



# Rationalized and Simplified Dietary Recommendations for Interstitial Cystitis/Bladder Pain Syndrome (IC/BPS) Patients Based On Responses to a Questionnaire

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## Abstract

**Background:** We set ourselves the objective to highlight the therapeutic effect of the implications of a disease-specific diet in interstitial cystitis/bladder pain syndrome patients and to collect subjective impressions of the diet directly from the patients. We also aimed to critically analyze the many dietary suggestions available for BPS patients and select the simple, easy-to-follow that would make their lives easier. Since dietary habits, spices, etc., vary widely from even country to country, the present study provides a picture of Hungary's BPS dietary habits. Still, several of our findings may also provide valuable information at the international level.

**Methods:** Self-administered questionnaires were sent out to 246 already diagnosed BPS patients about their tried or regularly used diets and personal experiences. These data have been statistically evaluated and compared with patients' dietary habits before and after the diagnosis of BPS.

**Results:** Our diet recommendations are mainly based on international recommendations of BPS, the national experiences of different patient organizations, and statistical evaluation of the patients' returned questionnaires. We set up a rationalized, much easier-to-follow dietary recommendation based on our experiences gained over the last ten years with more than 600 BPS patients and their responses.

**Discussion:** Despite the partially contradictory dietary recommendations, the answers to the questionnaire of diagnosed BPS patients let us recommend an easy-to-use essential dietary guidance, supplemented by the enormous importance of continuous high-rate diuresis and the neutral pH value of the urine. As the constant chemical irritation of the bladder wall and the BPS diet reducing the irritation can be observed as a causal treatment of the disease.

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**Keyword:** Bladder pain syndrome; Interstitial cystitis; Special diet; Glycosaminoglycan layer; Liquid consumption; Acidity of the urine.

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## Background

Interstitial Cystitis (IC), also known as Bladder Pain Syndrome (BPS) represents a less known, poorly diagnosed, widespread progressive disease resulting in a miserable quality of life. This associated symptoms, frequent urination, and various sort of pain in the bladder and urethra, but often also in the external genitals in both genders. Without appropriate treatment, the IC/BPS can progress and lead to bladder shrinkage and even kidney failure after many years.

The estimated number of IC/BPS patients in Hungary is around 50,000-60,000. However, no exact figures are available as diagnosis rates are poor (2-3%). Therefore, we can draw our conclusions based on foreign data sources and project those to domestic population numbers. Based on the current IC/BPS diagnosis rates, the number of patients registered in our country is around 1000 [1-6]. The disease affects both sexes but is 4-5 times more frequent in women.

The origin of IC/BPS is still unknown, but there is evidence that it is due to insufficient production of the superficial lymph layer of the bladder [7]. This layer is composed mostly of Glycosaminoglycan (GAG) molecules or a combination of polysaccharide molecules such as collagen, elastin, fibronectin, and laminin. The bladder wall also contains heparin, hyaluronate, chondroitin sulphate, keratin sulphate and dermatine sulphate [8]. Thus, the proteoglycans and glycoproteins in the GAG layer form a dense film that shields the pain receptors in the submucosa from irritating substances such as salts, acids and degradation products that are excreted in the urine. This layer is not essentially impenetrable, but in its intact, undamaged state maintains a balance between inflow and outflow [9]. The problem is caused by the discontinuity of the GAG layer with respect to the excretory substances in the urine. Thus, a chronic chemical irritation triggers an inflammation of non-bacterial origin (sterile inflammation) in the bladder wall layers (Figure 1). This is confirmed by analysis of biopsy samples from patients suffering from IC/BPS. Barrier disruption is associated with pathophysiological, gene expression, and molecular changes. An example of this is blisters with Hunner lesions, which exhibit diffuse and intense inflammation due to overexpression of genes that promote inflammation [10].

Pain is also increased by the proliferation of mast cells and their histamine production. Furthermore, due to the prolonged stimulation of pain receptors, there is an increase in the number of receptors at these sites, leading to further pain [11]. As inflammation increases over the years, connective tissue cells migrate into the edematous tissue, causing the bladder to lose its elasticity. This process may lead to the development of a scarred, shrunken bladder with consequent deterioration of kidney function for years.

According to the MalaCards database, IC/BPS has several non-urolological co-morbidities. Examples: rhinitis, panic disorders, irritable bowel syndrome, adenomyosis, esophagitis, gastric ulcer, keratoconjunctivitis, and radiculopathy. These pathologies are more likely to occur in the presence of IC/BPS [12].

## Material and Methods

The protocol designed for the medical management of IC/BPS was based on international recommendations and national experience.

A dietary questionnaire was designed to investigate the

importance of the diet of patients with IC/BPS and to identify which foods have the most expressed positive or negative impact on the symptoms, possibly even on the outcome of the disease. The data obtained from the questionnaire: "Impact of medications, non-medicinal products, dietary and lifestyle patterns on symptoms of interstitial cystitis (bladder pain syndrome) - questionnaire survey" should improve the quality of patient care. Data were collected and managed anonymously. The (self-administered) questionnaire was sent out to 246 patients, and 126 responded (52%). Their age distribution ranged 30-99 years.

The questionnaire contains 30 questions providing single and multiple-choice options and some short answer options. In the first half of the questionnaire, we asked more general questions, e.g., gender, condition, symptoms, and food consumption in the second half. Based on literature data (diet recommendations) we focused on the following main groups during the preparation of the questionnaire: vegetables, fruits, dairy products, and known irritative drinks: including coffee, tea, and energy drinks.

The study was conducted under authorization number 8230-2/2019 of the Medical Research Council Scientific and Research Ethical Committee.

## Results

The answers proved a wide variety of symptoms and conditions of the patients. Nonetheless, we successfully created a questionnaire to investigate patients' dietary practices and their impact on the pain associated with this chronic urological disease.

General treatment of the IC/BPS was determined by the severity of the patient's symptoms, condition, and age (systemic oral GAG-layer replenishment protocol, or local intravesical instillation therapy, or both of them, in combination). But in all cases, we added lifelong dietary substitution therapy to it.

### Findings of the questionnaire-based survey

Upon assessing the dietetic questionnaires, the following conclusions can be drawn:

The difficulty of diagnosing the disease also became apparent as 37% of patients were only diagnosed after four years; in the most fortunate cases, 10% of patients were diagnosed within one year.

The most common complaints, which were consulted with physicians by the patients, were bladder pain (30%), frequent urge to urinate (28%), urethral pain (24%), vaginal pain (11%), and blood in the urine (7%).

Before diagnosis, 60% of patients were taking antibiotics, 19% were taking painkillers, and 14% were taking herbal remedies or combinations of these. Respondent patients found that antibiotics deteriorated their condition.

More than 50% of the patients surveyed had other chronic diseases. Most of these patients had high blood pressure (43%) and high cholesterol (30%), but many also had allergies (27%) and complaints of reflux (25%).

For women, we looked whether there was a correlation between their menstrual cycle and the increase in symptoms. Among the female patients surveyed, 58% did not experience a correlation, and 42% experienced an increase in symptoms

immediately before or after menstruation.

82% of patients changed their food habits after being diagnosed with the disease. In general, they switched to diets recommended for IC/BPS patients, but these diets were not wholly consistent.

After reviewing several recommendations and dietary suggestions, we focused on the following during the design of the questionnaire:

Most of the respondents consume 1000-2000 mL (46%) or 2000-3000 mL (44%) of fluids per day.

Of the dairy products, milk consumption is recommended by other food protocols (13,14). In contrast, 23% of former milk drinkers surveyed stopped drinking milk altogether. A similar decrease was observed for yoghurt, cottage cheese, sour cream, and long-aged cheeses. 16% of the patients reported no longer consuming dairy products at all (Figure 2). Regarding coffee, black and green teas, and energy drinks, the majority (79%) had regularly consumed one of these before their diagnoses. After diagnosis, this habit fell to 21%. By contrast, consumption of decaffeinated coffee increased by 32%. Consumption of green and black tea has also fallen dramatically by 39% and 29% respectively, and energy drink consumption has also fallen in the same manner. 35% of respondents indicated that they did not drink coffee, tea, or energy drinks at all (Figure 3). Here it is worth mentioning that leaving caffeinated coffee awoke the most expressed resistance in the patients of both genders.

In addition, we also assessed what types of drinks intensified the symptoms:

Patients listed alcoholic beverages (e.g., red wine, beer, short drinks), orange juice, blackcurrant juice, and carbonated soft drinks.

We were also curious to know about patients' vegetable consumption patterns. Tomato consumption decreased the most (by 60%) after diagnosis. In addition, consumption of onions, green onions, beans, and potatoes also reduced. However, only 2% said they did not eat these vegetables at all (Figure 4). In addition, spinach, broccoli, and pumpkin were also mentioned as having increased their unpleasant symptoms.

We also surveyed the consumption of some popular fruits (apples, bananas, apricots, peaches, watermelons, and blueberries). The questionnaire survey revealed that consumption of each of these had fallen by about half following diagnosis. There was also a nearly 5% increase in the number of people who said they did not consume these fruits at all (Figure 5). Some patients indicated that citrus fruits, grapes, blackberries, raspberries, cherries, and pears also increased their symptoms. However, some patients found no correlation between fruit consumption and the worsening of their symptoms.

According to international recommendations, spicy and highly spiced foods may worsen patients' symptoms. Accordingly, most people surveyed (66%) did not consume these foods [13,15,16]. We also asked about alcohol consumption habits. 60% said they did not drink any alcohol. 37% said "yes, but rarely", and only 2% of respondents said they drink alcohol on a regular basis.

We were also interested in the prevalence of allergies and intolerances among patients. 71% of the patients did not have any allergy or intolerance. 29% said they did have one of these, and

the majority (69%) were lactose intolerant. The next most common was gluten allergy (36%) and much less common were egg, peanut, and nuts allergies. The astonishingly high rate of lactose and gluten intolerance far exceeds our expectations. 64% of our patients take dietary supplements and vitamins. The most common products were vitamin preparations: vitamin C and acid-free vitamin C, vitamin D, and multivitamins, but they were also taking vitamins A, K, B6, and B12. For minerals and trace elements, the most common were calcium, magnesium, and iron preparations. In addition, many patients also mentioned cartilage strengthening preparations (chondroitin sulfate, collagen), probiotics, poppy seed oil, fish oil, humic acid, Omega3, herbal teas and herbal extracts (e.g., grapefruit drops, rose root and milk thistle extracts).

17% use herbal products regularly, and 49% only rarely. The most common herbs were lemongrass (37%), cranberry (29%), and medicinal bearberry (25%). Preparations were also used for nettle, chamomile, hibiscus, goldenseal, birch, and small-flowered willow herb.

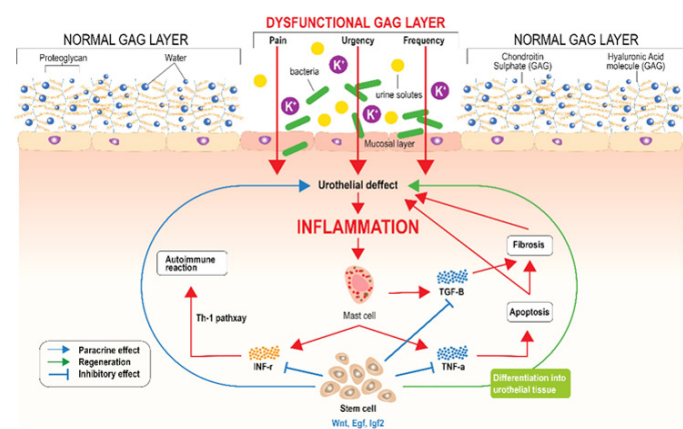


Figure 1: Dysfunction of the GAG layer in IC/BPS disease.

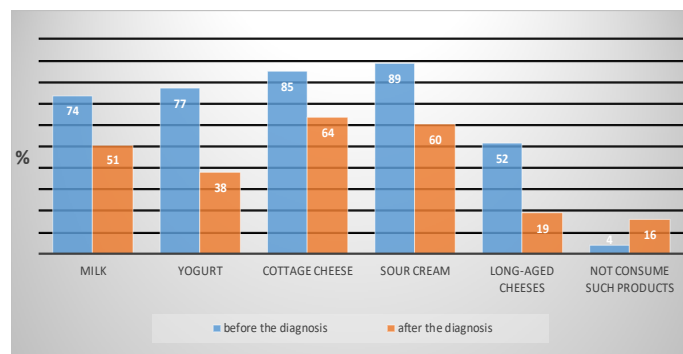


Figure 2: Consumption of dairy products in case of IC/BPS before and after diagnosis (n=126).

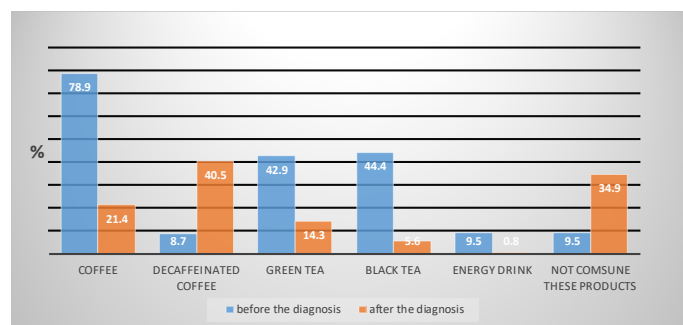
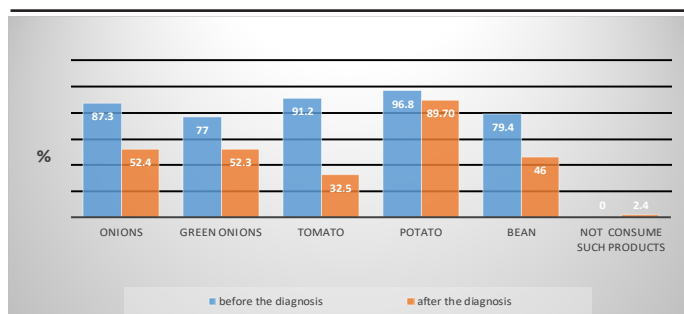
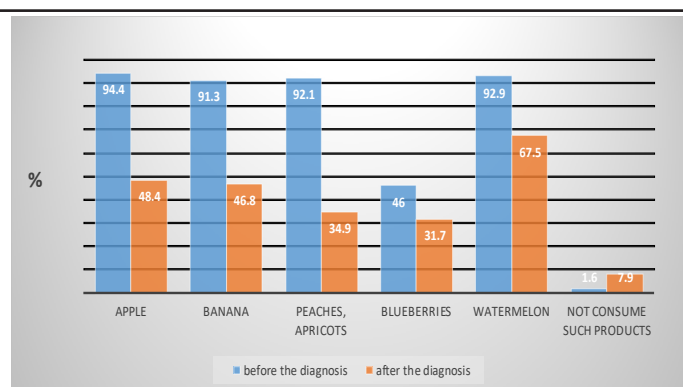


Figure 3: Irritative drink consumption in case of IC/BPS before and after diagnosis (n=126).



**Figure 4:** Vegetable consumption for IC/BPS before and after diagnosis (n=126).



**Figure 5:** Fruit consumption for IC/BPS before and after diagnosis (n=126).

**Table 1:** The proposed simplified food diet based on study results.

FORBIDDEN	CONSUMABLE (to a certain extent)
Alcoholic drinks	Decaffeinated coffee
Coffee, Black tea, Green tea	Milk, Cottage cheese
Energy drinks	Sour cream
Hot spicy foods	Onion, Green onion, Bean, Potato
Tomato	Lemon, Watermelon, Pear, Blueberries,
Fruits: Banana, Peach, Apricot, Grapes, Blackberries, Apple, Raspberries, Citrus fruits	Any other foods not listed as forbidden and based on the patient's individual experience do not cause discomfort and should freely be consumed.
Foods prepared with vinegar	
Fibrous soft drinks, fruit juices	
Carbonated soft drinks	
Long-aged cheeses, Yogurt	
Spinach, Pumpkin	

**Discussion**

Dietary recommendations are always used as an augmentary measure besides oral and/or local intravesical medications. The individual treatment protocol naturally depends on the patient's condition, but dietary support is inevitable.

The liquid intake is also an integrated part of the diet. All patients should continuously dilute the urine to reduce its irritative effect. Concentrated (hypertonic) urine contains all irritative compounds in high concentration. If a patient does not care about it and does not drink for 8 to 10 hours during nighttime, urine gets very irritative due to continuously growing concentration. As a result, the pH level of the morning urine and the symptoms during the whole daytime reduce remarkably. Therefore one of the most important messages is to drink approximately 1000 ml water at night.

The role of watermelon consumption in IC/BPS is quite debated, but we think that due to the enormously fastened diuresis, it has rather a positive than a negative influence.

By comparing the results of our dietary questionnaire with the recommended diet of the Interstitial Cystitis Association (14), we can conclude that there are some similarities and contrasting experiences. The American recommendation and the opinion of our patients agree that high acid fruit juices, carbonated soft drinks, and alcoholic beverages are worsening their symptoms. There is also agreement on the contraindications of consuming coffee, yoghurt, sour cream, long-aged cheeses,

and tomatoes. In the U.S. guidelines, onions, certain kinds of beans, and avoidance of spicy and highly seasoned foods are mentioned. Similar conclusions can be drawn during the assessment of the questionnaires.

There is a unique role of taking antibiotics in IC/BPS. As bacterial infections (UTI) may more frequently occur due to the damaged mucus surface, the use of targeted antibiotic therapy is legitimate or even required. In contrast, if the symptoms are not due to UTI but the IC/BPS causes them, any use of antibiotics is unjustified. Such incorrect antibiotic treatment cannot be efficacious but may have serious side effects or even directly increase bladder irritation.

Our survey revealed that our patients tend to avoid dairy products such as milk, cottage cheese, and fruit such as watermelon, pears, and blueberries. However, the U.S. recommendation is not opposed to dairy products such as milk, cottage cheese and fruit such as watermelon, pears, and blueberries; our patients tend to avoid these products. The U.S. guidelines do not recommend vitamin C because of its acidity. A corresponding result in the survey is that some patients prefer to consume the alkali metal salt of vitamin C. However, no adverse effects of vitamin B were reported by our patients.

In our practice, we always ask for the used dose of vitamin C because, in most cases, it proved to be taken in very high doses. Therefore we recommend not exceeding 200 mg/die of the ascorbic acid because this could result in an irritative, significant pH reduction of the urine.

Patients very often use herbal products. Plenty of them are available on the market and even actively pushed by advertisement. Their way of action, effect, and possible side-effects have never been thoroughly examined in detail. Therefore their use cannot be recommended in an evidence-based manner. On the other hand, the active agents in such extracts, mostly aromatic compounds excreted directly into the urine, usually have awful irritative effects. Other plant extracts make urine extremely acidic, and as a result, symptoms get rather worse than better.

The proper diet for each patient should be personalized and determined on an individual basis. This is because patients' pain threshold, sensitivity, and severity of the disease may show a high-grade variation. However, our results point out which foods IC/BPS patients should avoid the most and which foods are acceptable in moderate quantities (Table 1). In addition, for the first time in Hungary, we performed a dietary questionnaire survey on IC/BPS, gaining a series of essential information on this topic.

The assessment of our dietary questionnaire shows that juices containing higher amounts of natural acids, carbonated soft drinks, and alcoholic beverages may aggravate the disease. In addition, coffee, yogurt, sour cream, long-aged cheeses, and tomatoes are not recommended.

A high volume of liquid intake should always be recommended as an integral part of the diet.

In conclusion, bladder pain syndrome without treatment is a serious disease with a severe outcome, which requires prompt and adequate drug therapy. Besides oral systemic and local, intravesical drug therapy given by GAG-layer replenishment intention, a dietary treatment is still an essential and clinically proven efficacious adjuvant measure. It is the easiest, less expensive, and most rapid way of significantly reducing even intolerable symptoms of IC/BPS. By continuously decreasing the irritative effect of the urine, an appropriate alimentary diet is not just a symptomatic therapy. Still, it should also be considered an essential part of causal therapy. Based on their questionnaire responses, the real-life feedback of IC/BPS patients let us simplify the dietary recommendations and help patients successfully navigate the maze of countless suggested diet lists.

#### Ethical Approval and to participate

Approval of the research protocol by the Institutional Reviewer Board (approval No. 8230-2/2019 (Medical Research Council Scientific and Research Ethical Committee; Hungary).

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**Abbreviations:** IC: Interstitial cystitis; BPS: Bladder Pain Syndrome; GAG: glycosaminoglycan.

#### Authors' Contributions

- Literary research (A.H.)
- Disease-related data provision (S.L.; P.B.)
- Development of drug therapy protocol (S.L.; P.B.; A.H.)
- Questionnaire design (A.H.; Gy.H.; P. B.; S. L.)
- Evaluation of the survey answers and their comparison with the U.S. proposal (A. H.)

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#### Availability of data

The datasets used and/or analysed during the current study are available from the corresponding author on reasonable request.

**Supplemental material:** Supplemental material for this article is available online.

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