Psychosocial Phenotyping in Women With Interstitial Cystitis/Painful Bladder Syndrome: A Case Control Study

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Purpose: We characterized and compared psychosocial phenotypes in a female interstitial cystitis/painful bladder syndrome cohort and an age matched cohort without that diagnosis.

Materials and Methods: Female patients with interstitial cystitis/painful bladder syndrome and controls without the condition completed a psychosocial phenotyping questionnaire battery, including a demographics/history form and validated questionnaires focused on a range of presenting symptoms, psychosocial parameters and quality of life. Specific measures included interstitial cystitis symptom and problem index, McGill Pain Questionnaire, Medical Outcomes Study Sleep Scale, Center for Epidemiological Studies Depression Scale, State-Trait Anxiety Inventory, Pain Catastrophizing Scale, Female Sexual Functioning Index and Multidimensional Scale of Perceived Social Support and Medical Outcomes Study Short Form-12 quality of life. Direct comparisons and correlations were made to establish group differences and the strength of associations for psychosocial parameters in patients with interstitial cystitis/painful bladder syndrome.

Results: Questionnaires completed by 207 patients with interstitial cystitis/painful bladder syndrome were compared to those of 117 controls matched for age, partner status and education. Compared to controls patients reported significantly more pain (total, sensory and affective), worse physical quality of life, increased sleep dysfunction, depression, catastrophizing, anxiety, stress and moderately more sexual/social function problems. These suffering, coping and social parameters correlated with the degree of general pain but stress, anxiety, depression and catastrophizing further correlated with IC specific symptoms and strongly with decreased quality of life. Pain was strongly associated with physical quality of life, while depression, catastrophizing and stress, and to a lesser extent social support were associated with poor mental quality of life.

Conclusions: Patients with interstitial cystitis/painful bladder syndrome have significant cognitive and psychosocial alterations compared to controls.

Key Words: urinary bladder; cystitis, interstitial; questionnaires; quality of life; pain

Abbreviations and Acronyms

FSFI = Female Sexual Functioning Inventory
IC = interstitial cystitis
IC/PBS = IC/painful bladder syndrome
ICPI = IC problem index
ICSI = IC symptom index
MOS = Medical Outcomes Study
MPQ-SF = McGill Pain Questionnaire short form
PCS = pain catastrophizing scale
QOL = quality of life
SF12-MCS = SF-12 mental component status
SF12-PCS = SF-12 physical component status
UPOINT = urinary, psychosocial, organ specific, infection, neurological/systemic, tenderness
VAS = visual analogue scale

Submitted for publication April 9, 2009.

Study received institutional review board approval.

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† Financial interest and/or other relationship with Merck, Ortho Women's Health, GlaxoSmith-Kline, Farr Labs, Watson, Pfizer, American Medical Systems, Medtronic, Neuraxon and Genynus Biomed.

‡ Financial interest and/or other relationship with Sanofi-Aventis, Janson-Ortho and Purdue Pharma.

§ Financial interest and/or other relationship with Pfizer and Sanofi-Aventis.

¶ Financial interest and/or other relationship with Pfizer, Plethora and Ortho-McNeil.

‖ Financial interest and/or other relationship with Astellas, Allergan and Pfizer.

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0022-5347/10/1831-0167/0
THE JOURNAL OF UROLOGY®

Vol. 183, 167-172, January 2010
Printed in U.S.A.
DOI:10.1016/j.juro.2009.08.133

INTERSTITIAL cystitis/painful bladder syndrome is a common medical condition that negatively impacts QOL. Symptom duration, pain severity, depression, poor coping strategies,[1–3] stress,[4] sleep disturbance[5] and sexual functioning[1] have been identified as some key parameters that predict symptom severity and QOL in patients with IC/PBS. However, these previous groups did not examine all of these potentially relevant psychosocial parameters in a single cohort or compare an IC/PBS cohort with individuals not diagnosed with the condition.

Clinical phenotyping in patients with chronic pelvic pain syndrome was proposed to understand the heterogeneity of this population and improve management using targeted therapies in individuals. The UPOINT clinical phenotyping classification system (see Appendix), which includes an important psychosocial domain, was clinically validated for IC.[6] Phenotypes expressed outside the bladder (P or psychosocial and N or neurological/systemic) had the most significant impact on general QOL. Interaction of the multiple psychosocial factors that may influence the experience of patients with IC/PBS should be indentified, and their impact determined and exploited to improve management outcomes. We used a multicenter case control cohort design study to perform psychosocial phenotyping of an IC/PBS patient population and compared this to phenotyping in individuals without an IC/PBS diagnosis. We compared symptoms, suffering, coping, behavioral and social factors using a battery of validated questionnaires in patients with IC/PBS and age matched controls.

METHODS

Participants

Patients were recruited from existing IC/PBS patient databases and investigator clinical practices at the 9 participating centers. All patients were female and English speaking. Eligible patients had chronic pelvic pain greater than 6 months in duration, pressure or discomfort perceived to be related to the bladder and accompanied by at least 1 other urinary symptom, such as urgency or frequency. Urine had to be sterile at initial diagnosis and assessment. All other diseases that could cause pelvic symptoms were excluded at the various clinics by standardized history and physical examination, including previous pelvic examination. Cystoscopy was not a study inclusion criterion but at almost all centers cystoscopy was done using local or general anesthesia according to the diagnostic algorithms. Thus, patients would have mostly fulfilled the diagnostic criteria of the IC Data Base Study[7] and the most recent definition of IC/PBS described at the National Institutes of Health Urological Chronic Pelvic Pain consensus in Baltimore in December, 2007. Female controls were recruited from the general population by advertisement and included in the study when no self-identified IC/PBS diagnosis was confirmed by questionnaires.

Survey Design

At each of the 9 participating sites there was an IC/PBS patient database and patients with IC were treated concurrently. Patients identified with IC/PBS and interested controls were contacted by telephone, personal contact or letter to determine interest in this study. After initial contact a package containing 2 copies of the informed consent (specific institutional review board approved consent for patients and control participants) and the packet of questionnaires were mailed to participants with an enclosed self-addressed postage paid envelope from the contacting research center. The packet contained a modest financial incentive for controls only ($20.00). Patients and controls were asked to return a signed copy of the informed consent and a completed set of questionnaires. The research coordinator contacted cases and controls at 1 and 2 weeks to remind them to complete the questionnaires.

Measures

Demographics and symptoms. Participants completed a demographic and history questionnaire. 1) IC/PBS symptoms were assessed using ICSI and ICPI,[8] also known as the O'Leary-Sant Questionnaire, which assesses symptom severity and problems associated with the 4 IC associated issues frequency, urgency, nocturia and bladder pain. 2) Pain was assessed by MPQ-SF,[9] which measures pain quality by asking patients to rate the intensity of 15 verbal descriptors of pain on a 0 to 3 rating scale. The pain rating index is composed of 2 scores, including a sensory pain score and an affective pain score. This version of MPQ-SF also uses a standard pain intensity VAS. 3) Sleep problems were assessed using the MOS Sleep Scale, which addresses 7 sleep domains (sleep disturbance, snoring, awakening short of breath or with headache, sleep adequacy, somnolence and 2 problem questions).[10] An additional single item assessed sleep quantity.[10]

Suffering and coping. 1) Depressive symptoms were assessed using the Center for Epidemiological Studies Depression Scale, a 20-item validated depression scale that has been used in similar chronic pelvic pain biopsychosocial studies.[11] 2) Anxiety was assessed using the trait anxiety scale of the State-Trait Anxiety Inventory, a 20-item subscale from the longer 40-item instrument.[12] 3) Stress was assessed using the perceived stress scale,[13] a widely used instrument to measure the degree to which life situations are appraised as being stressful. Items assess how unpredictable, uncontrollable and overwhelming respondents find life. 4) PCS was used to measure catastrophizing cognitions concerning pain.[14]

QOL, sexual functioning and social support. 1) Functional health status was assessed using the MOS SF-12® QOL questionnaire.[15] A summary score for physical functional (SF12-PCS) and mental health (SF12-MCS) status may be calculated by combining and weighting the various individual scales. 2) Female sexual functioning was assessed using FSFI.[16] This brief index provides an overall metric of sexual functioning and subscales for desire, arousal, orgasm, lubrication difficulty, satisfaction and