

## **SYMPTOMS, TREATMENTS AND QUALITY OF LIFE AMONG MEMBERS OF THE INTERSTITIAL CYSTITIS SUPPORT GROUP IN THE UK**

### **Aims of Study**

Interstitial cystitis is an uncommon and poorly understood inflammatory bladder disease. Prevalence estimates and epidemiological data on the disease and its associations are available from the United States of America, but there are no good quality data from the United Kingdom. The Interstitial Cystitis Support Group (ICSG) is a registered charity for sufferers, and conducted a questionnaire survey of its members in 1999 to investigate duration of symptoms, delay in diagnosis and treatment variations.

### **Methods**

A postal questionnaire was sent to all members of the ICSG and asked about risk factors, associated diseases, symptoms, exacerbating and relieving factors, coping strategies, medications received and their effectiveness and impact upon lifestyle of the disease. Information was sought on the length of time to diagnosis, and the way in which the diagnosis was reached. Data were entered onto SPSS v 11. Data are described as median (range) or number (%) and comparisons were made using Mann Whitney U test. Odds ratios are presented with 95% Confidence intervals (OR, 95% CI)

### **Results**

736 of 1148 (64%) questionnaires were returned. 696 patients (94.6%) were women. Women were slightly younger at the onset of symptoms (45 vs 53 years,  $p=0.05$ ). The median duration of symptoms was 9 years (1-59) and the median duration of symptoms before diagnosis was 3 (0-60). 37 patients (5%) (36 women) reported an affected family member, of whom 50% were female. 36% patients reported sensitivity or allergy to drugs; and 43% sensitivity to foodstuffs. 61% had symptoms of irritable bowel syndrome; 35% reported arthritis, 55% back pain; 22% sinusitis, 28% candidal infection; 29% bacterial cystitis; 25% migraines, and 31% constipation. Back pain (OR 2.47; 1.24, 4.90); thrush (OR 4.90; 1.49, 16.13); cystitis (OR 5.01; 1.52, 16.46) were more common in women.

The following triggers of disease onset were identified: pelvic surgery (18%), bacterial cystitis/thrush (17%), emotional stress (17%). 87% patients described at least daily pain when their symptoms were at their worst, and 37% described daily pain at the time of the survey. Pain occurred in the bladder (56%), urethra (49%), lower abdomen (37%), & suprapubic area (28%). Symptoms included: frequency (92%), urgency (84%), nocturia (87%), pain (63%), dyspareunia (45%), post-coital frequency (41%), bladder spasms (54%), & urethral pain (63%). Median reported frequency was 10 (2-70), nocturia 3 (0-20), at the time of survey and 20 (1-92), 8 (0-48) respectively at the worst time. Patients reported having received the following treatment: antidepressants (47%); antibiotics (66%); cimetidine (36%); antihistamines (5%); NSAIDs (40%); anticholinergics (37%); pentosan polysulphate (12%); DMSO (33%); anticonvulsants (2%); potassium citrate (32%), and sodium bicarbonate (52%). %% patients had undergone diversionary or storage surgery to the bladder. 47% patients admitted to moderate depression or worse. 51% patients considered that IC had "completely taken over" their life. 49% found sexual intercourse a considerable problem (30), or were unable to tolerate it at all (19%). 73% were diagnosed by a urologist, 11% by the patient themselves, and 8% by a (uro)gynaecologist. The diagnostic procedure involved a cystoscopy in 47% of cases and a combination of tests in 31%. The number of cystoscopies per patient was 2 (0-60), and 85% patients had a general anaesthetic for this. 83% patients had been referred to a specialist, of whom 75% were urologists.

### **Conclusions**

In keeping with data from the USA, IC in the UK is a disease of delayed diagnosis, and chronic progression. Patients experience severe symptoms and disturbance to quality of life. Many patients have received multiple treatments. It is noteworthy that several treatments of

proven efficacy are used infrequently in this cohort of patients. Education of medical staff is still necessary.