459

Hatchett L[1], Fitzgerald M P[1], Potts J[2], Winder A[1], Mickelberg K[3], Barrell T[3], Kusek J W[4]
1. *Loyola University Medical Center,* ***2.*** *Cleveland Clinic Foundation,* ***3.*** *University of Pennsylvania,* ***4.*** *National Institutes of Health*

LIFE IMPACT OF UROLOGIC PAIN SYNDROMES

Hypothesis / aims of study

Painful Bladder Syndrome/ Interstitial Cystitis in men and women and Chronic Prostatitis/ Chronic Pelvic Pain Syndrome in men, termed the Urological Chronic Pelvic Pain Syndromes (UCPPS) are characterized by pelvic pain and urinary symptoms. The purpose of the present study was to explore the life impact of UCPPS in terms of symptoms and role limitations.

Study design, materials and methods

For this analysis we used written responses to open-ended questions presented to participants enrolled in a randomized therapeutic trial for treatment of UCPPS. Results of that study have been previously presented. Before any treatment, patients were invited to complete a 3-page written response to questions asking them to describe their pelvic symptoms and how they affect their lives. These prompts reflect the major quality of life domains used in past studies: 'For me, this is a description of what my pelvic symptoms are like on a typical day:', 'These symptoms affect my home life and my family as follows:', 'These symptoms affect my working life as follows:', 'These symptoms affect my social life as follows:'. Responses were independently reviewed by three researchers. Major themes were summarized following an inductive approach[1] without regard to study treatment assignment.

Results

47 completed symptom journals (23 (49%) men, 24 (51%) women), of mean age 43 years (range 22-76). Patient journals revealed three major themes concerning 1) physical health, 2) emotional health and 3) role limitations/social health. Each of the major themes were associated with sub-themes, considered in turn below.

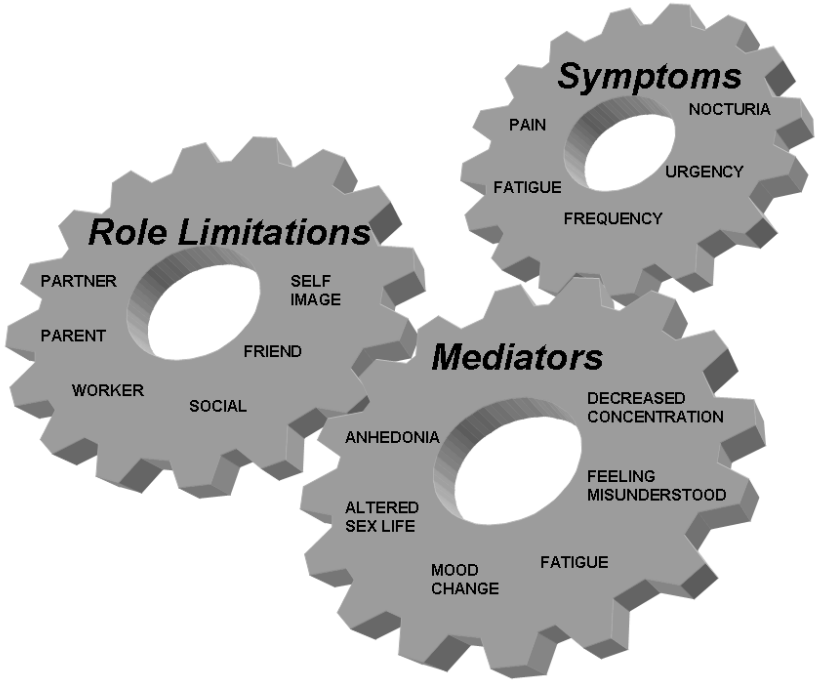
Physical Health: 38(81%) mentioned pain/discomfort as a symptom. Pain was variably described, including severe, unpredictable, with characteristics such as pressure, burning, stabbing, and heaviness, aching, jabbing, sharpness, pulling, cramping, throbbing, and needle-like sensations. Fifteen (32%) patients gave prominence to the symptom of fatigue, a symptom not been previously considered to be part of the UCCPS syndromes. Patients reported fatigue throughout the day and noted a lack of energy to devote to family, friends, or daily tasks.

Emotional Health: About half of the participants discussed negative mood changes including irritability, frustration, anger, and depression. 23(49%) patients wrote that decreased enjoyment affected their lives, limiting their desire to be involved with friends; others noted the feeling they could not enjoy activities that they had in the past. Two respondents said they felt hopeless. Reports of sexual dysfunction were frequent, including reports of painful ejaculation in men, and reports from women about their inability to have sex because of associated pain and discomfort. The sexual disruption was an important sub-theme for both men and women. Fatigue also had a marked interpersonal effect. Patients reported feeling tired and listless, lacking energy to engage with family or carry out daily tasks. Others wrote about decreased ability to concentrate and preoccupation with symptoms, their condition, or the location of bathrooms. Several patients described being misunderstood by others and reported frustration when their symptoms and emotions were misunderstood by family and friends, e.g. "I feel as though my husband doesn't understand me."

Role Limitations/Social Health: Many patients wrote statements reflecting role limitations due to physical and emotional symptoms. Symptoms disrupted work life both through daily functional limitations and through long term loss of career opportunities. Some patients also worried about their inability to complete work tasks because of their lack of energy, concentration, and fatigue. Others described avoiding new job opportunities and new assignments because of the same fear. Some patients described limitations in their concept of their ideal role in life: symptoms created a difference between their current concept of self and their past concept of self as being more 'happy' and 'normal'. Patients described feelings both of a loss of self and a longing for their 'old self'.

Interpretation of results

Our review of patient journals explored the impact of symptoms on home/family, work, and social life for UCPPS patients from six clinical centers, as expressed in their own wordsThe journals and abstracted themes offer an overview of how chronic UCPPS symptoms cause personal and interpersonal effects that mediate role limitations, which themselves can amplify those mediators and perpetuate the role of the patient burdened with chronic illness (conceptualized in Figure below).



Role limitations have been studied in other chronically ill populations and demonstrate the tremendous burden that chronic illness places on patients' physical and emotional functioning. The present study suggests that both physical health and emotional health concerns are equally important in UCPPS. Our patients report a longing to regain their 'old' or 'happy' personae, and describe leading restricted lives, experiencing social isolation, and the burdening of others. Significantly, the journal entries indicate that fatigue and affective symptoms may be important mediators of role limitations. Fatigue and affective symptoms may represent unappreciated symptoms of UCPPS, or may reflect the presence of other overlapping functional somatic syndromes (FSS).

Concluding message: UCPPS studies may benefit from renewed focus on life impact and from further exploration of symptoms, mediators and role limitations that disrupt our patients' daily lives. We hope that the recognition of the importance of fatigue and other mediators offers clinicians important new therapeutic targets as we work together to lessen the burden of chronic illness.

References

1. American Journal of Evaluation, 27(2), 237-246

Specify source of funding or grant	**USA National Institutes of Health / NIDDK**
Is this a clinical trial?	**Yes**
Is this study registered in a public clinical trials registry?	**Yes**
Specify Name of Public Registry, Registration Number	**ClinicalTrials.gov identifier: NCT00434343**
What were the subjects in the study?	**HUMAN**
Was this study approved by an ethics committee?	**Yes**
Specify Name of Ethics Committee	**Loyola University Institutional Review Board**
Was the Declaration of Helsinki followed?	**Yes**
Was informed consent obtained from the patients?	**Yes**