

## INTERSTITIAL CYSTITIS PATIENTS' USE AND RATING OF COMPLEMENTARY AND ALTERNATIVE MEDICINE THERAPIES

### Hypothesis / aims of study

With few very effective treatments available for interstitial cystitis (IC), the interest in complementary and alternative (CAM) therapies among patients is high. A number of supplements are marketed directly to patients. No studies have gauged patients' use of these therapies or compared their perceived effectiveness. The aim of this study is to determine the use and perceived efficacy of CAM therapies among IC patients.

### Study design, materials and methods

In April 2009, the Interstitial Cystitis Association (ICA) surveyed patients on their use of CAM therapies for IC. Respondents rated the effectiveness of 49 therapies known to be used by patients in eight categories: diet, acupuncture, movement therapies, mind-body techniques, physical manipulation, herbal supplements and topicals, nutritional supplements, and lifestyle changes. Ratings for control of IC symptoms on a five-point scale were: completely controlled, pretty well controlled, somewhat controlled, not at all, or made symptoms worse. Responses of those reporting an IC diagnosis were analyzed.

### Results

2,101 subjects responded from the ICA email list, the highest number to date for any IC patient survey. Responses from the 1,982 patients who confirmed receiving a diagnosis, were used for this analysis. The 10 highest-rated therapies, based on positive ratings (controlled symptoms completely, pretty well, or somewhat) by patients trying them were: eliminating food and beverages prompting symptoms, heat or cold, completely avoiding all foods and beverages listed in ICA diet guidelines, stress reduction, relaxation, calcium glycerophosphate, massage, meditation, physical therapy for the pelvic floor, and regular exercise (Table 1). Among herbs and supplements listed, six were rated positively by  $\geq 50\%$ : calcium glycerophosphate (74.6%), probiotics (58.8%), fish oil or other omega 3 supplement (57.6%), vitamin D (55.0%), herbs prescribed by a Chinese medicine practitioner (54.0%), and a proprietary glycosaminoglycan supplement (53.5%). The majority (61.9%) of patients discussed CAM therapies' safety and effectiveness with a traditional healthcare provider. When a therapy was recommended, the recommendation was most often (51.4%) made by a doctor.

### Interpretation of results

The large response to this survey demonstrates IC patients high interest in CAM. Interest is also high among traditional healthcare providers. Patients rated management of dietary triggers and nondrug adjuncts to pain management as the most helpful. Among supplements perceived as helpful, many are not marketed for the condition.

### Concluding message

IC patients' interest in and use of CAM therapies is high and interest of providers is higher than expected. This large data pool can help clinicians counsel IC patients about CAM and direct future research initiatives, such as selection of a particular treatment for randomized placebo-controlled trials, or studies regarding impact of specific CAM on IC patients' quality of life.

Table 1. Responders for the top 10 therapies in the ICA CAM survey (N=1,982)

Therapy	Controlled symptoms, n (%):				Total trying modality
	Completely	Pretty well	Somewhat	Total responders	
Food/beverage symptom exacerbators	64 (4.2)	703 (46.3)	562 (37.0)	1,329 (87.5)	1,517
Heat/cold	24 (2.6)	325 (34.5)	474 (50.4)	823 (87.5)	941
"ICA diet"	76 (6.0)	564 (44.9)	442 (35.2)	1,082 (86.1)	1,257
Stress reduction	14 (2.0)	250 (35.8)	298 (42.7)	562 (80.5)	698
Relaxation	20 (2.6)	201 (26.3)	362 (47.4)	583 (76.3)	763
Calcium glycerophosphate	25 (2.5)	355 (36.0)	356 (36.1)	736 (74.6)	987
Massage therapy	17 (3.4)	144 (29.2)	205 (41.6)	366 (74.2)	493
Meditation	14 (2.3)	136 (22.8)	248 (41.6)	398 (66.7)	596
Physical therapy (with internal)	15 (2.8)	194 (36.7)	140 (26.5)	349 (66.0)	528
Regular exercise	22 (2.3)	259 (27.6)	330 (35.2)	611 (65.1)	937

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<i>Is this a clinical trial?</i>	No
<i>What were the subjects in the study?</i>	HUMAN
<i>Was this study approved by an ethics committee?</i>	No
<i>This study did not require ethics committee approval because</i>	Participation in the internet-based survey was voluntary.
<i>Was the Declaration of Helsinki followed?</i>	Yes
<i>Was informed consent obtained from the patients?</i>	No