

PREVALENCE OF INTERSTITIAL CYSTITIS/ PAINFUL BLADDER SYNDROME IN THE UNITED STATES

Hypothesis / aims of study

The Rand Interstitial Cystitis Epidemiology (RICE) study was designed to develop an epidemiologic definition of interstitial cystitis/painful bladder syndrome (IC/PBS) and use that definition to estimate the prevalence of IC/PBS in United States women.

Study design, materials and methods

We first reviewed the literature and conducted a structured expert panel process to arrive at an initial symptom-based IC/PBS case definition. We then recruited a cohort of 599 adult women who had been diagnosed with IC/PBS and/or overactive bladder, endometriosis or vulvodynia (conditions that produce symptoms similar to IC/PBS). Interviewers who were blinded to diagnoses conducted telephone interviews using RICE items and other standard measures for IC/PBS. An iterative approach was then used to construct and test multiple different variations of the RICE definition for the presence of IC/PBS. This process resulted in a High Sensitivity definition (sensitivity 81%, specificity 54%), and a High Specificity definition (sensitivity 48%, specificity 83%). We then conducted a two-stage population screening survey over a period of one year. The first stage involved asking a brief series of screening items on a national telephone omnibus survey of approximately 2000 households per week (~100,000 households) over a period of one year. Households that were identified as having one or more women with possible IC/PBS were asked to allow a referral to RAND for more intensive screening using the case definition shown on the Table. We then calculated a population prevalence estimate after weighting for non-response to initial and follow-up interviews, multiple women in the household, and other missing data.

Results

RICE definitions and corresponding prevalence estimates are provided in the Table.

Definition	Criteria	National Prevalence Estimate (95% CI)
High Sensitivity	<p>Pain: During the past 3 months, have you ever had a feeling of pain, pressure or discomfort in your lower abdomen or pelvic area? (Yes, No)</p> <p>Frequency: During the past 3 months, how many times on average have you had to go to the bathroom to urinate during the day when you are awake? 10+</p> <p>Urgency1: During the past 3 months, have you had a strong urge or feeling that you had to urinate (or "pee") that made it difficult for you to wait to go to the bathroom? (Yes, No)</p> <p>Urgency2: Would you say that this urge to urinate is mainly because of pain, pressure or discomfort, or mainly because you are afraid you will not make it to the toilet in time to avoid wetting? (Pain, pressure, discomfort; or Fear of wetting)</p> <p>Note: A positive response to the pain question plus either the frequency question or both of the urgency questions is required.</p>	<p>6.5%</p> <p>(6.1 to 6.8%)</p>
High Specificity	<p>Pain1: During the past 3 months, have you ever had a feeling of pain, pressure or discomfort in your lower abdomen or pelvic area? (Yes, No)</p> <p>Pain2: As your bladder starts to fill does your feeling of pain, pressure, or discomfort usually: (get worse, get better, or stay the same)</p> <p>Frequency: See above</p> <p>Urgency1: See above</p> <p>Urgency2: See above</p> <p>UTI: Did all of your symptoms disappear (each time) after you took antibiotics? (Yes, No)</p> <p>Endometriosis: Did you ever have hormone injections (such as depolupron) to treat endometriosis? (Yes, No)</p> <p>Note: A positive response to both pain questions plus either the frequency question or both of the urgency questions is required. In addition, negative responses to the UTI and endometriosis questions are required.</p>	<p>2.7%</p> <p>(2.5 to 2.9%)</p>

Interpretation of results

Approximately 3-6% of United States women age 18 or over meet RICE symptom criteria for IC/PBS. This is consistent with previous estimates based on other, less extensive population screening efforts.

Concluding message

The lack of objective disease markers for IC/PBS is partly to blame for the limited amount of epidemiologic information that exists related to IC/PBS. However, it is important to continue to study the epidemiology of IC/PBS, as this is of interest to policy makers and physicians who treat women with this very challenging condition. The results of our study suggest that the public health burden of IC/PBS may be underestimated. It is clear that no single questionnaire-based definition of IC/PBS is able to simultaneously identify all IC/PBS cases (sensitivity) and also distinguish these cases from similar conditions such as OAB, endometriosis and vulvodynia (specificity). Therefore, the use of two definitions (such as the high sensitivity and high specificity definitions presented here) may be the best approach, as these definitions will provide a prevalence range that 'brackets' the true prevalence value.

<i>Specify source of funding or grant</i>	NIDDK
<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>	Yes
<i>Specify Name of Ethics Committee</i>	RAND Insitutional Review Board
<i>Was the Declaration of Helsinki followed?</i>	Yes
<i>Was informed consent obtained from the patients?</i>	Yes