



Review

Addressing quality of life in the patient with interstitial cystitis/bladder pain syndrome



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Abstract Interstitial cystitis/bladder pain syndrome (IC/BPS) is a debilitating, chronic condition characterized by chronic pelvic pain, urinary urgency, and frequency and is well-known to be associated with a decrease in work productivity, emotional changes, sleep, sexual dysfunction, and mobility. Many metrics of quality of life (QoL) in this patient population have been developed; however, a unified, standardized approach to QoL in these patients has not been determined. The effects of IC/BPS and co-morbid conditions on QoL are described using current validated metrics. Next, data regarding successful treatment of IC/BPS in terms of QoL improvement are reviewed. While QoL is the single most important clinical measure of success in the treatment of patients suffering from IC/BPS, addressing QoL in this patient population remains a significant challenge, as its effects on QoL are highly variable and unable to be differentiated from the effects of comorbid conditions on QoL, including depression, poor sleep, and inability to work. Future studies will need to address treatment efficacy on the basis of IC/BPS specific QoL metrics, and multi-modal assessment and therapy to address comorbid disease will also play an important role in the future to ensure comprehensive management of these patients.

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1. Introduction

Interstitial cystitis/bladder pain syndrome (IC/BPS) is a debilitating, chronic condition characterized by chronic pelvic pain, urinary urgency, and frequency in the absence of other well-defined pathologies such as urinary tract

infection or malignancy. IC/BPS is well-known to be associated with a decrease in work productivity, emotional changes, sleep, sexual dysfunction, and mobility.

Quality of life (QoL) continues to be a challenging term to define, and therefore a challenge to assess. Ultimately, most authors will agree that QoL is a qualitative judgement, made

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by the individual in question, about his or her overall health status [1]. A complete definition of QoL must acknowledge the presence of life conditions, personal satisfaction with life conditions, and account for personal goals and expectations [2].

In order to develop a comprehensive and quantitative assessment of QoL, the World Health Organization (WHO) created a 100-question metric that evaluated six domains: physical health, psychological health, levels of independence in activities of daily living and work, social relationships, and environment. Of note, physical QoL included assessment of overall energy levels and fatigue, pain and discomfort, sleep and rest. Meanwhile, mental QoL involved the development of bodily image and overall appearance; negative and positive feelings; overall self-esteem; and ability to learn, memorize, and concentrate [3]. Since the development of this metric, most practitioners agree that physical and mental QoL are distinct but essential entities in the assessment of QoL. Many validated metrics have been developed since this time, all with a distinct approach to QoL in this patient population; however, a unified, standardized approach to QoL in these patients has not been developed.

In this review, we will discuss the effects of IC/BPS and co-morbid conditions on QoL and validated metrics that have been used for assessment. We will also explore varied treatments for IC/BPS and their QoL impact.

2. How does IC/BPS affect QoL? What concomitant conditions may also reduce QoL?

In the most thorough assessment of health-related QoL in IC/BPS patients to date, Michael et al. [4] demonstrated that the 36-Item Short Form Health Survey (SF-36) scores in IC/BPS patients as compared to healthy controls were lower across five of seven health-related QoL dimensions, including physical role, bodily pain, vitality, social functioning, and mental health. Smaller scale studies have demonstrated that females with IC had an overall lower QoL than patients with end-stage renal disease (ESRD) [4,5]. Moreover, when adjusted for the effects of comorbid conditions, this difference in QoL remained statistically and clinically significant. Since this time, many valuable metrics have emerged to assess IC/BPS-specific QoL have arisen, ranging from focused to comprehensive questionnaires (Table 1) [6–14].

While IC/PBS alone is well known to be associated with a lower QoL, this decrease in health-related QoL is often compounded by the presence of worsening psychological health, sexual function, sleep hygiene, work productivity, and mobility [4,15].

2.1. Lower urinary tract symptoms (LUTS)

LUTS are known to have a significant impact on the QoL in patients with IC/BPS. Pain and dysuria account for an increase in the Interstitial Cystitis Symptom Index Score (ICSI) scores in 54% of patients, with a focus on the QoL assessment [16].

2.2. Anxiety/depression

Patients with IC/BPS are more likely to develop depressive symptomatology than healthy controls or even other chronically ill populations [17]. Further, patients with IC/BPS and anxiety are known to have a significantly decreased QoL, most noticeably in the psychological, social, and environmental domains [17]. Most authors agree, therefore, that treatment of comorbid anxiety and depression is imperative to improve QoL in this population [17,18]. Further, improving depression will affect other areas in QoL, thereby improving the patient's ability to work, physical health and social functioning [18].

2.3. Sexual dysfunction

Sexual function has been shown to be an important predictor of physical and mental QoL in patients with IC/BPS in some studies, although other studies have questioned the validity of this finding [11,19]. Dyspareunia also indicates that patients are more likely to suffer from comorbid LUTS, decline in libido, and decrease in orgasm frequency when compared to health counterparts [20,21]. This has been clearly demonstrated in prospective analysis comparing patients with IC to asymptomatic controls. Female sexual dysfunction affects 43% of women in the US overall, and there are several validated metrics to assess sexual QoL in this population. The female sexual function index (FSFI) and the sexual function scale (SexFn) are the two most commonly used instruments (Table 1) [11].

2.4. Sleep disturbance

In an initial survey of patients with BPS, 635 of patients reported fatigue and 49% insomnia, often attributed to nocturia, which afflicts 87% of patients with IC [22]. Incidence of nocturia in BPS is 62%, and the average patient reported sleep disturbance due to urinary urgency three and eight times per night. Sleep deprivation may also be attributed to comorbid depression [23]. Treatment of IC/BPS symptoms can subsequently improve sleep quality and also significantly improve QoL in up to 42% of patients [24].

2.5. Work productivity

The RAND Interstitial Cystitis Epidemiology (RICE) survey has been used in studies to assess the effects on IC/BPS on work productivity and overall gross income [12]. In one series, 42% of women were unemployed, of which 11% of patients stated that this was a direct result of IC/BPS symptoms [25]. Of women working part-time, 6% reported that their limitation was related to IC/BPS. If the patient was diagnosed with IC/BPS after starting employment, she was more likely to remain a full-time employee than a patient who had started working after the onset of IC/BPS symptoms. Patients with IC/BPS were also more likely to miss more work days or half days. Of note, comorbid depression was also more likely to affect work productivity. IC/BPS was not significantly associated with earning potential. A significant decrease was noted in work-related QoL.

Table 1 Validated questionnaires used to examine IC/BPS-related QoL.

References	Scale	Description	QoL assessment
Goin et al., 1998 [6]	University of Wisconsin Interstitial Cystitis Inventory (WICI)	Assess seven (short form) or 18 (long form) domains and is scored from 0 to 42. This scale has also been validated to evaluate patients' improvement with treatment	Pelvic pain Pelvic discomfort Nocturia Day frequency Sleeping Urgency Burning
Oleary et al., 1997 [7] Lubeck et al., 2001 [8]	Oleary-Sant/Interstitial Cystitis Symptom and Problem Questionnaire	A validated questionnaire that has been used to assess both baseline QoL impact from IC/BPS as well as treatment efficacy	Urinary symptoms Pain Sexual function General health Relationship with menses QoL
Ware 2000 [9]	Medical Outcomes Study 36 Item Short-Form Health Survey (SF-36)	A comprehensive validated diagnostic tool that is inclusive of both physical and mental health metrics	Physical functioning General health Bodily pain Vitality Social functioning Mental health Emotional health
Parsons et al., 2000 [10]	Pelvic Pain and Urinary Frequency Patient Symptom Scale (PUF)	Validated QoL scale correlated with K ⁺ sensitivity test in determining whether a patient had IC/BPS	Frequency Urgency Pain Nocturia Sexual function QoL
Nickel et al., 2009 [11]	UPOINT	A validated questionnaire from the US examining six domains of QoL	Urinary Psychosocial Organ-specific Infection Neurologic/systemic Tenderness
Bogart et al., 2012 [12]	RAND Bladder Symptom Impact Scale (BSI-6)	IC/BPS specific QoL scale	Interest in daily activities Energy level Mood Self-worth Social life Ability to perform home duties
Wagenlehner et al., 2013 [13]	NIH – Chronic Prostatitis Symptom Index	Validated in trials conducted by the International Prostatitis Collaborative Network workshop, only validated in assessing severity of prostatitis	Pain Sexual activity Dysuria Frequency Incomplete emptying Micturition function QoL
Hebbar et al., 2015 [14]	Kings Health Questionnaire	A validated questionnaire from Europe evaluating multiple domains of QoL, scored from 0 to 80. Higher scores indicate better overall QoL	Sleep Symptom bother Physical limitation Role limitation Emotions

IC/BPS, interstitial cystitis/bladder pain syndrome; QoL, quality of Life.

2.6. Mobility

The McGill Pain Questionnaire, Dutch Leiden/Leuven Version (MPQ-DLV) QoL scoring system has been used to assess activity related QoL effects of IC/BPS. Patients have reported significant disability as a result of IC/BPS [16].

2.7. Other concerns

Further, most patients with IC/BPS will describe significant limitations in the areas of long travel, partner relationships, and family responsibility [11]. In all patients with IC/BPS, poor coping strategies, depression, impaired social relationships, and genitourinary/pelvic pain portend a poorer prognosis in terms of QoL. A tendency to catastrophize, or to anxiously worry about pain, also has significant overall impact on QoL [19].

3. QoL after treatment

The success of treatment in the IC/BPS population is largely contingent upon an improvement in QoL; however, little data is available on whether a qualitative improvement has been seen with most treatment modalities. No specific studies have used validated metrics to specifically evaluate QoL; the available studies employ instruments such as the ICSI, SF-36 and the King's Health Questionnaire where the QoL domain has improved after treatment.

3.1. Medical therapy

The mainstays of medical therapy remain the use of antibiotics, antihistamines, steroids, and antidepressants. However, a large degree of variability has been noted in different populations, and little-to-no data has been gathered using validated QoL questionnaires to assess overall improvement using these therapies.

3.2. Intravesical therapy

Although some controversy remains, several studies have confirmed that Botox leads to a successful improvement in QoL after retreatment. Further, when question 8 of the IPSS score was used to address QoL, several patients reported inferior QoL scores to baseline prior to original treatment prior to re-injection [26]. Criticisms of these data implicate improvement in QoL related to hydrodistension during cystoscopy as opposed to Botox administration alone. Pentosan sulfate sodium instillations have been shown to lead to a significant improvement in overall QoL within the confines of ICSI scoring [9]. Dimethyl sulfoxide (DMSO) instillations have been shown in multiple trials to lead to overall improvement in LUTS-related QoL [27–29]. Treatment effects are typically seen for a minimal of 16 and maximum of 72 months.

Resiniferatoxin (RTX) also leads to significant improvement in the King's Health Questionnaire scores of a small series of 15 patients; however, this improvement in QoL was not replicated in a follow-up, randomized, double-blind, placebo-controlled trial [30,31].

Asintravesical Bacillus-Calmette Guerin BCG instillations failed to show a significant response rate in terms of LUTS related QoL, this treatment has largely fallen out of favor in the treatment of IC [32,33]. Studies are also lacking regarding QoL with chondroitin sulfate and hyaluronic acid [34,35]. Larger scale studies and placebo-control studies will be needed to assess these results.

3.3. Neuromodulation

In a randomized control study of 48 patients, all patients undergoing posterior tibial nerve stimulation (PTNS) were found to have significant improvement in the SF-36 questionnaire at 12 weeks and 6 months when compared to the control group. Over half of patients undergoing PTNS also indicated that they felt they were cured of their symptoms at 6 months follow-up [35].

3.4. Surgical therapy

Interstitial cystitis remains one of the most common indications for cystectomy in patients without malignancy refractory to medical therapy [36]. In one small series examining QoL after cystectomy, seven out of twelve patients reported optimal ICSI scores of 0 after definitive surgery [36]. Hydrodistension has yielded extremely variable results in terms of QoL improvement [37–39].

4. Conclusion

QoL is the single most important clinical measure of success in the treatment of patients suffering from IC/BPS, yet addressing QoL in this patient population remains a significant challenge, as its effects on QoL are highly variable and unable to be differentiated from the effects of comorbid conditions on QoL, including depression, poor sleep, and inability to work. Ultimately, while a thorough assessment of the patient's symptoms is of paramount importance, more metrics are needed to specifically focus on QoL. Diagnosis and treatment of associated conditions is mandatory in the treatment of IC/BPS, and screening for comorbid depression and sexual dysfunction is crucial to ensure that the patient experiences a significant improvement in overall QoL.

Future studies will need to address treatment efficacy on the basis of IC/BPS specific QoL metrics, and multimodal assessment and therapy to address comorbid disease will also play an important role in the future to ascertain comprehensive management of these patients.

Conflicts of interest

The authors declare no conflict of interest.

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