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Life Impact of Urologic Pain Syndromes

Lena Hatchett¹, MP FitzGerald¹, J Potts², A Winder¹, K Mickelberg³, T Barrell³, JW Kusek⁴, and the Urologic Pelvic Pain Collaborative Research Network⁴

¹ Loyola University Medical Center, IL

² Cleveland Clinic Foundation, OH

³ University of Pennsylvania, PA

⁴ National Institutes of Health, MD

Abstract

Prior studies have suggested that urologic chronic pelvic pain syndromes (UCPPS) can have severe adverse impact on quality of life. The purpose of the present study was to explore the impact of UCPPS symptoms in terms of symptoms and role limitations. We used a qualitative study based on a grounded theory approach, to describe patients' perspective of symptoms and their life impact. Forty-seven patient in-depth semi-structured written responses were reviewed and major themes were summarized. Three significant themes emerged from the data, relating to physical health, emotional health and social health (role functioning). We propose a model suggesting that symptoms and mediated by personal and interpersonal factors to affect personal and social roles and QoL. Fatigue emerged as both a symptom and a consequence of UCPPS. Our model suggests that the significant role limitations associated with UCCPS may be mediated by modifiable personal and interpersonal factors not currently addressed in UCPPS treatment paradigms.

Background

Painful Bladder Syndrome/ Interstitial Cystitis (PBS/IC) in men and women and Chronic Prostatitis/ Chronic Pelvic Pain Syndrome (CP/CPPS) in men, termed the Urological Chronic Pelvic Pain Syndromes (UCPPS) are characterized by pelvic pain and urinary symptoms. UCPPS symptoms are variable and their pathophysiology is not known; effective treatments are lacking. Estimates of the prevalence of UCPPS vary widely. IC may affect as many as 500,000 U.S. citizens (Held et al., 1990), with recent estimates varying between 0.2% and 3.4% of the population (Temml, et al., 2003; Nickel et al., 2005; Clemens, et al., 2007; Leppilahti, et al., 2002; Clemens, et al., 2005; Ibrahim, et al., 2007) depending upon whether estimates were based on a physician diagnosis or assessment of symptoms characteristic of the syndrome. Estimates of the prevalence of the symptoms of CP/CPPS also vary: community based surveys demonstrate prevalence of 8-11.5% of men younger than age 50 (Collins, et al., 1998; Nickel et al., 2001).

Prior studies have suggested that UCPPS can have severe adverse impact on quality of life (Temml, et al., 2003; Nickel et al., 2005). Population-based studies (e.g. Michael, et al., 2000) using the SF-36 have found significant decrease in QoL dimensions, including role/ physical, bodily pain, vitality and social function, results that were supported by Rothrock's (et al., 2002) cross-sectional study of IC patients showing decreased physical functioning, decreased ability to function in one's normal role, decreased vitality, and depression. These

studies provide a general perspective of QoL through the use of structured, validated questionnaires. However, there remains a limited understanding of how patients themselves describe symptoms and their life impact. Exploring the perspectives of patients may provide unique insights and suggest directions for clinical practice and research.

A multi-center pilot clinical trial of manual physical therapy in men and women with IC/PBS and in men with CP/CPPS provided an opportunity to conduct a qualitative study permitting study participants to identify and describe symptoms and their life impact. The findings from this study may provide insights into new approaches to clinical management of these syndromes as well as guide future research efforts.

Methods

For this analysis we used written responses to open-ended questions presented to participants in a study of manual physical therapies for treatment of UCPPS. The results and methods of that trial are published elsewhere (FitzGerald et al, In Press). Briefly, 47 participants were adult men and women with UCPPS recruited from six clinical centers affiliated with the Urological Pelvic Pain Collaborative Research Network, funded by the National Institutes of Health. Clinical centers were located in Illinois, California, Ohio and Michigan. The study was approved by the Institutional Review Boards of each participating site and written informed consent was obtained from all study participants. Eligible patients were randomized to receive ten weeks' treatment with either manual physical therapy or global therapeutic massage.

Semi-structured written responses from patient journals were gathered to explore patients' description of symptoms and their life impact. A grounded theory method was used to summarize and analyze the qualitative data. This approach is frequently used in qualitative studies as "hypothesis-seeking" of patients' experience with other chronic illness; breast cancer (Luoma, 2004) diabetes, (Huang, Gorawara-Bhat, & Chin, 2005) fibromyalgia (Cunningham & Jillings 2006); chronic pain (Sofaer, et al., 2005); HIV-related neuropathy (Ownby & Dune 2007). The basic premise of this approach is to generate theory from data rather than impose a pre-existing theory or model (Strauss & Corbin, 1990). We hoped to reveal significant themes within the data by capturing the unique perspective of the patient.

Procedure

Before any study treatments, 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 QoL domains used in past studies (Michael, et al., 2000; Rothrock, et al, 2002):

1. 'For me, this is a description of what my pelvic symptoms are like on a typical day.'
2. 'These symptoms affect my home life and my family as follows:'
3. 'These symptoms affect my working life as follows:'
4. 'These symptoms affect my social life as follows:'

ANALYSIS

Responses were independently reviewed by three researchers (LH, MPF, AW). Major themes were summarized following an inductive approach (Thomas, 2006) without regard to study treatment assignment.

The first step in the qualitative data analysis was to develop a code list. Each journal was reviewed by three independent individuals to identify the major themes using a grounded theory

approach (Straus & Corbin, 1998) to data analysis and the constant comparison method. As a first step, members of the research team independently performed open coding of the transcripts, which means they read transcripts to identify key themes raised in participants' comments that were relevant to our study question. The coders then met to review and compare their list of themes, which were then collapsed into broader categories in a collaborative process referred to as *axial coding*. We returned to the QoL framework to organize the final code list which allowed us to organize participants' comments in a manner that we felt best addressed our initial study question. The axial coding thus yielded a final code list which was then used to uniformly recode each transcript. When there was disagreement over themes all three reviewers discussed the theme until there was consensus. The journals were then reviewed again to assess the frequency with which each theme occurred. A descriptive analysis was performed by calculating frequency counts for categorical data.

Results

Forty-seven patients completed symptom journals, including 23 (49%) men and 24 (51%) women. Of the 23 men enrolled, 2 (4%) were diagnosed with IC. Mean patient age was 43 years (range 22-76); 40 (87%) were White/Caucasian. Prior to treatment, 96% rated their pain as moderate to severe, 91% rated their urgency as moderate to severe, and 89% rated their frequency of urination to be moderately to severely abnormal.

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 (detailed in Tables 1- 3), considered in turn below.

Physical Health (see Table 1)

The majority (38 or 81%) of participants mentioned pain and discomfort as a symptom. Pain was variably described, including references to its being severe and unpredictable, with characteristics such as pressure, burning, stabbing, and heaviness, aching, jabbing, sharpness, pulling, cramping, throbbing, and needle-like sensations.

Ten (21%) patients wrote about symptoms of increased urinary frequency, which were usually described as a daily bother disrupting activities at home and work. Nine (19%) patients wrote about feeling a constant urge to urinate and having a feeling of incomplete bladder emptying. The persistent urge to urinate was experienced as a frustrating symptom causing embarrassment and lack of concentration. Only 4(8%) patients wrote about nocturia (interruption of sleep to urinate).

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 (see Table 2)

About half of the participants discussed negative mood changes including irritability, frustration, anger, and depression. These moods affected their general outlook; one patient described "mental and emotional anguish." Twenty-three (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 (see Table 3)—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.

Patients wrote about role limitations affecting their social life with friends and family, with symptoms leading to withdrawal and isolation from family, co-workers, and friends. Many patients wrote they elect to “stay home” and avoid socializing. Furthermore, relaxing and planning social events around symptoms was difficult.

Sexual dysfunction limiting the role as intimate partner was commonly noted. As a result of severe pain and discomfort during sexual intercourse, many patients experienced reduced libido and avoidance of sex completely, giving rise to a feeling of guilt and “letting others down.”

Patients discussed limitations in their role as a parent, spouse and family member. Irritability and depression affected family and close friends the most. Many patients felt saddened and guilty for the impact their symptoms had on their family (e.g. “I can’t share my kids’ activities”).

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’. One wrote about how their symptoms and the illness had taken over her identity: “IC becomes a continuation of yourself.”

Discussion

This is the first published qualitative study of UCPPS symptoms. 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 words. We believe that analysis of patients’ journals offers unique insight into the life impact of UCPPS, expanding the understanding of UCPPS in an especially meaningful way, through the self-expression of patients’ prose. The 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 1).

Role limitations have been studied in other chronically ill populations, including patients with irritable bowel syndrome (Gralnek, et al., 2000), obesity (Katz et al., 2000), end-stage renal disease (Kimmel, 2000) and arthritis (Kosinski et al., 2002). Those studies 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. We suggest that future studies should further explore the personal, interpersonal effects of symptoms and role limitations that result from UCPPS.

Our patients report a longing to regain their 'old' or 'happy' personae. The deep longing our patients express for their past lives/selves aptly describes the loss of self conceptualized by Charmaz (1983), who emphasizes that the usual biomedical view of the disruption caused by chronic illness tends to minimize the reality of patients' experience. She describes suffering in terms of leading restricted lives, experiencing social isolation, and the burdening of others - each of which was described by our UCPPS patients. Similar results have been reported in studies of other chronically ill populations. For example, Asbring (2001) found that women with fibromyalgia described life after their illness felt like they had taken on a new personal identity or self-concept.

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). In this study we did not assess patients for the presence of other diagnoses such as irritable bowel syndrome, fibromyalgia or chronic fatigue syndrome but the overlap of FSS with UCPPS has been previously noted: for example, when comparing 127 chronically fatigued twins with their co-twin, Aaron et al (2001) found the fatigued twin was more likely to have fibromyalgia, irritable bowel syndrome, prostatitis and IC/PBS. Other investigators have observed a significantly higher prevalence of some FSS as well as SLE and Inflammatory bowel disease in patients with PBS/IC (Alagiri et al., 1997) and 65% patients with CP/CPPS have diagnoses or symptoms consistent with other FSS (Potts et al., 2001). Wessely and colleagues suggest that FSS represent a single unifying syndrome, while the myriad of diagnoses used to describe these patients are merely artifacts of medical sub-specialization (Wessely, Nimnuin, Sharpe, 1999).

A limitation of the present study is the small sample size which did not allow any further tests of strengths of associations between identified themes. A strength of this study is that the population was drawn from multiple centers across the USA.

We hope that recognition of the wide-ranging physical, emotional, and social impact of UCPPS symptoms may lead to the development of investigative tools which might more efficiently capture this information, although we recognize that "short cuts" should not always be the goal of our clinical practices. Simple acknowledgement of the wide-ranging impact of UCPPS by the healthcare provider can itself play a significant part in the successful management of patients: physician empathy has been noted as one of the factors leading to more favorable responses in patients suffering with Functional Somatic Syndromes (Wessely, Nimnuin, Sharpe, 1999).

Fatigue is a symptom that merits further attention. Patients describe fatigue both as a symptom of UCPPS and also a consequence of UCPPS. Qualitative studies in chronically ill patients have found similar descriptions of the complex role fatigue plays in chronic illness; e.g in cancer patients (Magnusson, et al 1999; Wu, 2006) and in rheumatoid arthritis patients (Hewlett, 2005). It is possible that fatigue is a constitutional condition that points to UCPPS being a systemic disorder. Alternatively, fatigue may be related to depression and/or other emotional effects of the disorder. The effect of currently offered UCPPS treatments upon fatigue is unknown, and may prove to be an important mediator of treatment outcome.

More generally, 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.

Urological Pelvic Pain Collaborative Research Network (UPPCRN) Study Group

Northwestern University/Rehab. Institute of Chicago

Colleen Fitzgerald, MD (Co-Investigator)

Suzanne Badillo, PT

Cynthia E. Neville, PT

Darlene Marko, RN

Cleveland Clinic

Jeannette Potts, MD (PI)

Elizabeth O'Dougherty PT

Donel Murphy, RN

William Beaumont Hospital

Kenneth Peters, MD (PI)

Lisa K. Odabachian, MPT, RN, BSN

Andrea Sanfield, PT

Eleanor Anton, RN

Loyola University

Mary Pat Fitzgerald, MD (PI)

Rhonda K. Kotarinos, MS, PT

Carole Fortman PT

Rick Halle-Podell LMT

Judith Senka, RN

Janet Rindels, RN

Lucia Raducanu, RN

Stanford University

Rodney U. Anderson, MD (PI)

Annemarie Cosby, PT

Angie Morey, MS

Christopher K. Payne, MD (PI)

Laura C. Fraser, MPT

Debra Clay, RN

Anna Ramakrishnan, MS

University of Michigan Medical Center

J. Quentin Clemens, MD (PI)*

University of Pennsylvania School of Medicine

J. Richard Landis, PhD (PI)

Keith Mickelberg, RN, BSN

Marie Durborow

Ted Barrell, BS

Shannon Chuai, MS

Liyi Cen, MS

The National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK)

John W. Kusek, PhD (Project Officer)

Leroy M. Nyberg, PhD, MD

Christopher Mullins, PhD

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*Dr. Clemens conducted this research while at Northwestern University

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Figure 1. Urologic pain symptoms are amplified by intra- and inter-personal mediators to produce role limitations.

Table 1

Themes related to Physical Health.

Symptom	N(%) noting that symptom in their journal
Pain/Discomfort *	38 (81%)
Fatigue	15 (32%)
Urinary Frequency	10 (21%)
Constant Urge to urinate/ Feeling of incomplete emptying	9 (20%)
Nocturia *	4 (8%)

* Many more mentioned their symptoms were troublesome at night, but it was unclear whether it was pain or urination that was interrupting sleep.

Table 2

Themes relating to Emotional Health.

Domain/Theme	N (%)	Representative quotes
Mood change / irritability/frustration / depression	24 (51%)	"I am irritable, short with my kids." "I am anxious." "I am frustrated and angry." "It affects my mood and general outlook." "I am depressed." "There is mental and emotional anguish." "I am angered and frustrated."
Decreased enjoyment / anhedonia	23 (49%)	"It stops my desire to be involved with friends, I turn down invitations to do things." "I am hopeless." "I hate my life." "I'm not able to enjoy sports I once did." "I never really want to go anywhere."
Effect on sex life	19 (40%)	"There is a reduction in sexual performance." "Ejaculation is painful." "I am unable to have intercourse with my husband."
Fatigue	15 (32%)	"I am tired all of the time". "I am completely worn out." "I get no sleep". "It's hard to get a good night's rest." "I tire easily." "I often feel tired and don't want to do anything." "I am always resting." "I get tired more often." "I don't have energy to spend with my family."
Decreased ability to concentrate	13 (28%)	"It's difficult to concentrate." "I am always thinking about where the bathroom is." "It's hard to deal with everyday issues." "It overrides logical thinking." "I am preoccupied." "It's distracting."
Feeling misunderstood	9 (19%)	"I feel misunderstood" "People don't believe this pain." "No-one really understands unless they have it." "I feel as though my husband doesn't understand me." "Family and friends don't understand what I go through."

Table 3

Themes related to Social Health.

Social Health (Role Functioning)	N(%)	Representative quotes
Unable to work effectively	23 (49%)	"There are many good, interesting jobs I have had to turn down." "During meetings I take care to sit near the exit." "I am not able to work as much as I used to." "I don't want to start anything at work because of fear that I won't be able to finish it." "I can barely work." "I lost my job because of being ill."
Unable to be a friend/less social/withdrawal	23 (49%)	"I don't participate in my family affairs." "I feel like an outcast." "I really don't have a social life." "I can't sit through a movie or a play without needing to urinate." "I don't enjoy time out with friends and family." "Co-workers have stopped asking me to lunch." "It lessens my desire to socialize or be in public." "I just want to stay home." "It is always a factor when I am planning something fun." "It's difficult to relax socially."
Unable to fulfill role as intimate partner	12 (25%)	"I haven't had intercourse for 2 years." "It has decreased my libido." "I don't want to have sex or be touched by my partner in a sexual way." "Sex is difficult." "I feel like I'm letting my boyfriend down."
Unable to be the parent they would like to be	10 (21%)	"I take it out on the people I see the most." "I am sad for my husband and family." "I can't share my kids' activities."
Unable to be ideal self	9 (19%)	"My life isn't everything it could be." "I hate my life." "I do not feel myself." "So much time has been spent on this that would otherwise be spent on more important things." "I want to be pretty (on the inside) again." "I want to be happy again and not feel like I burden people." "IC becomes a continuation of yourself. It is with you all the time." "I can't do anything I used to." "I dream of being my old self again." "It's as if the hands of time stopped and I've been unable to move forward." "I do not feel good about myself." "Will this all go away? Will I be back to normal?"

Note: Figures represent the number (%) of patients mentioning that theme. Patients may have mentioned more than one theme.