

Incidence and clinical characteristics of interstitial cystitis in the community

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Abstract We utilized physician-coded diagnoses and chart reviews to estimate the incidence of interstitial cystitis (IC) in women. A computer search of the Kaiser Permanente database was performed to identify newly coded diagnoses of IC (ICD-9 code 595.1) between May 2002 and May 2005. Chart reviews were performed and patient demographics, diagnosing physicians, and symptom characteristics were recorded. The IC incidence rate was 15 per 100,000 women per year. The mean age of the patients was 51 years (range 31–81 years). The most common presenting symptoms were frequency (70%), dysuria (52%), urgency (50%), suprapubic pain (50%), nocturia (35%), and dyspareunia (13%). Cases diagnosed by primary care physicians had a shorter median symptom duration (9 months) compared with those diagnosed by urologists

(1 year) and gynecologists (3 years). IC is an uncommon diagnosis in the community setting, with an incidence rate of 15 per 100,000 women per year.

Keywords Epidemiology · Pelvic pain · Chronic

Introduction

Interstitial cystitis/painful bladder syndrome (IC/PBS) is a chronic pain syndrome of the bladder which consists of persistent discomfort or pain in the bladder or pelvic region, often accompanied by urinary frequency and nocturia [1, 2]. The majority of studies about IC have concentrated on individuals with long-standing and severe symptoms. Consequently, little is known about the incidence of newly diagnosed IC/PBS and the clinical characteristics of these newly diagnosed patients. The purpose of this study was to estimate the incidence of IC/PBS in a managed care population, and to describe the clinical characteristics of these patients using a comprehensive population-based electronic medical record and subsequent chart review.

Materials and methods

Study population

The study population has been described previously [3]. In brief, the population included members of Kaiser Permanente Northwest (KPNW), a health maintenance organization (HMO) based in Portland, Oregon with 436,000 medical plan enrollees (20% of the Portland metropolitan population). The demographics of the KPNW reflect those of the metropolitan Portland area. Of the members, 92% are

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white. The majority of members (85%) are insured through an employer (1/3 public, 2/3 private), while 10% are self-insured and 5% participate in Medicaid. A search of the KPNW administrative database was performed after excluding from analysis those younger than 25 or older than 85 years, those who were not current KPNW members at the time of the analysis, those with dental coverage only, those with less than two continuous months of eligibility, and those on the Do Not Contact list for research studies. The lower age limit of 25 years was chosen because previous epidemiological studies of this population have shown that these younger members are typically quite transient and difficult to follow over time. The data was collected during the interval May 2002 to May 2005. Institutional Review Board approval was obtained from KPNW and Northwestern University before study initiation.

Sampling strategy

ICD-9 based database queries were used to identify patients with typical IC exclusion criteria (genitourinary malignancies, history of radiation, tuberculosis, or chemical cystitis). Individuals with one of these diagnoses were excluded from further study but remained in the denominator for incidence calculation.

Identification of interstitial cystitis

During the 3-year study interval, 80 women were identified with newly coded diagnosis of IC (ICD-9 595.1) in the medical record. No new male diagnoses were present. Subsequent chart reviews of the 80 patients revealed 46 incident cases and 34 prevalent cases (previously diagnosed with IC). The 34 prevalent cases were excluded from this study. Details regarding character and duration of symptoms, diagnostic testing, therapy, and specialty of diagnosing physician were abstracted.

Incidence calculation

The denominator for the incidence calculation consisted of 315,922 person—years included in the period May 1 2002–April 30 2005. The numerator consisted of newly coded IC diagnoses that were confirmed with electronic chart reviews.

Results

Incidence rate

Of the 80 patients with newly identified IC diagnoses, 34 had been diagnosed previously (prevalent cases). The

remaining 46 incident cases yielded an incidence rate of 15 per 100,000 women per year. The mean age of the patients was 51 years (range 31–81 years).

Of the 46 incident cases, 25 (54%) were diagnosed by urologists, nine (20%) by gynecologists, nine (20%) by primary care physicians (PCPs), and two (4%) by emergency room physicians. Eight of the 21 patients who were initially diagnosed by non-urologists were subsequently seen and had the diagnosis confirmed by urologists. Therefore, 72% (33 of the 46 cases) of the women had a diagnosis assigned by a urologist.

Presenting symptoms

Type and percentage of presenting symptoms in those patients diagnosed with IC are shown in Table 1. The most common symptoms were frequency, dysuria, urgency, and suprapubic pain. Of the presenting symptoms not included in Table 1, the other most common symptoms were pain as the bladder filled (5), bladder spasms (3), intermittency (2), and urge urinary incontinence (2). Symptom duration prior to diagnosis was recorded in 34 patients. In these, the median duration of symptoms was 1 year (range 2 weeks–30 years). Four additional patients had symptoms for ‘years’ prior to the diagnosis. IC cases diagnosed by PCPs had a median symptom duration of only 9 months, whereas those cases diagnosed by a urologists had a median symptom duration of 1 year and those diagnosed by gynecologists had a median duration of 3 years. There were no other significant differences in clinical characteristics among those patients diagnosed by a urologist and those diagnosed by a non-urologist.

Diagnostic testing

Type (and number) of diagnostic tests for these patients included: cystoscopy (32 total; 19 of which included hydrodistention), urodynamics (eight), potassium sensitivity testing (seven), urine culture (six), bladder biopsy (six), intravenous pyelogram (five), and urine cytology (four).

Table 1 Most common presenting symptoms of IC

Symptom	Percentage of IC patients with symptom
Urinary frequency	70
Dysuria	52
Urgency	50
Suprapubic pain	50
Nocturia	35
Dyspareunia	13
Incomplete voiding	11

Other tests performed in the exclusion of other disease processes include pelvic ultrasound (three) and testing for sexually transmitted diseases (two).

Therapy

Initial therapy in these IC incident cases included anticholinergic medications (16), pentosan polysulfate sodium (12), hydroxyzine (eight), tri-cyclic antidepressants (eight), antibiotics (seven), pyridium (five), DMSO (five) and oral narcotics (four). Some patients received more than one of these therapies.

Discussion

Interstitial cystitis is a condition that results in recurring discomfort or pain in the bladder and surrounding pelvic region. The symptoms vary between and within individuals, making obtaining a consensus definition difficult. Nickel et al. estimate IC accounts for nearly 2.8% of all outpatient urology clinic visits in Canada [4]. Our findings based on the KPNW population indicate an IC incidence rate of 15 per 100,000 women. This incidence rate is based on a physician-based diagnosis, rather than National Institutes of Health (NIH) criteria-based diagnosis. Of the 46 incident cases, only 19 (41%) underwent cystoscopy with hydrodistention to establish a formal diagnosis of IC. Therefore, these patients would be considered to have PBS rather than confirmed diagnoses of IC. This is consistent with previous reports which have indicated that the use of the NIH or National Institute of Diabetes and Digestive and Kidney Diseases criteria for IC has largely been abandoned [5, 6].

Our observed incidence rate is approximately tenfold higher than the estimated incidence rate in the Olmsted County-based population (1.6 per 100,000 in women) [7]. The discrepancy between our results and those of the Olmsted County population may partly be attributed to differences in dependence on cystoscopy or hydrodistention findings by physicians for diagnosis of IC in the latter study.

A substantial proportion (46%) of the diagnoses was made by non-urology physicians, although a third of these were subsequently seen by urologists to confirm the diagnosis (eight out of 21). IC cases diagnosed by PCPs had the shortest median duration of symptoms prior to the diagnosis (9 months). This earlier diagnosis may relate to easier access to a PCP, particularly in the managed care setting of the KPNW population. IC cases diagnosed by gynecologists had the longest median duration of symptoms prior to the diagnosis (3 years). As gynecologists often function as PCPs for young woman, it is important for them to consider the diagnosis of IC in their patients who

complain of pelvic pain, particularly when it occurs with urinary symptoms. This finding suggests that education of gynecologists to recognize the condition may lead to earlier diagnosis and treatment.

There are several limitations to our study. The primary limitation is that the definition of IC was based only on the coded diagnosis (ICD-9 code 595.1) in the electronic medical record. Because Kaiser is a group model HMO, diagnostic coding is not directly linked to payment. This may lead to different physician coding patterns than those that would be seen in a non-HMO population. Also, these methods do not take into account any potential differences or omissions in diagnostic testing in the patients. Because IC is largely a diagnosis of exclusion, an appropriate evaluation to identify other conditions which could be causing the irritative bladder symptoms is essential. Although no consensus exists regarding the appropriate diagnostic evaluation of women with suspected IC, a typical assessment includes a pelvic examination, urinalysis, and cystoscopy. It is somewhat reassuring that the majority of individuals (72%) underwent office cystoscopy to exclude other bladder pathology that could be causing the symptoms. Furthermore, the symptoms reported by these individuals were consistent with current consensus IC/PBS definitions [1, 2]. However, there is still a potential for misclassification in patients who did not undergo certain diagnostic procedures (cystoscopy or hydrodistention). This may affect the incidence rate, which is relatively labile given the small sample size. The use of KPNW administrative data to define the presence of IC also means that those who were treated outside of the KPNW health plan and those with IC who did not seek medical care could not be identified.

A second limitation is that chart reviews (rather than patient questionnaires) were used to assess patient symptoms. Therefore, unrecorded symptoms that contributed to the IC diagnosis could not be assessed. Third, the lengthy duration of symptoms in some patients may have led to a time-bias in report of symptoms. Also, because the KPNW population is 92% white, these findings may not be generalizable to other ethnic groups.

Despite these limitations, our study indicates that the incidence of physician-diagnosed IC in women in a population-based setting is low. This is contrary to the much higher rate of IC-like symptoms in the population [8]. Both patient and physician factors may explain this discrepancy. Studies are needed to assess why certain women with IC symptoms seek care and why others do not. In addition, increased awareness of the clinical characteristics of IC among non-urologist physicians may lead to increased diagnoses, earlier treatments, lower diagnostic costs, and potentially improved outcomes for these patients.

Conflicts of interest None.

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