Health Concerns of Patients With Nonbacterial Prostatitis/Pelvic Pain

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Background: Heightened awareness of patients’ reasons for physician visits for male pelvic pain (nonbacterial prostatitis) and symptom concerns may increase patient satisfaction with care and help guide better management of this syndrome, for which evidence-based treatment is lacking.

Methods: We interviewed men with recent health maintenance organization visits for new episodes of nonbacterial prostatitis (N = 286; mean age, 46.7 years) and again 3, 6, and 12 months later. We inquired about their reasons for the visit and, at each interview, symptom concerns. We used Poisson regression to examine the association between baseline symptom worry and health care utilization during the 14 months after the index visit.

Results: Most patients reported concern at the index visit that they might have an infection (73%) or cancer (68%). One year later, 43% reported prostatitis symptoms in the past month. Among these, many were still concerned that their symptoms would worsen if untreated (71%), that they had cancer (46%) or an infection (45%), and that they might need surgery (44%). Controlling for patient age and baseline symptom severity, we found that baseline symptom worry predicted prostatitis-related health care visits over the 14 months after the index visit (P = .005).

Conclusions: Despite symptom improvement following a health care visit for a new episode of pelvic pain/nonbacterial prostatitis, continued patient concerns about cancer, infection, and symptom worsening without treatment were common, even 1 year later. Patient worry may be associated with increased health care utilization.

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NONBACTERIAL PROSTATITIS accounts for about 2 million ambulatory visits annually in the United States.1 Despite its prevalence (estimated at 5%-16%) and negative impact on patients’ quality of life,7,8 little is certain about the etiology, diagnosis, and treatment of this syndrome involving pelvic pain with or without voiding symptoms. Although labels of prostatitis and prostatodynia are commonly applied to these symptoms, associated prostate disease is unproven. Reflecting the unknown etiology in over 90% of cases,9,10 the National Institutes of Health (NIH) classification has labeled chronic male pelvic pain in the absence of bacteriuria as chronic prostatitis/chronic pelvic pain syndrome (CP/CPPS).11 Gold standard diagnostic tests and evidence-based treatments are lacking,10,12,13 and little is known about the natural history.

Although this syndrome has been the subject of increased attention over recent years in the urology literature, it has received relatively little notice in primary care journals.

Given the uncertain state of medical knowledge, physicians find the diagnosis and treatment of men with nonbacterial prostatitis/pelvic pain frustrating;8,14 patients are confused and dissatisfied with medical care10,14; and there is widespread use of antibiotics and other non–evidence-based treatments for this syndrome.8 In light of this situation, male pelvic pain patients’ expectations for physician visits and concerns about their symptoms need to be better understood. Heightened awareness in these areas may help guide better management and increase patient satisfaction with care, even if definitive treatment is not possible. The objectives of this prospective, longitudinal study were to determine (1) the reasons for seeking care and symptom concerns among men with a recent health care visit for a new episode of nonbacterial prostatitis/pelvic pain, (2) the extent to which symptom concerns continued over the subsequent year,
and (3) whether baseline symptom worry predicted subsequent prostatitis-related health care utilization. Because we studied men with recent-onset symptoms, we use the terms male pelvic pain and nonbacterial prostatitis rather than CP/CPPS in describing the sample.

METHODS

PARTICIPANTS AND PROCEDURES

Potential study participants were identified from April 1999 to May 2000 by weekly database searches at Group Health Cooperative (GHC), a health maintenance organization (HMO) in western Washington State. Men aged 18 to 65 years were telephoned if they received a prostatitis or prostatodynia diagnosis at a recent visit (“index visit”), had no HMO visits with these diagnoses in the previous year, and had no evidence of specific conditions that might cause pelvic pain or urinary symptoms (eg, urinary tract or kidney infection, bacterial prostatitis, cystitis, urethritis, gonorrhea, and chlamydia), as determined by the HMO’s database of patient International Classification of Diseases, Ninth Revision, Clinical Modification codes. During the telephone call, patients were screened to confirm that they had pelvic pain at the index visit and did not have specific genitourinary conditions. Among 730 patients identified, 64 (9%) could not be contacted, 162 (22%) were ineligible, 147 (20%) declined study participation, and 357 enrolled (71% of eligible patients contacted). We excluded from data analyses 71 patients with laboratory test results in the year after the index visit indicating pyuria, Chlamydia trachomatis, Neisseria gonorrhoeae, or positive urine culture (>10 000 colony forming units/mL), leaving a sample of 286 men. The study was approved by the GHC institutional review board, and all participants provided informed consent. We have previously reported detailed study inclusion/exclusion criteria and patient baseline characteristics.

Trained interviewers administered a baseline structured computer-assisted telephone interview to study participants after the index health care visit and at 3-, 6-, and 12-month follow-up assessments (88%, 83%, and 83% response rates, respectively). Those who completed the 12-month interview (n=236) did not differ significantly from those who did not (n=50) in proportion with first vs recurrent prostatitis episodes at the index visit, race, or baseline symptom duration; however, they were older (mean age, 47.4 vs 43.8 years; t=–1.99; P=.05), more highly educated (55% vs 39% completed college; χ²=8.29; P=.02), and had lower baseline symptom severity (NIH Chronic Prostatitis Symptom Index [NIH CPSI] mean, 12.8 vs 15.8; t=2.08; P=.04).

At the baseline interview, patients were asked about sociodemographic characteristics, symptom history, reasons for the index visit, and symptom concerns at the time of the index visit and currently. They also rated their prostatitis symptoms during the past week on the NIH CPSI, a valid and reliable measure of prostatitis symptom severity that includes pain, urinary symptoms, and quality-of-life subscales. At each interview, patients rated their worry about their symptoms on a scale from 0 (not at all worried) to 10 (extremely worried). At each follow-up interview, patients were asked whether they (1) experienced in the past month the prostatitis symptoms for which they initially sought care, (2) currently had each of 8 symptom concerns, (3) thought they needed further symptom evaluation, and (4) thought they had a good understanding of their condition. Using GHC administrative data, we calculated the number of prostatitis-related health care visits in the 14 months after the index visit. We selected this period because it included the first 2 months after the index visit, when most care related to the index visit occurred, plus the subsequent year (this period roughly corresponded to the time between the index visit and the 12-month follow-up interview). We defined prostatitis-related visits as visits with a nonbacterial prostatitis diagnosis or for prostate or scrotum ultrasound, intravenous pyelogram (urography), cystoscopy, urodynamics, or abdominal or pelvic computerized axial tomography.

STATISTICAL ANALYSIS

We used descriptive statistics to characterize demographics, NIH CPSI scores, reasons for seeking health care, and symptom presence and concerns. We performed repeated measures analysis of variance to determine whether symptom worry changed significantly over the course of the study, differed for those with first vs recurrent episodes, or showed differential change over time for these 2 groups. We used Poisson regression to examine the association of baseline worry with the number of prostatitis-related visits during the follow-up after controlling for patient age and baseline symptom severity, as assessed by the NIH CPSI pain and urinary symptom scales (categorized because of nonnormal distributions). We did not include the NIH CPSI quality-of-life scale because it does not directly assess pain and urinary symptom severity and may be confounded with worry (eg, one item asks how much the patient thought about his symptoms over the past week).

RESULTS

SAMPLE BASELINE CHARACTERISTICS

Among the 286 study participants, the index visit was to a primary care physician for 242 men (85%) and to a urologist for 44 men (15%). The index visit was for a first-ever prostatitis episode for 100 participants (35%) and for a recurrent episode for 186 (65%). The median symptom duration before the index visit was 4 weeks, and the median number of days between the index visit and the baseline interview was 25 (range, 15-85 days). The mean (SD) patient age was 46.7 (10.2) years. Patients were generally highly educated; only 1% did not graduate from high school and 51% were college graduates. Most were white (87%) and married (73%).

REASONS FOR PHYSICIAN VISITS

Most patients, regardless of whether the index visit was for a first-ever or recurrent episode of nonbacterial prostatitis/pelvic pain, said that their goals for that visit were to obtain information about the cause (93% of first episode and 87% of recurrent episode patients) and estimated time course of their symptoms (66% and 50%, respectively), pain relief (78% and 75%, respectively), reassurance (83% and 70%, respectively), and diagnostic testing (58% and 61%, respectively) (Table 1). The goal most often cited by patients as being most important was to obtain information about the cause of the symptoms, although this was a more common primary goal among men with first (43%) episodes than among those with recurrent (27%) episodes (Table 1).
SYMPTOM CONCERNS

The study participants expressed a variety of concerns about their prostatitis at each interview over the year after the index visit (Table 2). At the baseline interview, almost all reported that at the index visit they had been worried that their problem would worsen if untreated (93%), and most reported worrying that they might have an infection (73%), their symptoms might not resolve (72%), or they might have cancer (68%). Similar proportions of men younger than 45 years (66%), aged 45 to 54 years (69%), and older than 54 years (67%) reported concern about cancer (χ²=0.32; P=.85). About half reported concern at the index visit that they were unable to do all their customary activities, and about half reported worrying that they might need surgery. These concerns declined considerably after the index visit. However, most patients reported at least 1 concern throughout the next year, even though many did not have symptoms at the follow-up interviews and most of those with symptoms had a mild level of severity.

At the 12-month follow-up interview, 65% of all study participants (94% of those with symptoms in the past month and 44% of those without) reported at least 1 concern about their prostatitis/pelvic pain syndrome (Table 2). Even those with no symptoms in the previous month (n=135) reported concerns that the problem would worsen if untreated (25%; the most common primary concern) or might not resolve (27%) and that they might need surgery (13%). Among those with symptoms in the previous month (n=101), most expressed concern that their problem would not resolve (86%) and might worsen if untreated (71%). Slightly less than half reported concern that they might have cancer (46%) or an infection (45%) or might need surgery (44%). A substantial minority were concerned that they could not do customary activities (35%) and that their symptoms might be caused by a condition other than cancer, sexually transmitted disease, or infection (30%).

Table 3 gives the symptom concerns (of men with concerns) identified as most important at the index visit (for patients with first vs recurrent episodes) and 1 year...
later (for men with and without symptoms in the previous month). At the index visit, for both patients with first lifetime episodes as well as those with recurrent episodes, the most common primary concerns were that the problem would worsen if untreated (29% [first] vs 35% [recurrent]) and that they might have cancer (38% [first] vs 26% [recurrent]). The primary worry of a substantial minority was that they had an infection (19% [first] vs 14% [recurrent]). At the 12-month follow-up interview, among men with recent symptoms, the most common primary concerns were that the symptoms might not resolve (32%), they might have cancer (23%), and the problem might worsen if untreated (21%).

Men whose index visit was to a urologist vs primary care physician did not differ in worry at baseline or 12 months (t tests, \( P = .89 \) [baseline] and \( P = .57 \) [12 months]). Worry about prostatitis symptoms declined significantly over the year after the baseline interview (repeated measures analysis of variance, \( F = 46.52; \ P < .001 \)) (Figure), paralleling the decreases in NIH CPSI scores we found previously in this sample.\(^1\) Across assessments, men who made the index visit for a recurrent episode showed significantly greater symptom worry than did men with first episodes (\( F = 8.64; \ P = .004 \)). Patients with first vs recurrent episodes did not show differential change in worry over time. The proportion of patients with moderate to severe worry (defined as \( > 5 \) on the 0-10 scale) decreased gradually (baseline, 53%; 3 months, 32%; 6 months, 29%; and 12 months, 24%).

At 12 months, almost half (47%) of men with symptoms in the past month believed that they needed further evaluation of their symptoms. Only 60% of the total sample and 48% of those with symptoms in the past month believed that they had a good understanding of the cause of their symptoms.

The baseline worry rating was associated significantly with the number of prostatitis-related health care visits over the 14 months after the index visit, even after controlling for patient age and baseline NIH CPSI pain and urinary symptom scores (Poisson regression, \( z = 2.80 \); \( P = .005 \)). The incidence rate ratio was 1.06 for a 2-point and 1.13 for a 4-point difference in baseline worry. Thus, if 1 man has an estimated rate of 5 prostatitis-related visits during the follow-up period (the sample median), a man at the same age with the same NIH CPSI scores but with a baseline worry rating 2 points higher would have an estimated rate of 5.3 visits (5 \times 1.06) (if 4 points higher, 5.7 visits).

**Table 3. Most Important Concern Before Index Visit and at 12 Months Among Patients With Concerns**

<table>
<thead>
<tr>
<th>Concern</th>
<th>Index Visit, %</th>
<th>12-Month Follow-up Interview, %</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>First Episode (n = 97)</td>
<td>Recurrent Episode (n = 184)</td>
</tr>
<tr>
<td>Problem will worsen if untreated</td>
<td>28.9</td>
<td>34.8</td>
</tr>
<tr>
<td>Cancer</td>
<td>38.1</td>
<td>26.1</td>
</tr>
<tr>
<td>Infection</td>
<td>18.6</td>
<td>14.1</td>
</tr>
<tr>
<td>Symptoms might not resolve</td>
<td>3.1</td>
<td>12.5</td>
</tr>
<tr>
<td>Cannot do normal activities</td>
<td>5.2</td>
<td>4.3</td>
</tr>
<tr>
<td>Other specific concern</td>
<td>2.1</td>
<td>4.3</td>
</tr>
<tr>
<td>Might need surgery</td>
<td>3.1</td>
<td>1.6</td>
</tr>
<tr>
<td>STD</td>
<td>1.0</td>
<td>2.2</td>
</tr>
<tr>
<td>Disease other than infection, cancer, STD</td>
<td>0</td>
<td>0</td>
</tr>
</tbody>
</table>

Abbreviation: STD, sexually transmitted disease.

**Figure.** Worry about symptoms at each assessment. This box plot displays the medians (horizontal line in each box), means (asterisks), 25th and 75th percentiles (solid line box), nearest values not beyond 1.5 times the interquartile range from the 25th and 75th percentiles (whiskers), and outliers (bubbles).

The most common reasons for health care visits for new nonbacterial prostatitis episodes, each cited by over three quarters of the sample, were to obtain information about the cause of the symptoms, pain relief, and reassurance. Although more than half of the patients desired diagnostic tests, fewer than 10% cited this as the most important reason for the visit. Compared with previous studies of patient visits for various symptoms, fewer patients wanted diagnostic tests and specialist referrals. This might reflect the HMO study setting.
Despite the fact that, on average, symptoms were mild and improved over time, most patients reported multiple symptom concerns that persisted over the year after the initial health care visit. Twelve months after the initial visit, even some patients with no prostatitis symptoms in the past month reported concerns that their problem might not resolve or might worsen. A possible explanation for this relates to the finding that most patients had recurrent episodes of prostatitis; perhaps even if they were currently asymptomatic, some patients still worried that they had a disease that might again become symptomatic.

Most patients, regardless of age, reported concern at the initial visit that they might have cancer, and this concern was not uncommon among men with recent symptoms 1 year later. Fears of prostate and testicular cancer have been reported previously in studies of men with genitourinary symptoms. In a population-based survey of Finnish men with current or previous prostatitis, 17% reported fear of having prostate cancer and 69% wanted regular medical check-ups because of a constant fear of undiagnosed prostate cancer or sexually transmitted disease. In a study of primary care patients with genitourinary symptoms, even though most said that their symptoms were not sufficiently bothersome to discuss with their physician, 22% reported worrying that their symptoms might be due to prostate cancer and 8% that their symptoms might be caused by testicular cancer.

A simple rating of symptom worry at baseline predicted prostatitis-related health care visits over the next year even after controlling for pain and urinary symptom severity. This raises the possibility that more adequately allaying patient worries might prevent unnecessary health care utilization. Although it is possible that both worry and utilization were related to the presence of a specific disease etiology of symptoms that was discovered at some time after the index visit, the study findings suggest the potential fruitfulness of further research to more thoroughly examine the relationships among patient worry, physician responses, and subsequent health care utilization.

Reasons for seeing physicians and symptom concerns in this group of patients with prostatitis are consistent with findings in other patient populations: many patients who make health care visits are concerned that their symptoms represent a serious illness and desire an explanation of the symptom’s cause and information about prognosis. However, information provision may be viewed as more important by patients than by physicians, and patient symptom-related concerns and expectations are often not addressed by physicians. Physicians are less likely than patients to consider symptoms to have an underlying serious cause, perhaps owing to their training and clinical experience with the favorable prognosis of common symptoms. Thus, physicians may not recognize or may underestimate patients’ level of worry.

The study findings underscore the potential value of physicians eliciting and satisfactorily addressing symptom concerns and reasons for visits of patients with prostatitis. Unmet expectations and desires for information as well as serious worry about illness after a visit may worsen patient satisfaction, trust in the physician, compliance, and outcomes. Conversely, patients whose expectations were met after a health care visit were found to have significantly greater satisfaction and less worry about serious illness, and patients who received information about symptom cause or prognosis were more likely to have symptom alleviation and functional improvement.

Specifically, it may be helpful to inform patients making health care visits for nonbacterial prostatitis/pelvic pain that these symptoms tend to improve over time regardless of treatment and that mild symptom persistence or recurrence is common and not necessarily a sign of cancer or infection or need for surgery. Given evidence that men overestimate their risk of prostate cancer and that reassurance may reduce symptom bothersomeness, it may also be helpful to provide information regarding the actual risk of developing and of dying from prostate cancer. A recent study found no association of prostatitis with cancer. Finally, physicians often do not recognize and do not ask about the extent to which symptoms interfere with everyday activities. This may be a motivator of seeking care and an important area for discussion, given the importance of functional status as an outcome in health care and patient desire for physicians to inquire about their functioning.

Study limitations include possible sample selection bias and follow-up nonresponse bias. Study participants were generally highly educated and white; further research is needed to determine the generalizability of our findings to other populations. Furthermore, although we excluded patients found to have specific symptom causes, study participants were evaluated as per usual clinical care and were not all systematically assessed for sexually transmitted diseases, urinary tract infections, or other potential symptom causes. Thus, it is possible that some participants might have had a specific symptom etiology that was undiagnosed. In addition, we did not collect information on therapies received and thus could not examine their effect on symptoms and concerns. Finally, recall bias might have influenced subjects’ baseline interview reports of their index visit expectations and concerns.

In conclusion, even in the absence of gold standard diagnostic tests and evidence-based treatments, it may prove helpful for physicians to elicit and address concerns of patients with nonbacterial prostatitis/pelvic pain. Further research is needed to study the effects of such communication on physician and patient satisfaction and clinical outcomes.

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REFERENCES