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The impact of chronic prostatitis/chronic pelvic pain syndrome on patients

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Abstract Chronic prostatitis/chronic pelvic pain syndrome (CP/CPPS) is a common condition, affecting men of all ages. Since mortality and serious complications are extremely uncommon, CP/CPPS is primarily a quality-of-life disease, and, therefore, the patient's perspective is of paramount importance. As with other non-life threatening diseases, the goal of treatment is to maximize quality not quantity of life. Scientifically validated methods to measure patients' health related quality of life have been applied in other urological diseases such as benign prostatic hyperplasia and interstitial cystitis; the same process is now underway in the study of CP/CPPS. Recent studies have shown that CP/CPPS takes a substantial toll on physical and mental health. In addition to examining the health related quality of life of patients with CP/CPPS, future studies should address additional patient-centered outcomes, such as satisfaction with care and the economic burden of the illness, in order to allow a more comprehensive understanding of the impact of this condition on patients.

Keywords Prostatitis · Health Related Quality of Life · Chronic Pain

Chronic prostatitis/chronic pelvic pain syndrome (CP/CPPS), the predominant type of prostatitis, is a common condition affecting men of all ages [10]. Since mortality and serious complications from the condition are extremely uncommon, CP/CPPS is primarily a quality-of-life disease. As with other non-life threatening diseases,

the goal of treatment is to maximize quality not quantity of life.

The hallmark of CP/CPPS is the symptom complex of pelvic area pain and lower urinary tract symptoms. Because of the emphasis on symptoms, the patient's perspective is critical to understanding the full impact of the condition. Patients seek relief from the debilitating symptoms, but they report feeling confronted with a medical community that is confused and uncertain about how to alleviate or manage their pain [7]. Similarly, physicians report frustration in caring for patients with this condition, and the frustration is fueled, in large part, by the lack of a gold standard diagnostic test and the absence of effective treatment [13]. This summary will review the impact of CP/CPPS on patients, beginning with the definition of terms and concepts related to outcomes research, then focussing on data and the measurement of CP/CPPS symptoms and health related quality of life (HRQOL), and concluding with future patient-centered research needs in CP/CPPS.

Outcomes research in chronic prostatitis—definition of terms and concepts

The importance of evaluating health outcomes has become increasingly evident in medicine and surgery. Outcomes, or results of care, may include clinical outcomes, patient-focused outcomes such as quality of life, functional status, and satisfaction, and costs or resource use. One of the primary goals of physicians should be a better understanding of how patients perceive their disease. This type of understanding helps optimize clinical decision-making in terms of achieving outcomes that are important to patients. Traditionally, measures of anatomic or physiologic phenomena have been considered "hard" or objective, whereas measures with questionnaires of illness from the patient's perspective (such as quantification of symptoms, degree of bother, worry, functional limitation or change in quality of life) have been thought of as "soft" or subjective [19]. Scientifically

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validated methods for obtaining this type of patient-focused information have been applied to patients with urological diseases such as benign prostatic hyperplasia and interstitial cystitis; the same process is now underway in the study of chronic prostatitis.

HRQOL broadly describes how well individuals function in life and their perceptions of well-being. The measurement of HRQOL is important for understanding the impact of chronic disease and for informing patient management and policy decisions [8]. Although interest in examining HRQOL in chronic diseases has increased substantially in recent years, little is known about the HRQOL among men with chronic prostatitis.

The comprehensive evaluation of a patient's health status should include both generic and disease-specific assessments, in addition to symptom scores. Generic measures, such as the 36-item short form (SF-36) constructed to survey health status in the Medical Outcomes Study, examine broadly defined dimensions of physical, psychological, and social functioning and are relevant across a variety of disease and sociodemographic groups. Generic health status measures are useful for comparisons of different diseases and treatment groups. However, one cannot attribute directly any dysfunction reported to a particular condition or problem. Since these generic measures are also affected by other conditions, there is value in getting patients' assessments of condition-specific effects on their lives. Disease specific measures reflect functional impacts that relate to specific conditions. To capture the full impact of chronic prostatitis on patients, outcomes studies in chronic prostatitis might measure symptoms, disease-specific and generic overall health status, as well as satisfaction with care and economic burden.

Symptom measures in chronic prostatitis

Review of published symptom lists and symptom indices

Several different symptom indices have been used in clinical research in prostatitis: a four-question instrument was developed by Neal and Moon for use in an open-label study of alpha-blockade for treatment of chronic prostatitis [15]; a ten-item symptom frequency questionnaire and a ten-item symptom severity questionnaire were developed by Nickel and colleagues for use in a Canadian randomized double-blind sham controlled trial of transurethral microwave thermotherapy for chronic prostatitis [16]; a 21-item instrument to assess pain, sexual dysfunction, and voiding symptoms in a standardized fashion was developed by Krieger and colleagues at the University of Washington [11]; an 18-item "Giessen Prostatitis Symptom Score" was developed by Braehler and colleagues from Germany and; a ten-item symptom severity score chart was used by Chiang et al. in a pilot study of transurethral needle ablation in the treatment of nonbacterial prostatitis to assess treatment outcomes [3]. However, none of the

previously published symptom measures was believed to be completely satisfactory, in part because standards for what was considered a rigorously "validated" instrument may not have been met. Nonetheless, these indices, along with the results from studies that used chronic prostatitis symptom lists and inventories [1, 4], served as a solid base from which to make the National Institutes of Health Chronic Prostatitis Index (NIH-CPSI) [12], which is a valid, well-accepted outcome measure for men with chronic prostatitis.

National Institutes of Health Chronic Prostatitis Symptom Index

In 1997, the National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK) funded the Chronic Prostatitis Collaborative Research Network (CPCRN), a five-year, multi-center program to conduct well-designed epidemiological studies and therapeutic trials aimed at providing answers to unresolved questions of diagnosis and treatment of chronic prostatitis. The first step in achieving these goals was to develop a reliable and valid instrument to measure the symptoms and quality of life impact of chronic prostatitis for use in research protocols as well as clinical practice.

The steps followed in developing the NIH-CPSI included: (1) literature review, (2) focus groups, (3) cognitive testing, (4) expert panel, (5) validation testing, and (6) psychometric analyses. The process yielded an index of nine questions that address three different aspects of the chronic prostatitis experience. The primary component is pain, which was captured in four questions that focus on location, severity, and frequency. Urinary function, another important component of patients' symptoms was captured in two questions—one irritative and the other obstructive. Quality of life impact was captured in three additional questions that asked about the effect of symptoms on daily activities. The nine questions have high test-retest reliability ($r=0.83-0.93$) and internal consistency ($\alpha=0.86-0.91$). All but the urinary questions discriminated well between men with and without chronic prostatitis.

The NIH-CPSI is a reliable and valid means of capturing the symptoms and impact of the clinical entity called chronic prostatitis. It is a comprehensive but brief measure that quantifies the qualitative experience of men with this condition. It can be self-administered in less than 5 min and is well understood by patients. Although the index was intended to be more evaluative than discriminative, it does have robust discriminative ability between chronic prostatitis, BPH, and healthy control populations. Nonetheless, caution is necessary in using the index as a screening or diagnostic tool. For men identified as having chronic prostatitis, the index appears highly appropriate for measuring the severity and evolution of symptoms and quality of life over time. Since its publication, it has been used as a primary endpoint in clinical trials and clinical practice. It has

been translated and linguistically validated in Spanish, German, and Korean.

Prevalence of symptoms

Chronic prostatitis-like symptoms are common and represent an international health problem, with prevalence ranging from 2–16%, depending on the definition used. Using the NIH-CPSI, Nickel and colleagues found a prevalence of chronic prostatitis-like symptoms was 10% among patients of family practitioners in Canada [18].

Generic health status measures in CP/CPPS

Sickness Impact Profile

The degree to which chronic prostatitis has an impact on patient quality of life and daily functioning was examined, using the Sickness Impact Profile (SIP). The SIP assesses sickness related dysfunction in 12 different life areas: ambulation, mobility, body care and movement, social interaction, emotional behavior, alertness behavior, communication, eating, work, sleep and rest, household management, and recreation and pastimes. Wenninger and colleagues found that the mean SIP total score of the chronic prostatitis patients was in the range of scores reported in the literature for patients with myocardial infarction, angina, or Crohn's disease [20]. The results of this important study indicated a need for careful evaluation and attention to sickness related dysfunctions in patients with chronic prostatitis.

Short Form 12

General HRQOL in chronic prostatitis patients has also been assessed with the Short Form 12 (SF-12), a 12-item, generic instrument that measures the following domains of HRQOL: physical functioning, role limitations due to physical health problems, bodily pain, general health, vitality, social functioning, role functioning, role limitations due to emotional problems, and mental health. Scores range from 0–100; higher scores indicate better quality of life. Two SF-12 subscales can be computed, the Physical Component Summary and the Mental Component Summary.

Results from the NIH/NIDDK-funded Chronic Prostatitis Cohort Study, which used the SF-12 to measure HRQOL, revealed that both mental and physical domains of HRQOL were impaired, and that increased chronic prostatitis symptom severity was associated with worse scores. Chronic prostatitis patients' mental health scores were worse than patients in the most severe subgroups of diabetes mellitus and congestive heart failure [14].

Disease-specific health status measures in CP/CPPS

NIH-CPSI

The quality of life impact subscore of the NIH-CPSI is a condition-specific measure of HRQOL. The quality of life impact subscore ranges from 0 to 12, and results from summing responses to three items related to impact of symptoms and overall quality of life. The three items are: (1) How much have your symptoms kept you from doing the kinds of things you would usually do, over the last week?; (2) How much did you think about your symptoms, over the last week?; and (3) If you were to spend the rest of your life with your symptoms just the way they have been during the last week, how would you feel about that? A higher score indicated worse quality of life.

The examination of condition-specific HRQOL among men in the Chronic Prostatitis Cohort Study, as measured by the QOL subscale of the NIH-CPSI, revealed high scores, suggesting severe impairment in HRQOL. As with generic HRQOL, there was also a significant worsening of condition-specific HRQOL with increasing symptom severity [14].

Psychological impact in CP/CPPS

Several studies have examined whether men with chronic prostatitis show signs of depression and impairment in their intimate relationships. The mental health of men with chronic prostatitis was assessed using two validated instruments, The Minnesota Multiphasic Personality Inventory and the Beck Depression Inventory. About two-thirds of men reported anxiety and over half reported depression. Longitudinal follow-up of the study participants showed that anxiety and stress increased with time, and physical well-being and social functioning decreased [9]. In one study, depression and a tendency to somatize differentiated chronic prostatitis patients from controls [5], and in another, men with chronic prostatitis consistently scored worse than controls on hypochondriasis, depression, hysteria, and somatization scales [2]. Another study showed that over 50% of the patients with chronic prostatitis met criteria for depression [6]; since none had been diagnosed previously or was on medication for depression, this seems to be an under-recognized condition among men with chronic prostatitis and might complicate their treatment. Because the psychological profile of patients before the onset of chronic prostatitis symptoms was unknown, causality cannot be determined. Thus, it is unclear whether chronic prostatitis symptoms lead to psychiatric disease (i.e., depression) or whether psychiatric disease leads to worse chronic prostatitis symptoms. Since the assessment and management of men with chronic prostatitis might be complicated by concurrent psychiatric illness (i.e., depression), it would be prudent for future

outcomes studies of chronic prostatitis to include validated depression scales for comprehensively assessing outcomes.

Future areas of research in CP/CPPS

Chronic prostatitis/chronic pelvic pain syndrome is an international health problem. In 1998, the National Institutes of Health organized the first International Prostatitis Collaborative Network (IPCN) workshop to address this problem. A worldwide, multi-disciplinary panel of investigators convened to discuss issues of classification, diagnosis, and treatment. Because the perspective of patients is of paramount importance, representatives from the Prostatitis Foundation (a patient advocacy organization) and patients were also invited to participate [17]. Concurrently, the Chronic Prostatitis Collaborative Research Network has been conducting bench research and clinical trials to answer questions regarding the diagnosis and effective treatment of men with CP/CPPS. While great strides have been made in recent years to fill the many knowledge gaps in CP/CPPS, there are several fundamental aspects of CP/CPPS that remain murky and unresolved. While an understanding of what causes CP/CPPS and how to treat it is a central focus, there is also a requirement for more research on how the condition impacts patients.

Three types of “non-traditional” endpoints that are of growing interest: health related quality of life, satisfaction with care, and economic cost impact, hold the promise of improving our ability to understand the full burden of CP/CPPS.

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