

WHAT IS THE PAIN OF INTERSTITIAL CYSTITIS LIKE?

Hypothesis / aims of study

To describe the characteristics of pain experienced by patients with Interstitial Cystitis (IC) in terms of pain site, severity, character and persistence.

Study design, materials and methods

The Interstitial Cystitis Database (ICDB) was a multi-center prospective longitudinal cohort study conducted to study the natural treated history of IC. Eligibility criteria for entry into the study were similar to NIDDK criteria (1987), and patients were required to have urinary urgency and/or urinary frequency and/or pelvic pain for at least six months prior to enrollment. 637 eligible patients were enrolled between May 1993 and January 1997 and followed through November 1997. The median length of follow-up of 31 months (range 1-52).

Patients participating in the ICDB answered questions about whether they had pain, about the location, characteristics, persistency and intensity of their pain during the prior 4 weeks. Data from that study was analyzed and descriptive statistics calculated for the 629 patients who had a completed baseline symptom questionnaires.

Results

94% of patients at baseline reported pain or discomfort associated with their urinary symptoms during the past 4 weeks. This dropped to 85% of patients at month 6, and also remained at approximately 85% at months 12, 18, and 24.

Of the 589 patients who reported some pain at baseline, 74% reported pain in the urethra, 65% reported pain in the lower back, 80% reported pain in the lower abdomen, 24% reported pain in the rectum, and 27% reported pain in "any other area".

Of the 540 women who reported some pain at baseline, 51% reported pain in the vagina. Of the 49 males who reported some pain at baseline, 53% reported pain in the perineum.

The median number of pain descriptors reported was 3 for the urethra and lower abdomen, but was 2 for the remaining sites. The most common descriptors of pain in the urethra were pressure (68%) and burning (63%), of pain in the lower back were aching (85%) and dull (50%), of pain in the lower abdomen were pressure (75%), aching (55%), and bloating (51%), of pain in the rectum was pressure (59%), of pain in the vagina were burning (55%), aching (52%), and pressure (50%), of pain in the perineum were aching (62%) and dull (50%), and of pain in "any other area" was aching (66%).

The majority of the patients described the pain as intermittent, regardless of the site of the pain. The lower abdomen and lower back had the greatest proportion of patients reporting that the pain was constant (26% and 21%, respectively), while the rectum had the smallest proportion of patients reporting that the pain was constant (5%). Also, the majority of patients described the intensity of the pain as moderate, across the pain sites. Pain in the urethra and "any other area" had the highest proportion of patients describing the intensity as severe (25% and 26%, respectively).

Among the patients who reported pain present at baseline and who had at least one additional follow-up, the proportion of patients who later reported any pain absent was 21%.

Pain in the lower abdomen appears to be the most persistent over time. 62% of patients who reported pain in the lower abdomen at baseline, always reported pain in the lower abdomen at later follow-ups. Even among the patients who had all 5 follow-up visits available, 58% reported pain in the lower abdomen was always present. Pain in "any other area" and in the rectum appear to be the least persistent over time. 26% of patients who reported pain in "any other area" at baseline, always reported pain in "any other area" at later follow-ups. 36% of patients who reported pain in the rectum at baseline, always reported rectum pain at later follow-ups.

Interpretation of results

There has been a recent shift in methods used to define IC, towards a symptom-based definition that includes pain thought to be of bladder origin, along with urinary urgency and frequency. Although it is a constant feature of IC, the pain of IC has not been previously well

described in the literature. Description of this pain may be important in distinguishing the nature of IC as being a distinct visceral pain syndrome with a primary bladder focus, different from a sensory disorder in which multiple body sites are painful. Knowledge of the expected distribution and nature of IC pain will be helpful in designing IC trials that use pain as an outcome measure.

Concluding message

Among IC sufferers, pain is common and occurs at several sites other than the bladder, is usually intermittent and rated as moderate in severity.

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