



Understanding IC and Diet

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Who Am I?

- IC patient since 1998...likely had it since HS
- In denial about diet for awhile
- Moderator Diet and IC message boards for Interstitial Cystitis Network (ICN)
- Counseled IC patients on diet
- Wrote "*Confident Choices: Customizing the Interstitial Cystitis Diet*" & "*Confident Choices: A Cookbook for IC and OAB*"

Quote

"Changing our diet is something we choose to do, not something we are forced to do. Instead of dreading it, try saying, "There's another thing I get to do to help myself."

Greg Anderson, athlete and cancer survivor in "The 22 Non-Negotiable Laws of Wellness"

Objectives

- Brief History of IC Research
- Is There an IC Diet?
- How Does Diet Affect IC Symptoms?
- Elimination Diet Strategies

Objectives for Dietitians

Often as dietitians we are trying to change the invisibles (blood sugar, cholesterol), or we deal with very difficult problems such as obesity or eating disorders. Helping interstitial cystitis patients, on the other hand, can be extraordinarily satisfying! IC patients are generally highly motivated to regain some control over their symptoms in a situation which often seems out of control.

Objectives for Dietitians

- Learn how to counsel patients to use food and voiding diaries
- Learn how to teach patients to implement an elimination diary, and navigate the various IC Diet lists
- Explore the various supplements marketed for IC patients
- Gain valuable insight into other lifestyle aspects of an interstitial cystitis patient.

History of IC/PBS

1836	Mercier describes first documented case of IC.
1887	Skene first describes inflamed bladder with damaged mucosa calling it "interstitial cystitis."
1914	Hunner documents bladder ulcers: Hunner's ulcers
1944	IC is documented in men
1953	IC is documented in children
1950's	The beginning of the "dark ages"
1984	Vicki Ratner, physician with IC forms Interstitial Cystitis Association—advocacy, patient support, research
1987	First NIDDK research criteria established/updated 1988
1991	Interstitial Cystitis Data Base (NIDDK)
2001	Interstitial Cystitis Clinical Trials Group (ICCTG)
2006	October 25, 26: International Symposium U of Maryland

1987 NIDDK Research Criteria

- Hunner's ulcers (automatic diagnosis)
- At least two of the following:
 - Pain with full bladder—relieved by emptying
 - Suprapubic, pelvic, vaginal, and/or perineal pain
 - Glomerulations on endoscopy
 - Reduced bladder capacity

1987 NIDDK Research Criteria

- Hunner's ulcers (automatic diagnosis)
- At least two of the following:
 - Pain with full bladder—relieved by emptying
 - Suprapubic, pelvic, vaginal, and/or perineal pain
 - Glomerulations on endoscopy
 - Reduced bladder capacity
- 1988: Revised for exclusions:
 - No disease that could mimic IC (cancer, prostatitis, bacterial cystitis, genital herpes)
 - Age restrictions
 - Metrics placed on cystoscopy

Problem?

- NIDDK criteria were for research only—to establish homogeneous subject groups
- Physicians (unfamiliar with IC) used NIDDK guidelines for clinical diagnosis
- Reinforced the "all in your head" theory
- Men with non-bacterial prostatitis—IC?
- Children?



Good for Research, Bad for Patients

In 1999, Hanno, et al. examined patient charts and compared them with the NIDDK values:

- 1988 criteria worked for research...90% of subjects had clinical confirmation of IC
- But...the criteria excluded about 60% of the estimated population.

Did that exclude people with less severe cases who might show response to diet?



Full Disclosure: Current Research

- Interstitial Cystitis Data Base (ICDB)
 - Five-year prospective cohort study
 - Enrolled "real" people
 - Followed 1993 through 1997
 - Currently considered the gold standard for patient characteristics
- Second five year phase:
 - IC Clinical Trials Group
 - Currently, IC Clinical Research Network
- MaGIC (Maryland Genetics of IC)
- EPIC (Events Preceding IC)

Is There an IC Diet?

- Historical resistance to diet connection
- Understanding “evidence-based”
- Anecdotal reports from IC patients and physicians
- Various versions of the “IC Diet”

ICA 2004 Online Survey*

- 92% of patients reported that certain foods or beverages make their symptoms worse.
- Over 84% of those patients reported some symptom relief by modifying their diet.
- I do not know of any other therapy for IC that can boast those numbers.

*<http://www.ichelp.org/youropinion/Survey-Diet-Results.html>

2006 Formative Research

ARTICLE IN PRESS

Effect of Comestibles on Symptoms of Interstitial Cystitis

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Purpose: Anecdotal evidence suggests that patients with painful bladder syndrome/interstitial cystitis report symptoms exacerbated after consuming particular foods, beverages, and/or supplements. We determined the prevalence of the effect of comestibles on painful bladder syndrome/interstitial cystitis symptoms and identified particular comestibles those were likely to affect such symptoms.

Methods: An 84-item oral validated questionnaire designed to detect whether food, beverage, and/or supplements have an effect on bladder symptoms was administered to 106 patients meeting National Institutes for Diabetes and Digestive and Kidney Diseases criteria for interstitial cystitis. In addition to assessing general questions about the effect of comestibles on painful bladder syndrome/interstitial cystitis symptoms, patients were asked to indicate whether each of 70 individual items worsened, improved or had no effect on symptoms. Each response was numerically scored on a scale of -2 to 2 and mean values were generated for each comestible item.

Results: Of the surveyed patients with painful bladder syndrome/interstitial cystitis (PBS/IC), 60.4% indicated that the consumption of certain foods or beverages caused symptom exacerbation. There was no correlation between dieting and the effect of comestibles on symptoms. Patients who reported that specific foods worsened symptoms tended to have higher urinary tract interstitial cystitis symptom index and problem index, and/or pelvic pain and hyperreflexic pain symptoms index scores. A total of 25 comestibles items had a mean score of lower than -1.0, including carbonated, caffeinated and alcoholic beverages, meat, fruits and juices, artificial sweeteners and spicy foods.

Conclusions: There is a large cohort of patients with painful bladder syndrome/interstitial cystitis in whom symptoms are exacerbated by the ingestion of specific comestibles. The most frequently reported and most bothersome comestibles were coffee, tea, soda, alcoholic beverages, citrus fruits and juices, artificial sweeteners and hot pepper.

Key Words: bladder cystitis, interstitial, diet, interstitial status, questionnaire

Conclusions:

*“There is a large cohort of patients with (PBS/IC) in whom symptoms are exacerbated by the ingestion of specific comestibles. The most frequently reported and most bothersome comestibles were coffee, tea, soda, alcoholic beverages, citrus fruits and juices, artificial sweeteners and hot pepper.”**

*Shorter, B., Moldwin, R. (2007). Effect of Comestibles on Symptoms of Interstitial Cystitis. *The Journal of Urology*, 178 (145-152).

How Does Diet Affect IC Symptoms?

- IC patients have “wounded” bladders
- Allergic reaction (sensitivity)
- Exciting the nerves (such as caffeine)
- Exploring the acid/alkaline connection
 - Not necessarily scientifically valid
 - Acid in doesn't always equal acid out
 - Alkaline urine can affect the bladder also



“Elimination” Diet

- Just a way to sort out trigger foods
- Classic elimination diet
 - Rice
 - Chicken
 - Lamb
 - Green beans
- No need to start from scratch with IC! We know many of the most common bladder irritants.

Stages of Elimination Diet

- Determining patient's baseline—1 week
 - Voiding and Pain Diary
 - Food Intake Diary
- Wash-out period—2 to 3 weeks
 - Only foods from "Usually OK" list
 - Continue diaries
- Reintroduce foods—3 days plus per food

Plan When to Do This

- Don't do this when they are trying other new treatments/medications
- Make sure they have a couple of months "free" to focus on this (ex: not the months preceding their daughter's wedding!)
- Create menus in advance/grocery lists
- Include family in planning process

Foods to Test First

- Help patients make a plan of action!
- Foods high in nutrition
 - Blueberries and raspberries
 - Bananas
 - Whole grain breads
 - Low-acid orange juice
 - Almonds
- Foods that add flavor (onions, spices)
- Foods that they miss the most

Other Ways to Maintain Nutrition

- Determine individual personal trigger foods and only avoid those, not what others avoid.
- Portion size and preparation techniques may make a difference.
- Different foods may affect patients' at different stages of the disease
- "Rotate" troublesome foods

Be Persistent!

- Sometimes diet doesn't seem to help
- Many factors can influence the intensity of IC symptoms
- Use voiding/pain diary to record
 - Medications
 - Activities
 - Sleep patterns
 - Stress
- Consider waiting to do the elimination diet at a later date

Medications that Can Affect IC

- Pseudoephedrine (original Sudafed™)
- Ephedrine (used in weight loss products—ma haung)
- Medications with alcohol
- Ibuprofen
- Green tea extracts
- Kola nuts
- B vitamins

Activities that Can Bother IC

- Running or jogging (alt: walking)
- Sit-ups or crunches (alt: pilates, yoga)
- Kegels (mixed reviews)
- Riding bikes/exercise cycles (alt: recumbent bike)
- Sexual intercourse (talk to a pelvic floor therapist, nurse, or learn more from other IC patients online)

Stress and IC

All in patients' heads? Yes! But not what you think:

- Stress causes incredible chemical changes
- "Fight or Flight"
- Mind/Body connection or psychoneuroimmunology (PNI)
 - *Molecules of Emotion* by Candace Pert, PhD
 - *Everything You Need to Know to Feel G(o)od* by Candace Pert, PhD

Minimizing the Effect of Stress

- Avoid stress when possible
- Don't procrastinate
- Take on a hobby, or learn something new
- Progressive relaxation, massage (give or get!)
- Exercise
- Three deep breaths
- Pray or meditate
- Get plenty of sleep



"I am so tired!" Sleep and IC

Why?

- Interrupted sleep
- Body needs sleep to heal—wants to heal!
- Stress hormones, cycle of non-sleep
 - Connection to fibromyalgia?



Getting Good Sleep with IC

- Relaxation methods (pray, meditate, guided imagery tapes)
- Take a 30 minute walk after dinner
- Stretch out legs before bed
- Epsom salts or baking soda bath
- Stick-on heating pads (not electrical)
- Chamomile or "Sleepytime" tea
- Warm milk with a few drops of vanilla
- Turn off the TV
- Read something soothing
- Change positions (sleeping on tummy seems to be best, but experiment!)

Supplements & Alternatives

- Acid reducers (Prelief® & pH Science®)
- L-Arginine (increases nitric oxide)
- Glucosamine
- Chondroitin
- Fish oil (omega-3 oils)
- Quercetin
- Valerian root (used as directed, not with other sedating medications)
- Chamomile

Other Alternative Preparations

- Cystoprotek
- CystaQ
- BladderQ
- Desert Harvest Aloe products
- Pure H.A. - hyaluronic acid



For More Information

Confident Choices™ Website: www.ic-diet.com

To Contact Julie:

NutraConsults@aol.com

Interstitial Cystitis Association: www.ichelp.org

Interstitial Cystitis Network: www.ic-network.com (also IC friendly food and comfort products for sale)

Quote

"There is always hope.
Sometimes there's no cure,
but there is always healing."

Dr. Daniel Brookoff, MD
Interstitial Cystitis and Pain Management
Northern California Summit on Chronic Pain - Sept. 27, 1997
<http://www.ic-network.com/handbook/brookoff.pdf>

Confident Choices™: Customizing the Interstitial Cystitis Diet

This easy to use workbook walks a patient through the maze of determining their personal trigger foods. Includes:

- Menus
- Recipes
- Grocery store lists
- A diet for flares
- Exercise and stress reduction hints
- List of IC resources
- Supplement facts and
- Patient stories

To order: www.Amazon.com or www.ic-diet.com
Or phone 248-961-3613 for bulk shipments.



Confident Choices™: A Cookbook for IC and OAB

- Contains over 200 recipes, food preparation hints, and personal reflections that only a dietitian with interstitial cystitis can offer.
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