrate), and adrenergic blockers (doxazosin, terazosin). None of these has been approved by the FDA specifically for IC.

Intravesical medications. Although oral medications are used more frequently to treat IC, medications instilled directly into the bladder still are considered a mainstay of treatment. DMSO (dimethylsulfoxide) — approved for use in IC in 1978 — commonly is used as part of a “cocktail” instillation combined with heparin, steroids, and/or anesthetics. BCG (*Bacillus Calmette-Guérin*) is an experimental treatment currently in phase III clinical trials; hyaluronic acid

also is undergoing clinical trials.

Transcutaneous electrical nerve stimulation. Some IC patients have reported temporary relief of symptoms with the use of transcutaneous electrical nerve stimulation (TENS). A small study comparing TENS (using the posterior tibial nerve) with acupuncture found little benefit for either;¹⁵ other studies have found TENS to be a useful tool in treating the pain of IC.¹⁶⁻¹⁸ Transvaginal biofeedback and electrical stimulation have also been used to treat pelvic pain caused by IC; no trials were identified on this treatment in IC patients.

Surgery. Laser surgery is used specifically to treat Hunner's ulcers. While it is not a cure, laser therapy can help to alleviate the symptoms of Hunner's ulcers for extended periods of time.¹⁹ Other types of surgery for IC, such as augmentation cystoplasty or urinary diversion, rarely are recommended because of potentially serious complications and its failure to relieve IC pain in many cases.

Sacral nerve stimulation implants. Sacral nerve stimulation implants, recently approved by the FDA for urge incontinence, urinary frequency, and urgency, currently are undergoing preclinical trials testing for use in the treatment of IC and pain. A case series tested percutaneous sacral nerve root neuromodulation (via test stimulation, not permanent implant) in 15 women with refractory IC.²⁰ Mean voided volume during treatment increased from 90 to 143 ml ($P < 0.001$). Mean daytime urinary frequency significantly decreased (from 20 to 11) and nocturia decreased (from six to two times) ($P = 0.01$ for both). Mean bladder pain decreased from 8.9 to 2.4 points on a 10-point scale ($P < 0.001$). Several quality-of-life parameters significantly improved; 73% of participants requested to proceed to complete sacral nerve root implantation. Another case series

in six women found significant improvement in voiding frequency, pelvic pain and urinary urgency (all $P < 0.05$) after five days of continuous sacral nerve root stimulation.²¹ Controlled trials of this therapy should be done.

Self-Help Techniques

There are no treatments that work for all IC patients. Patients with mild cases of IC may find significant symptom relief by implementing self-help strategies. Patients with more severe IC symptoms also may benefit by adding these strategies as adjuncts to their treatment regimen. None of the following treatments have been subjected to controlled clinical trials, but have been reported helpful by patients.

Diet. (See *Table 1*) Avoiding caffeine, artificial sweeteners, alcohol and tobacco can help to reduce IC symptoms. A diet low in acidic foods and beverages may help symptoms; some patients add Prelief® (a dietary supplement containing calcium glycerophosphate) to foods and beverages to reduce acidity. Diets low in the amino acids tyramine, tyrosine and tryptophan are used by some patients. Some IC patients follow salt-and/or sugar-restricted diets; others avoid foods containing

yeast.²² The consumption of vitamin C or some stimulant supplements, such as ephedra, may aggravate IC symptoms.

Stress-reduction techniques. Strategies used by IC patients include meditation, visualization, biofeedback, self-hypnosis, massage therapy and psychotherapy tailored toward the needs of the chronically ill.

Exercise. Exercise plans may include gentle stretching exercises that avoid tightening or jarring the pelvic region, pelvic floor relaxation exercises, yoga, low-impact aerobics, Tai Chi, and swimming. However, chlorinated swimming pool water may cause IC symptoms to flare.

Bladder retraining. The bladder retraining program is a self-help process by which patients learn to control their urge to urinate. It is essential that pain be under control before this program is attempted. When patients experience bladder pain or urgency, the normal impulse is to urinate to stop the symptom. A pattern of frequent voiding can be difficult to reverse. The goal of the bladder retraining program is to use a series of simple steps to achieve longer and longer periods between urinations. Working with a health care practitioner, a program is established for each patient beginning

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Table 1: THE IC DIET

Restricted Foods, Beverages and Other Ingredients

Milk/Dairy Products: aged cheeses, sour cream, yogurt, chocolate

Vegetables: fava beans, lima beans, onions, tofu, soybeans, tomatoes

Fruits: apples, apricots, avocados, bananas, cantaloupes, citrus fruits, cranberries, grapes, nectarines, peaches, pineapples, plums, pomegranates, rhubarb, strawberries, juices made from these fruits

Carbohydrates and Grains: rye and sourdough bread

Meats and Fish: aged, canned, cured, processed or smoked meats and fish, anchovies, caviar, chicken livers, corned beef, meats that contain nitrates and nitrites

Nuts: most nuts with the exception of almonds, cashews, pine nuts

Beverages: alcoholic beverages, beer, wine, carbonated drinks, such as sodas, coffee, tea, cranberry juice

Seasonings: mayonnaise, miso, spicy foods (especially such ethnic foods as Chinese, Indian, Mexican and Thai), soy sauce, salad dressing, vinegar

Preservatives and Additives: benzol alcohol, citric acid, monosodium glutamate (MSG), aspartame, saccharin and foods containing preservatives, artificial ingredients and colors

Miscellaneous: tobacco, caffeine, diet pills, junk foods, recreational drugs, cold and allergy medications containing ephedrine or pseudoephedrine, certain vitamins

Adapted from: Interstitial Cystitis Association's IC & Diet brochure.



From the Chair

Alyce Thomas, RD and
Barbara Luke, ScD, MPH, RD

As I write this last Chair's column, I am experiencing mixed emotions. On the one hand, I will be able to get back to some things that had to sit for almost a year. On the other, I will miss the excitement of being the leader of a fantastic, innovative, and future-thinking dietetic practice group. This has been a year of tremendous growth and expansion. You already know that our name was changed and with it a new venture into the area of women's health issues. This change will be reflected in next year's publications, which will feature both maternal and non-maternal topics.

ADA's recognition of WHRN's expertise in women's issues was evident as our DPG was consulted on several issues, including interviews for JADA, as content reviewers for publications and position papers, and as authors for upcoming ADA publications. We are looking forward to partnering with ADA on future projects.

As a result of a very successful breastfeeding workshop at last year's FNCE, we will have another workshop in San Antonio! This will be a full day session and CPEs and CERPs will be applied for. Look for the flyer in the issue. For additional information, go to our website: www.dietetics.com/whrmdp.

Lastly, I want to thank the most marvelous group that I could ever work with, the WHRN Board. I would never have survived this year without your help, encouragement and prayers. I salute you and I wish you much success in your future endeavors. For those who will be leaving the Board, I do hope that you stay in touch. Your expertise will be called upon in the future. Also, I want to extend a very special thank you to Dr. Yolanda Gutierrez, the outgoing past-Chair, who offered many words of wisdom.

Sometimes when you give something up, you wonder what will happen next. I fortunately don't have that concern because WHRN is being left in very, capable hands. Dr. Barbara Luke, the Chair-Elect, comes with a wealth of experience in women's health issues and I look forward to working with her in my new position as Past-Chair. I have asked Dr. Luke to give her perspective on the upcoming year. So without further ado, I introduce to you, the new Chair of WHRN, Dr. Barbara Luke!

Barbara It's official—our DPG has changed its name to Women's Health and Reproductive Nutrition, WHRN. With this change, we need to broaden our scope to encompass a wider breadth of issues related to women's health. Our editorial board has risen to the challenge, and I hope all of you will join us as we focus on more issues that span a greater part of the lifecycle. Attention to women's health issues are long overdue, and a good place to catch up on what's new and exciting is the US Department of Health and Human Services' Office on Women's Health website, www.4woman.gov. As our focus moves beyond the reproductive years, it is important to look at health along the lifespan continuum, with many factors from early childhood and adolescence affecting health well into the postmenopausal years.

All of us at the WHRN DPG are volunteers, each person with a busy other life filled with personal and work commitments. But one of the great benefits of volunteerism are the nonfinancial rewards of working with others who are also interested in women's health and in advancing the field of dietetics. You will have the opportunity to work with individuals across the country, and even



Editor's News

Selina C. Mkandawire, RD, EdD and
Kathy Scalzo, MA, RD

Well, I don't believe I am finally writing my farewell note for the WHRN Report. As I informed you in the spring issue, this would be my last column. I would like to thank all the Editorial Review Board and most of all, you, our most dedicated members. My work relied on each one of you to be successful. Lastly but not least, my best regards to our Chair, Alyce Thomas and my Assistant Editor, Kathy Scalzo, whose skills in editing gave us many great ideas.

Speaking of Kathy, she will be the new Publications Editor and it gives me pleasure to introduce this lady who has given her time beyond the call of duty.

It truly has been a pleasure serving as the Editor and I hope to see many of you in San Antonio, and now it is my pleasure to present to you, Kathy Scalzo.

Kathy I admit it. I don't need a TV. I find that, despite a significant monthly fee, my local cable company is getting away with playing repeat, after repeat, of the same old shows. And the new reality shows? Please!

As the incoming Publications Editor, I want you to get your money's worth. How? By providing you with cutting edge articles on topics you want to know about. With our recent name change, I am sure we have already attracted new members, and we can all learn from each other. My goal is to add a few new features to the Report, including Lactation Case Studies (we already have two volunteers); Practice Points, real-life applications of information presented in the articles; and Something to Think About, a member reaction column to a recent abstract or study. I will also be working with your new Board to expand the publication (hopefully) from eight to twelve pages.

So, I admit it. I like to read. I like to write. And I like to think that I will make a good Publications Editor. But I am counting on you, as my peers, to help me. I am already indebted to the outgoing Board for their leadership, particularly Alyce Thomas, outgoing Chair, who has been so patient and thorough in helping me learn the ropes! So, thank you all in advance. Call or e-mail me with your ideas; I won't make you wait for a commercial.

internationally, building professional alliances and personal friendships. This is the perfect time to become more active in our DPG. Feel free to email me if you want to become more involved—I promise you won't regret your decision.

Election Results

The Executive Committee is pleased to announce the results of the WHRN election. The following will begin their terms of office on June 1, 2003

Chair-Elect: Darlene Husch, MA, RD, CDE

Treasurer: Maria Duarte Gardea, PhD, RD

Nominating Committee

Chair-Elect: Claire Dalidowitz, MS, MA, RD

Awards: Andrea R. Jenkins, MS, RD, CLC

Many thanks to Maureen Wojtczak, Nominating Chair and the Nominating Committee for a job well done!

Practice Points for Interstitial Cystitis

Kathy Scalzo, MA, RD

Controlled studies on the effect of a specific diet prescription on interstitial cystitis (IC) symptoms are not available. However, there are some starting points for dietetic professionals working with women with IC.

- Coach patients through an elimination diet. The chart above can be used as a starting point to eliminate the foods most commonly irritating to women with IC. In addition, the Interstitial Cystitis Association (ICA) website (www.ichelp.org) includes a list of foods from each category best tolerated by IC patients.
- Establish a specific fluid time schedule. Adequate fluids can help promote the appropriate urinary dilution, but many patients avoid drinking liquids to decrease the number of trips to the bathroom. Also, be aware that many patients use baking soda, high in sodium, or potassium citrate on a daily basis to alkaline their urine.
- Evaluate the dietary fiber content. Work with the client to add sources of daily fiber to improve bowel function. Constipation, due to the many diet restrictions and food avoidances, is a common problem. Medications used to treat IC, including tri-cyclic antidepressants and pain medicines, can also contribute to the

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with a four-week period of holding the urine for a specific number of minutes or hours (based on the individual's current average voiding schedule). The patient is encouraged to wait a specified period after their first urge is felt before urinating (15 minutes, for example). If severe pain is felt before the period has elapsed, voiding is encouraged. If after waiting, the patient finds that the need to urinate has diminished, then she/he should wait until the next urge to void is felt. At the end of one month, the time interval is increased, and at the end of the second month, the interval is increased again. It is acceptable if intervals are occasionally longer or shorter, as long as the minimum interval occurs most of the time.

Pain relief. Self-help sources of IC pain relief include cold packs and/or hot packs placed on the pelvic floor region, sitz baths, and, for those not on salt-restricted diets, drinking a solution of water and a teaspoon of baking soda during flare-ups. There are no established guidelines for this practice, and patients should be cautioned about repeatedly consuming several teaspoons of baking soda be-

cause of potential health risks.

Other self-help techniques. Learning new sexual techniques that do not place as much stress and pressure on the bladder is helpful. Female IC patients have found that positions other than the missionary position put less stress on the bladder. Water-based lubricants can be helpful. Wearing loose-fitting clothing and using unbleached and unscented toilet paper can also help to alleviate IC symptoms.

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problem. Adequate fluid intake is important (see above).

- Evaluate safety of vitamin and mineral supplements. IC patients may benefit from vitamin supplementation due to their many dietary restrictions, but the various ingredients within a multi-vitamin preparation may irritate their symptoms. The ICA recommends that patients purchase individual vitamin or mineral supplements to make it easier to identify dietary triggers that may cause symptom flare-ups. Patients may be inappropriately supplementing their diet with megadoses or using synthetic vitamins to replace whole foods.

Remember, each patient is an individual and will respond differently to nutrition therapies.

Resources:

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Additional Resources:

- <http://www.niddk.nih.gov/health/urolog/pubs/cystitis/cystitis.htm#5> A patient education brochure by the National Institute of Diabetes & Digestive & Kidney Diseases (NIDDK).
- <http://www.nlm.nih.gov/medlineplus/interstitialcystitis.html> An excellent homepage of links to reputable IC pages.

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CONGRATULATIONS!

Jamillah Hoy Rosas, WHRN Report's Calendar of Events Coordinator, was selected for a 2003 Outstanding Dietetics Student Award from the New York State Dietetic Association in the Dietetic Internship/AP4 Dietetics Program category. Congratulations Jamillah, and all the best as you embark on your career in dietetics.

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Hospital practices play an important role in breastfeeding initiation. Implementation of the "Ten Steps to Successful Breastfeeding" has been shown to significantly increase breastfeeding initiation and duration.^{17,18,19} Hospitals must be held accountable when they provide human milk substitutes to breastfeeding infants without medical indication, when they discharge a breastfeeding dyad without documenting correct latch-on and assessment of effective feeding, and when they allow staff to provide breastfeeding information that is not evidence-based.

Most women stop breastfeeding in the first two weeks after delivery because they encounter difficulties or concerns related to quantity and quality of their milk. Seeing formula in the bassinet in the hospital or getting discharge packs of formula undermines the new mother's confidence in her ability to breastfeed exclusively. Every new breastfeeding mother needs ongoing support and information appropriate to her situation. Frequent telephone contact with a breastfeeding peer counselor or other support person can help a woman over the normal hurdles she encounters in the early weeks. Anticipatory education for new mothers includes how to recognize infant feeding cues, signs of satiety and the number of voids and stools to expect per day. Individual preferences affect traditional and non-traditional approaches to healthcare. The personal experiences of biases within healthcare systems are additional barriers for patients.²⁰

Because of the lack of diversity in the healthcare workforce, staff is likely to counsel clients from cultures other than their own. To work effectively in cross-cultural situations, healthcare providers should strive for cultural competency. The five essential elements of cultural competency include:

1) valuing diverse clientele and co-workers; 2) assessing personal cultural blind spots and biases; 3) understanding the dynamics of difference; 4) assessing cultural knowledge; and 5) adapting to diversity.²⁰

Strategies

All perinatal healthcare providers should be knowledgeable about the role their specialty plays in breastfeeding promotion, protection, and support.¹ Dietetic professionals have especially important roles because when they use their skills to assess the mother's eating habits, they may be the first to detect linguistic or cultural barriers or breastfeeding problems. Other roles for dietetic professionals include:

- Making appropriate referrals and taking the lead in ensuring that barriers and problems are addressed in all aspects of care in the hospital or clinic.
- Assembling an interdisciplinary team that may include the pediatrician, obstetrician, lactation consultant, social worker, and peer support and ensure that one interdisciplinary care plan is developed for the mother and infant.
- Modeling appropriate documentation within progress notes and thereby setting an example for other healthcare providers.

Healthcare providers should become aware of practices in the community that support or hinder breastfeeding. For example, some groups do not know the value of colostrum so they wait "until the milk comes in" to put the baby to breast. Some groups have dietary beliefs surrounding pregnancy, childbirth and breastfeeding including foods they must or must not eat and how they balance foods using yin and yang or hot and cold food theories. Healthcare providers can use cultural informants to learn about the community. They can gather and

categorize resource material related to the care of culturally diverse groups within the community and share those resources with coworkers. Once general community practices are known, the healthcare provider should not assume that all individuals from the community follow those practices. It is important to ask the client open-ended questions about what they believe or practice around an issue and document the responses. Healthcare providers should communicate information to clients in a way that the clients receive the message being communicated. They should check frequently to be sure that the client understands the information and accept responsibility if they are misunderstood.

Body language, gestures, what distance the client regards as personal space, and eye contact all influence the comfort level of clients when they meet with healthcare providers. The healthcare provider can build a rapport with the client by beginning with an open-ended question and affirming the response. The client will hear the educational message when there is rapport. The educational message should be targeted to what the client does not know or needs to change. When the client feels she has been heard and is involved in setting goals, there is greater likelihood of compliance with the care plan and meeting goals.

Pregnant and breastfeeding women need to hear the consistent message that human milk is for human infants from everyone involved with their care. To fulfill their role in the elimination of racial disparities in breastfeeding, many healthcare providers will need training. This training includes not only management of lactation, but also cultural competency and active listening skills training. Effective breastfeeding promo-

tion and support extends beyond pregnant and breastfeeding women and includes significant influential friends and family, especially the baby's father and grandmother. The national objectives for breastfeeding were not met in the last two decades. If everyone fulfills his or her role in protecting, promoting and supporting breastfeeding, the objectives for 2010 can be reached.

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