



Cognition, Emotion, and the Bladder: Psychosocial Factors in Bladder Pain Syndrome and Interstitial Cystitis (BPS/IC)

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Abstract

Purpose of Review To review findings from empirical studies assessing the role of psychosocial factors in bladder pain syndrome and interstitial cystitis (BPS/IC).

Recent Findings There is a high rate of psychosocial comorbidity in BPS/IC, including elevated levels of anxiety and depression. Recent studies assessing the role of illness perceptions in BPS/IC relate poorer illness perceptions to more unhelpful illness coping patterns. Conversely, positive illness perceptions including self-efficacy in illness management are associated with more adaptive coping behaviors such as exercising and acceptance. New research is investigating the role of trauma in BPS/IC and the impact of suicidality. There is a paucity of psychosocial interventions for BPS/IC over the last 5 years. The three small-scale studies reviewed included a mindfulness-based stress reduction (MBSR) intervention tailored for BPS/IC, a brief self-management intervention designed to increase patient knowledge and symptom management techniques and a 90-min interview aimed at increasing awareness about physiological affective relationship in IC.

Summary Illness-related cognitions impact illness-related coping behavior, distress, symptom severity, and QoL in BPS/IC. Positive illness perceptions can positively impact behavioral responses to illness and illness outcomes. Trauma, emotion regulation, and suicidality in BPS/IC are important factors for psychosocial interventions and multidisciplinary treatments to address. Insight from the existing evidence base and other functional illness areas such as IBS can be used to inform the design and assessment of interventions aimed to understand and treat BPS/IC as a biopsychosocial illness. The role of healthcare practitioners is fundamental to informing patient perceptions of their illness and providing adequate support for their own self-management approaches.

Keywords Interstitial cystitis · Psychosocial factors · Burden of illness · Coping behavior

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Introduction

Bladder pain syndrome/interstitial cystitis (BPS/IC) is a highly debilitating condition with no known cure and a far-reaching impact in individuals' lives. The International Continence Society defines BPS/IC as “persistent or chronic pelvic pain, pressure or discomfort perceived to be related to the urinary bladder accompanied by at least one other urinary symptom such as an urgent need to void or urinary frequency” [1]. Approximately 3–8 million individuals in the USA are affected by BPS/IC [2]. Prevalence rates across cultures are variable and difficult to compare due to changing nomenclature and disease classification over time [1, 3]; however, recent research suggests that BPS/IC is underdiagnosed and prevalence rates may be higher than reported [4]. There is an estimated \$750 million and £158 million spent a year on BPS/IC healthcare respectively in the USA and UK [1, 5]. In spite

of a need for more research into the condition and its mechanisms to advance treatment [6], inconsistent terminology and disease classification have slowed progress in this regard [7].

It is widely accepted that psychosocial factors play a substantial role in BPS/IC [1, 3]. BPS/IC may best be understood as a biopsychosocial disorder, whereby biological (physiological), psychological, and social factors interact to produce the symptoms experienced in BPS/IC [8–10]. The illness experience therefore extends beyond the physical sensations of pain to the impact on mental and physical well-being and quality of life (QoL). This review provides a current overview of recent research detailing psychosocial impact and processes related to BPS/IC, focusing on new developments and areas of needed study. We also highlight potential explanatory mechanisms informing the reciprocal nature between bladder and psychological symptoms.

BPS/IC and Psychological Comorbidity

The recent formation of the Multidisciplinary Approach to the Study of Chronic Pelvic Pain (MAPP) Network contributed to the increase in research investigating the role of psychosocial factors in BPS/IC increase over the last 5 years [11]. Prior to the last 5 years, there had been a scarcity of research on psychosocial factors compared with that in similar conditions [12], with little collation of findings across existing studies. A recent systematic review indicated that psychosocial comorbidity is significantly elevated in those with BPS/IC [13••]. Specifically, depression occurred in up to 70% of cases, while anxiety symptoms ranged between 14 and 52% [13••]. Panic disorder, low self-esteem, and trauma were other common psychosocial comorbidities found in BPS/IC. Previous research demonstrated a higher prevalence of exposure to abuse and historical trauma in those with BPS/IC compared with the general population [14, 15].

Until recently, studies had yet to assess the occurrence of post-traumatic stress disorder (PTSD) in BPS/IC. PTSD is an anxiety disorder characterized by reexperiencing of a traumatic event, accompanied by an intense emotional response, often horror, fear, or helplessness. The first study to assess this in BPS/IC to our knowledge found that 42% of individuals with BPS/IC met provisional diagnostic criteria for PTSD, which was significantly higher than the comparison general chronic pain group [16]. Among the 42% meeting provisional diagnostic criteria for PTSD, there was a significantly elevated rate of reported sexual abuse and childhood trauma. This subgroup was associated with poorer outcomes overall including higher pain severity, more emotional distress, and worse quality of life (QoL). Additional recent investigations indicate that women with BPS/IC who experienced childhood trauma were more likely to struggle with disassociation and increased anxiety [17].

Previously, research noted substantially higher suicidal ideation and attempts in BPS/IC [18]. More recently, Tripp and colleagues [19] found that compared with 6% of healthy controls, 23% of BPS/IC patients endorsed suicidal ideation in the past 2 weeks. This indicates the degree of impact and suicide risk potentially present in the BPS/IC population. It is therefore unsurprising that QoL in BPS/IC is substantially diminished [6, 20]. Mental and physical functioning is substantially impacted by both symptom burden and psychosocial factors [13••]. The impact spans day-to-day functioning such as travel, ability to participate in daily activities, sleep, diet, and sexual functioning [6, 20]. Further, a recent study of 2765 individuals with BPS/IC indicated that symptom severity, depression, and comorbidity impacted on individuals' ability to work culminating in increased days off sick and withdrawal from work [21].

Key Psychological Processes

Cognitive Processes and Patient Coping

Recent studies highlight the impact of specific psychological processes on patients' disease prognosis and coping, with a strong focus on cognitive processes. An individuals' perception of their disease and negative appraisal of their symptoms can alter behavior and mood, in turn worsening pain and urologic symptoms. Specifically, the perception of more serious negative consequences and concerns about symptoms is associated with greater pain, BPS/IC symptoms, and disability [22]. In addition, rumination and catastrophizing are consistently associated with worse physical and psychological outcomes [6]. Increased catastrophizing is directly associated with higher levels of affective pain [23]. "Affective pain" is the unpleasantness of the pain experience (e.g., "unbearable") in contrast to "sensory pain" which refers to the physical sensations associated with the pain (e.g., shooting or throbbing).

The mechanistic role of coping behaviors between cognitive processes and worsening symptom severity has also been suggested. One study found that negative illness perceptions were associated with increased unhelpful coping behaviors such as pain guarding, resting and soliciting assistance, and decreased positive coping behaviors such as exercising, relaxing, seeking social support, and self-talk [22]. In contrast, more positive illness perceptions—such as having perceived control over illness and treatment—were significantly associated with positive coping behaviors. Unhelpful coping behaviors were found to mediate the relationship between catastrophizing and sensory pain in BPS/IC [23]. In addition, high tendencies to self-sacrifice were found to increase distress and exacerbate pain in women with BPS/IC [24]. These findings suggest that poor coping may partially account for the

negative association between cognitive processes and outcome in BPS/IC.

Mood is another factor impacting the relationship between cognitive processes and pain outcome. Muere et al. [23] found that while unhelpful coping behaviors mediated the relationship between catastrophizing and affective pain, depression moderated this relationship. Thus, individuals with more severe depression experienced greater affective pain as the result of unhelpful coping strategies. This suggests that those with depression may be more vulnerable to the effects of unhelpful coping strategies. Further, Katz et al. [25] found associated positive coping behaviors with emotion regulation. Although the study design limits causal inference, this suggests that positive coping behaviors (e.g., relaxation, exercise) may positively impact the ability to regulate strong emotions and/or emotion regulation can enhance engagement with positive coping behaviors. Illness perceptions were also found to be predictive of emotion regulation, impacting both physical disability and mental health outcomes in BPS/IC [22]. These findings demonstrate that cognitions, coping, mood, and emotion regulation are factors that are strongly intertwined with a substantial impact on severity and QoL outcomes in BPS/IC, and may prove important targets for psychosocial intervention.

In BPS/IC, a reciprocal relationship exists between mood/affect and pain/symptom severity. In addition to mood affecting pain outcomes, pain also affects mood [6, 26]. Negative perceptions of the illness have been shown to mediate the relationship between pain and depression [26]. When individuals experience pain, the more negatively they perceive their experience, the more severely depressed they become. In the reverse relationship whereby depression influences pain, catastrophizing mediated the effect of baseline depression on pain outcome 12 months later [27]. Catastrophizing was also found to significantly predict suicidality and depression in tertiary care BPS/IC patients, with depression independently significantly predicting suicidality also [19]. Together, these studies demonstrate the importance of cognitive processes in BPS/IC specifically relating to their impact on mood. Interestingly, unlike catastrophizing, emotional regulation was not found to mediate the relationship between depression and pain [27].

Emotional Processing and BPS/IC Symptomology

Chiu et al. [28] proposed that while a subgroup of individuals with BPS/IC had verifiable lowered anesthetic bladder capacity, those with regular bladder capacity may have a specific psychosocial profile. They hypothesized that symptoms in this subgroup were somatic expressions of emotional arousal due to an underdeveloped ability to processes and/or access emotions. This hypothesis was based on the findings that higher rates of childhood relational trauma and dissociation were

more highly correlated with higher bladder capacity (presumed to denote a non-physiological cause) compared with lower bladder capacity [17, 28]. They also assessed the association between alexithymia and the two specified BPS/IC subtypes. Alexithymia was divided into cognitive alexithymia and affective alexithymia. Cognitive alexithymia refers to an inadequacy in cognitively processing and analysing emotions. Affective alexithymia refers to a diminished emotional experience and lack of emotional reactivity. Chiu et al. [28] found that high cognitive alexithymia and low affective alexithymia mediated the correlations between childhood trauma and dissociation and bladder capacity. Although this study demonstrates the importance of psychosocial variables in BPS/IC, the explanatory role of an alexithymic profile has limitations. Firstly, the mediation analysis was conducted on cross-sectional data limiting inferences about causality. Secondly, this hypothesis would only account for a subgroup of the IC/BPS populations that have experienced childhood abuse and/or dissociation, as these were presumed the reason for the development of alexithymia, i.e., that inadequate care and stressful life experiences compromised individuals' abilities to process emotions resulting in somatization. Furthermore, Katz et al. [22] did not find emotion regulation to mediate the relationship between depression and pain. As poor emotion regulation is an associated feature of alexithymia, if the alexithymic profile was a predominant explanatory factor for pain in IC/BPS, we would expect this mediation pathway to be significant [19, 22, 23].

Explanatory Models

The Bladder-Gut-Brain Axis

A hypothetical bladder-gut-brain axis (BGBA) has been proposed as a framework to guide a better understanding of the interaction between psychosocial factors in functional urological disorders including BPS/IC, and pathophysiological changes [29]. It is proposed that psychological and physical stress systems interact via communicating pathways across the central nervous system serving to falsify or sensitize alarm signals. "Alarm falsification" describes the process whereby stimuli that were once neutral or non-noxious provoke a threat response in the body that may be affective (e.g., anxiety), cognitive (e.g., catastrophizing), or physical (e.g., pain or urgency). "Sensitization" occurs where normally mildly experienced visceral stimuli produce a higher degree of sensation than they would usually. A review assessing the physiological mechanisms underlying BPS/IC highlighted that changes to cortical networks in areas of the brain particularly associated with emotional regulation have distinct effects on bladder sensation [30]. The paper concluded that plasticity within the

central nervous system is a fundamental component in BPS/IC and overactive bladder bridging the psychosocial input with the physiological changes to produce symptoms [30].

Central Sensitization in BPS/IC

Central sensitization therefore disrupts regular processing of pain, which can contribute to a broad range of overlapping conditions such as irritable bowel syndrome and fibromyalgia [31]. Evoked pain protocols are used to assess central sensitization and such studies have identified key clinical markers, which include widespread pain, increased pain intensity, and sensory amplification [32]. Central sensitization is also often associated with higher rates of childhood trauma [32]. Investigators involved in the MAPP Network have proposed that widespread pain of different body regions in BPS/IC may be indicative of central sensitization or neuroimmune processes in BPS/IC [33]. A “centralized pain” phenotype in BPS/IC is characterized by widespread pain and high somatic symptom comorbidity [33–35]. There is building evidence of the association with this phenotype with increased emotional distress, psychiatric comorbidity, catastrophizing, and poorer QoL [33, 34, 36•].

In addition to the central sensitization hypothesis, other mechanisms by which psychosocial factors may impact bladder functioning involve the disruption of normal bioregulatory functioning [37] such as disruption to bladder microbiota, damage to the microbiome layer, and neurogenic inflammation [37–39]. In the past 5 years, studies have begun to demonstrate an association between psychosocial factors and bladder microbiome and inflammation [40–42]; however, precise mechanisms of these interactions are yet to be established.

Treatment Needs

Research assessing the role of psychosocial factors in BPS/IC increasingly highlights the need for psychosocial interventions to accompany treatments. Guidelines from research networks in the field advocate for multidisciplinary and transdisciplinary approaches to BPS/IC in order to provide integrated assessment and care pathways [7, 36•, 37]. Increasingly, there is call for healthcare professionals to look beyond presenting physical symptoms to account for wider QoL factors and impact in order to understand the presentation within a biopsychosocial framework [1, 20]. Furthermore, in line with previous investigations [43], MAPP network researchers suggest the tailoring of treatment to the presenting clinical phenotype [33, 41]. This involves the assessment of several domains including physical and psychosocial factors to conceptualize patient presentation [43]. To facilitate this process, physician assessment, potential additional physical investigations, and psychological assessment using interviews and questionnaires are recommended. Individuals with increased

symptom severity, psychosocial impact, and worse QoL are directed to receive additional psychological support such as cognitive behavioral therapy or counseling [33, 41, 43]. Qualitative research indicates that a more integrated and patient-centered approach, such as this, is welcomed by individuals with BPS/IC [4, 6, 44, 45].

BPS/IC patients are likely to have had to encounter many different healthcare avenues in pursuit of answers and treatment for symptoms and often experience frustration, dismissiveness, and sense of disbelief by practitioners [44]. Lack of understanding from healthcare providers can make individuals feel as though they are hypochondriacal [4]. This can be alienating and reduce confidence in medical professionals as well as confidence in self-management of BPS/IC and lead to symptom concealment and disengagement from treatment [12, 46]. A qualitative study exploring the role of physician interactions found that individuals with BPS/IC preferred physicians who demonstrated empathy through listening and validation of their experience [4]. Furthermore, engendering hope and optimism was found to be important for the patients’ own perception of their illness and symptom trajectory. In addition to interpersonal style, patients favored physicians who co-constructed treatment plans and offered multiple options [4]. The importance of patient-centered care and decision-making has previously been identified in BPS/IC [44] but also more generally in chronic condition management [47, 48].

In the last 5 years, there has been a shortage of psychosocial intervention studies. The only three studies conducted to the best of our knowledge, included a mindfulness-based stress reduction course [49], an online video-education system [50], and a 90-min interview aimed at facilitating the link between stress, emotional conflict, and symptoms, and encouraging emotional expression [51]. Although studies had small sample sizes, the findings across studies demonstrated an acceptability of psychosocial interventions BPS/IC. Benefits included reduction in pain and improvement in symptoms [49–51], pain self-efficacy [49], and improved QoL [50]. However, symptom and pain improvements were not significant in two out of the three studies [49, 51].

Needs in the Field and New Research Directions

There is a need for more psychosocial intervention studies, particularly those designed to target the mechanisms found to impact on pain, distress, and QoL. Consistent research findings suggest that illness-related cognitions and coping are key potential mechanisms predicting these outcomes in BPS/IC. It is therefore surprising that there have not been any cognitive behavioral therapy trials in the last 5 years. The efficacy of future psychosocial interventions should be assessed in longitudinal trials across different chronic pelvic pain and BPS/IC phenotypes in order to determine optimal care pathways.

Moderation and mediation analyses can provide more precise understanding of key components to target, such as cognitive processes, and whether these differ across clinical phenotypes. Finally, the role of trauma and suicidal ideation in the exacerbation, maintenance, and onset of BPS/IC needs to be further elucidated. More information regarding contributing factors to suicidality is needed in order to mitigate risk for this patient population.

Conclusion

BPS/IC is a highly prevalent condition with extensive impact on the patient and economy. There is recent growth of research into psychosocial factors in BPS/IC, yet there remains a shortage of quality research trials assessing psychosocial interventions for this patient population. The research to date suggests the importance of multidisciplinary care and input in BPS/IC management; however, this is often not an option in practice. Clinicians should as best they can address the psychosocial impact of BPS/IC via referral for additional support and psychoeducation regarding the condition's biopsychosocial nature and ways to mitigate its impact and treatment options. Supporting patients' sense of perceived control, self-efficacy, and use of positive coping behavior is potentially important for influencing illness trajectory.

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Compliance with Ethical Standards

Conflict of Interest The authors declare that they have no conflict of interest.

Human and Animal Rights and Informed Consent

This article does not contain any studies with human or animal subjects performed by any of the authors.

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- Of major importance

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