

A Patient Survey on Nomenclature and Definition of Painful Bladder Syndrome / Interstitial Cystitis and the Nature of Urgency in PBS/IC Patients.

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Introduction and Objectives:

Recently much attention has been focused on new criteria and a new definition for interstitial cystitis. The new name "painful bladder syndrome" was proposed in 2004 with the ultimate aim of replacing the term IC. Additionally, there has recently been debate concerning use of the term 'urgency' for PBS/IC patients and whether this term should be reserved for overactive bladder/urgency incontinence patients. It has been controversially suggested that the urgent need to void experienced by PBS/IC patients is due to pain only and not to a specific urgency sensation. The aim of this international survey was to discover: 1) how patients would define PBS/IC and/or what they consider to be the most characteristic features; 2) whether, based on their own experience, they feel the sensation of urgency to be the same as pain, or a different sensation and also what happens if they cannot find a toilet immediately they feel an urgent need to void; 3) patients were also invited to express their views regarding the new name "painful bladder syndrome".

Method: A survey with 3 open questions was sent to patients in different countries, placed on a website and distributed by several patient support groups in late 2005/beginning 2006.

Use was made of open questions rather than ticking boxes so as to allow patients to provide background information rather than just answering yes or no. Although open questions are difficult to analyze, the detailed responses produced valuable insight into the impact of PBS/IC on patients' lives.

Responders:

78 patients responded in English, French, Dutch or Spanish from 12 different countries (Australia, Belgium, France, Ireland, Italy, Mexico, Netherlands, New Zealand, Sweden, Switzerland, United Kingdom, USA)
4 responders were male, 74 female.
Ages varied from 22 to 83 years. Average age 54.46 years. Symptoms varied from mild to very severe.

Question: How would you define PBS/IC?

Almost all responders felt that the definition of PBS/IC rests on three main symptoms:

pain, urgency and frequency.

Equal emphasis should therefore be paid to these three symptoms in a definition.

Many felt that the urgency/frequency had the most traumatic impact on their life and that this should most definitely not be omitted in any definition.

Conclusion: The definition should include pain, urgency and frequency.

Question: What are your views on the name Painful Bladder Syndrome?

In favour:	24 (30.7%)
Possibly in favour (with reservations):	5 (6.41%)
Against:	30 (38.5%)
No opinion:	19 (24.4%)

Those in favour felt that it would at least stop other people thinking they had an infection or asking "IC: what on earth's that?": "People would understand what you mean".

Some of those possibly in favour but with reservations felt that PBS was a good umbrella but further classification of patients was needed beneath this umbrella. Others felt that PBS is a very inadequate name, but on the other hand better than the confusion caused by IC.

Those against stated that they were reluctant to abandon the name interstitial cystitis because:
PBS is too vague, doesn't cover the symptoms as experienced by the patients, not strong enough, fails to convey the huge and intense impact of urgency/frequency.
"If we have a new name it has to be better than this".
"IC is the better name for the moment until research produces new insights".

Conclusion: Those with pain predominating as a symptom tended to favour PBS. Those in whom urgency/frequency predominated found the name inadequate. Many alternative names were offered.

Poignant quotes:

"I was not diagnosed as definite IC because my physician could not see ulcers"

"My IC causes me depression and anxiety"

"IC makes normal life almost impossible"

"I feel completely disabled"

"I often sit on the toilet and cry"

"Tears come to my eyes with the pain"

"I have urinated behind many bushes along the highway"

"If I travel by car, I take a bedpan with me"

"I never put myself in the position of not being able to find a toilet"

"When you are out of your home, the whereabouts of toilets is paramount"

"I stay at home and miss out on life"

Question: Is urgency the same as pain?

13 (16.6%) stated that urgency and pain are the same
53 (67.9%) stated that urgency is a completely different sensation to pain
12 (15.3%) expressed no opinion.

Patients stated that pain and urgency would sometimes occur simultaneously, sometimes pain without the urgency and sometimes urgency without the pain. Although the survey did not ask where the urgency sensation was localized, 3 responders volunteered the information that they felt it to be in the base of the bladder or urethra, while the pain in contrast was felt everywhere in and around the bladder. The responders who feel that pain and urgency are the same sensation tended to be those with severe pain predominating.

Conclusion: Urgency is a separate sensation to the sensation of pain.

Hypothesis: Constant severe pain may mask separate urgency sensations.

Action point: Desirable for an in-depth scientific study to be carried out into the nature, location and cause of urgency sensation in PBS/IC patients. The study population should include a cross-section of patients from mild to severe and specifically should not be all severe patients. Insight could lead to improved treatment.

Question: What happens if you can't find a toilet immediately?

In reply to the question concerning what happened if they could not find a toilet, the responses were very similar:
They felt nauseous, had an urge to vomit, began to sweat, go hot and cold, pain sensation over the whole body, flushed, bloated, faint, shaky, dizzy, suffocating sensation, panic, while many experienced increasing extreme pain and difficulty in starting urination if they had to wait to reach a toilet. Some reported that they might have to self-catheterize in such a situation.
6 patients reported that they would leak (ages 43-81 years).

Several responders emphasized that they would never place themselves in this position and would not leave the house if there was a risk of not finding a toilet.

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