**The Relationship between Illness Perception and Worsening of Interstitial Cystitis/Painful Bladder Syndrome Symptoms: A Cross Sectional Study**

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**DATA AVAILABILITY STATEMENT**

The data in support of the findings of this work is available on request from the corresponding author.

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**CONFLICT OF INTEREST DISCLOSURE**

We have no conflict of interest to declare.

**ETHICS OF APPROVAL STATEMENT**

Ethics approval was obtained from Ethics Research Governance Online II (ERGOII) of the University of Southampton, United Kingdom.

**PATIENT CONSENT STATEMENT**

Patient fully consented to participate in the study.

**PERMISSION TO REPRODUCE MATERIAL FROM OTHER SOURCES**

Permission granted.

**Clinical trial registration**

N/A

**AUTHOR’S CONTRIBUTION**

1. Conception and design: K. Garba, B.R. Birch, M. Avery and B.A. Lwaleed
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**Abstract**

**Objective**: To evaluate disease perception in a cohort of patients with Interstitial cystitis/painful bladder syndrome (IC/PBS) using the Brief Illness Perception-Questionnaire (BIP-Q) and to evaluate how this might relate to disease severity.

**Materials and Methods**: The study is a cross sectional survey amongst members of Bladder Health UK who had previously received a clinical diagnosis of IC/PBS. A hyperlink containing the questionnaire was sent to the patient group’s website and interested members accessed and completed the survey. Participants’ inclusion was based on a prior clinical diagnosis of IC/PBS, current O’Leary Sant scores supportive of the diagnosis and age between 18 and 80. A sample size of 171 was used in the study. The Brief Illness Perception Questionnaire (BIP-Q) and the O’Leary/Sant symptoms and problem indices questionnaire were used to collect data. A multivariable logistic regression analysis was used to test the relationship between items of BIP-Q and severity of IC/PBS. Content analysis was used for the causal domain and subsequently analysed as percentages.

**Results:** 601members accessed the questionnaire of whom159 returned completed questionnaires.122 of 159 (≥75%) respondents believe that their illness will continue indefinitely. The majority of the respondents indicated that IC/PBS had a negative impact on their daily lives, caused them worry and made them emotionally unstable. Of the 8 BIP-Q items, those most predictive of disease severity were (Adjusted Odd Ratio (AOR) and confidence intervals (CI)): Consequence 0.094 (0.023-0.386); Treatment control2.702 (1.256-5.812); Identity 0.141 (0.033-0.600); concern 9.363 (57.632-0.016)

**Conclusions**: Our findings show that IC/PBS negatively impacts participant’s quality of life and emotional wellbeing. Higher expectation for treatment benefit and increasing levels of patient concern are predictive for severity of IC/PBS.

**Key words**: Interstitial cystitis/painful bladder syndrome, Illness perception, Severity, O’Leary Sant score.

**INTRODUCTION**

Interstitial Cystitis/Painful Bladder Syndrome (IC/PBS) is a poorly understood, chronic, debilitating urological disorder that can significantly impair quality of life. 1 The precise aetiology of the disease remains unclear, thus hampering the development of an optimum management strategy. It is therefore reasonable to broaden the scope of disease management by talking to patients in order to better understand and so address their unmet needs which could help improve overall quality of life.

The concept of patient’s perception of illness was popularized by Leventhal, et al. 2 in the Common Sense Model for self-regulation wherein a patient’s set of beliefs regarding their illness was shown to be crucial in providing self-care for chronic diseases. 3 Thus, integrating these perceptions could help to form the basis of self-care in IC/PBS (chronic illness) management, which might then translate to an overall improvement of Health Related Quality of Life (HRQoL). More importantly, clinical assessment of disease morbidity is often difficult to establish due to the subjective nature of pain and discordance between patient and clinician perception of treatment outcomes in particular and the disease as a whole.4 In this respect incorporating patient voices helps gain more insight into some of the constructs of IC/PBS, which are not open to clinical measurement. The end result being a better understanding of the impact of IC/PBS on patient lives.

Likewise, an individual’s perspectives of their illness is as important as the caregivers views especially in chronic illnesses like IC/PBS with somatic components that necessitate physical and psychosocial evaluation. 5,6 Whilst much is known and utilised regarding Illness perception in many disease areas,7 to the best of our knowledge no study exists in IC/PBS. Studies utilising the Illness perception tool are mostly descriptive and seldom shed insight into how these views might be predictive of established clinical benchmarks of illness progression.8 Given this, we sought to describe Illness perception in IC/PBS and to asses any relationship between Illness Perception (IP) items of the Brief Illness Perception Questionnaire (BIP-Q) and IC/PBS severity in order to provide baseline data for patient’s views relating to disease severity.

**MATERIALS AND METHODS**

**Study design, sample and measurement**

Approval for the study was obtained from the University of Southampton, via the Ethics and Research Governance Online (ERGOII) application system and review by The Faculty of Medicine Ethics Committee. Participants fully consented following full disclosure of the study aim and objectives. In addition, personal identifying data were not sought from the survey.

The survey hyperlink was made available for access to the participants between February 2019 and March 2019, on the website of Bladder Health UK (BHUK) - a charity for bladder related problems in the UK. Convenience sampling was used in this survey. A sample size of 171 was projected based on Confidence Interval (CI) width of 0.15, Confidence interval of 0.5% and planning proportion of 0.5. A sample size calculator developed by Naing et al9 was used to arrive at the sample size. The survey questions comprised the Brief Illness Perception Questionnaire (B-IPQ), the O’Leary/Sant Symptoms and Problem Indices Questionnaire and a record of the age and gender of the participants.

The O’Leary/Sant Symptoms and Problem (ICSI/ICPI) Questionnaire was used to ensure that participants reporting a previous clinical diagnosis of IC/PBS fulfilled the criteria for this diagnosis and was also used for stratification of illness severity. The O’Leary/Sant symptom and problem scale was developed as a tool to complement other non-invasive techniques in IC/PBS diagnosis and treatment monitoring. A cumulative score of 12 and above has a predictive value that is both positive and specific. Respondents were dichotomised into 0-18 (mild to moderate symptoms IC/PBS) and 19-36 (moderate to severe symptoms IC/PBS). Similarly, the 10-point scale of the BIP-Q was stratified into a lower level (0-5) and a higher level >5. The covariates from the BIP-Q scale were: Consequence, timeline, personal control, treatment control, identity, concern, understanding and emotional response.

**Statistical analysis**

The study was supported by a medical statistician (Associate Professor Scott Harris). Data was collected using isurvey software that automatically entered participant responses into a spreadsheet. In addition, it also recorded start and completion times, completion status, number of participants that accessed and completed the survey - the latter being used to calculate the response rate. The data was transferred to an excel sheet for cleaning and assessed for missing values and thereafter imported into IBM SPSS statistics for windows version 26.0 (IBM Corp., Armonk, N.Y., USA) for analysis.

Categorical variables and open-ended items following content analysis were analysed as proportions, while continuous variables as means (SD) and ranges.

Simple logistic regression was used to screen for each of the independent variables (consequence, timeline, personal control, treatment control, identity, concern, understanding and emotional response) for inclusion in the multivariable analysis. Covariates with p<0.1 at the univariable stage were included in the multivariable analysis. Multivariable logistic regression was used to test for BIP-Q items as risk factors for IC/PBS severity. The results of the univariable logistic regressions are presented as crude OR, 95% CI and corresponding p values, while those of the multivariable logistic regression are presented as adjusted OR, 95% CI and their corresponding p values. P values less than 0.05 were considered statistically significant. Goodness-of-fit model assumptions were checked using Hosmer-Lemeshow and Omnibus tests. Multicollinearity (to ensure that independent variables are not correlated) was checked by standard error of mean of the B coefficients.

**RESULTS**

A total of 159 participants completed the questionnaire out of the 601 members that accessed the survey hyperlink, producing a response rate of 26.4%. The mean age of participants was 55.40 years (SD = 15.38). In total, 92.6% of the participants were females. The mean (SD) O’Leary/Sant score of the participants was 19.93 (9.13).

**BIP-Q scores of the sample**

Participants were of the opinion that the disease would proceed indefinitely, impact negatively on their well-being and had low belief that available treatments could help alleviate their symptoms (Table 1). In addition, participants felt a loss of control with respect to managing their disease and that their symptoms caused a high degree of both physical and emotional bother despite participants showing some understanding of their disease.

**Causal factors of IC/PBS**

Respondents identified many factors perceived to be the cause(s) of their disease. All of the primary stated causes were grouped into categories by author’s preference (Table 2). Infection and inflammation (UTIs, tonsillitis, cystitis, viral infection, auto-immune disease and pain) and Lifestyle (diet, stress, anxiety, emotions, bereavement, holding on urine for too long, obesity, dehydration and heatwave) accounted for more than half of all causes. Others, included Pelvic surgery/procedures (hysterectomy, surgery around the pelvis, caesarean section and childbirth); hormonal dysregulation (changes in hormones as a result of menopause); and an anatomical defect (poor bladder lining). Major causes of IC/PBS as understood by the respondents are represented in Table 2. About one-quarter of the sample did not know the exact cause of their illness. Other ancillary causes included: Fibroids, constipation, Irritable bowel syndrome, chronic fatigue syndrome and ketamine abuse.

**Logistic regression outcomes**

The logistic regression model is statistically significant χ2 (4) = 51.317, p= 0.000 and explained 37% (Nagelkerke R2) of the variance of IC/PBS severity and correctly classified 74.2% of the cases. Of the 8 BIP-Q items, only one item (understanding) was excluded in the multivariate analysis (Table 3; p>0.1). Of those included, consequence (expected effects and outcome of the illness), treatment control (extent to which the patient believes that treatment can help recovery from or control of the illness), Identity (the label the person uses to describe the illness and the symptoms they view as being part of the disease) and concern (anxiety about the disease) had odds of 0.094, 2.702, 0.141 and 9.363 for predicting the severity of IC/PBS, respectively (Table 4). This equates to a 0.094 and 0.141 fold reduction in the odds of predicting disease severity for the consequence (disease effects and outcome) and Identity (labelling) items of the BIP-Q. Whilst there was an increase in the odds for predicting disease severity by 2.702 and 9.363 times respectively for the treatment control and concern items.

**DISCUSSION**

To the best of our knowledge, this is the first study that describes and explores illness perception in people living with IC/PBS and examines its relationship with disease severity. The poor ratings of most of the items in the BIP-Q correlate with the negative impact on HRQoL seen in this disorder and are consistent with previous studies.8,10

Descriptively, the poor ratings of the psychological items of the BIP-Q point to the underlying mental health challenge experienced by these individuals. Psychological stress has long been reported as higher in IC/PBS cohorts compared to healthy controls. 11 Previous studies have also reported a higher prevalence of depressive disorders in IC/PBS patients compared to other lower urinary tract symptom sufferers. 12 Furthermore, the incidence of Post-Traumatic Stress Disorder (PTSD) and its associated psychological distress is higher in IC/PBS than in other Chronic Pelvic Pain conditions. 13 Deterioration of mental health as evaluated by depressive symptoms, isolationism and helplessness amongst IC/PBS patients was shown to be risk factors for suicide that further complicates the psychiatric burden of the disease. 14,15 Not surprisingly, participants that were anxious about their illness, as represented by the concern item of the BIP-Q scale, had a 9.363 times greater likelihood of having severe IC/PBS. The identity item assesses the description or labelling of illness in IC/PBS; higher scores in this item were negatively associated with the overall severity of the disease suggesting that the latter alone is not important in participants thoughts around being assigned a diagnosis of IC/PBS.

The higher scores of “concern” and “consequence” shown in response to the BIP questionnaire indicate depressive tendencies that have been recognised in IC/PBS patients.16 Furthermore, the cohort reported higher timeline scores and lower treatment control scores, which correlate strongly with poor psycho-social and physical outcomes.7 In the same manner, the cumulative BIP-Q scores in this sample were higher than those reported in cancer and periodontal diseases using a similar tool that serves to emphasise the poor quality of life associated with IC/PBS. 17,18 Participants generally indicated a lack of belief in the role of current IC/PBS treatments. This could be related to the need for hope that treatment will control symptoms, something that is more marked in those with more severe disease. Participants also indicated an inability to take personal control of their disease.

With respect to the causal factors - what did respondents believe to be the cause(s) of IC/PBS? It should be noted that, these are anecdotal views largely influenced by an individual participant’s level of knowledge and education. In addition, mass media and physician-patient education are influential. 15 However, they are no less valid for that.

Most respondents reported infection and inflammation as the primary cause of their IC/PBS. Recurrent UTI’s and other bladder infections are diseases that can be confused with IC/PBS and their presence usually excludes a diagnosis of IC/PBS. 19 Interestingly, participants identified inflammation as one of the causes of their illness, an outcome consistent with the mainstream understanding of IC/PBS pathogenesis, which is often characterised by activation of the bladder mast cells, cytokine and nitric oxide release. 20,21 However, the unsatisfactory outcomes of available antihistamines and other immune-modulatory agents in the treatment of IC/PBS confound this theory. The presence of both histaminergic receptors on IC/PBS biopsies and pro-inflammatory mediators in biological samples point to the fact that these cell membrane proteins are critical therapeutic targets.

Lifestyle measures, identified by respondents, may be flare triggers, which could be misconstrued as causes. In the same manner, pelvic surgery was perceived as a major cause of the disease. This is consistent with other work reporting pelvic trauma as a contributory factor for the pathogenesis of the disease. 22 Equally important, a history of pelvic surgery was documented in IC/PBS cohorts prior to the onset of the disease. 23 Our data is limited by the fact that the timing of pelvic surgery related to the diagnosis of IC/PBS was not sought in the sample. Other causes of IC/PBS identified by respondents included endometriosis, fibromyalgia and Sjogren’s syndrome

The strengths of this study include the fact that it is the first to look at illness perception and its relationship with severity of IC/PBS. Furthermore, data collection was from real world IC/PBS sufferers and so helps to bridge the knowledge gap between patients and the clinic.

With respect to limitations, the authors recognise that data was collected anonymously and that convenience sampling was used. As a consequence, the results should be interpreted with caution because bias due to misrepresentation cannot be entirely excluded. Another weakness of the study is that it relies on respondents reporting an IC/PBS diagnosis made by a clinician without recourse to review of their clinical records. However, the fact that members of the charity have been consulting their care providers, are very engaged with their disease management and fulfil the criteria for a diagnosis of IC/BPS using the O’Leary Sant questionnaire serves to reduce such bias. Our study did not extract data on educational levels of participants. Thus, data on perceived causes of the disease should also be interpreted with caution due to technical nature of this domain.

**Conclusion**

The outcome of this study has shown poor illness perception in all items of the BIP-Q by individuals with IC/PBS. Of these items, belief in the fact that treatments will control symptoms and concern about the disease demonstrated a positive predictive value for severity of IC/PBS symptoms. Such findings confirm the importance that cognitive and emotional factors play in those affected by IC/PBS.

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**LEGENDS TO TABLES**

Table 1: Means (SD) of IC/PBS of perception from BIP-Q scale (n=159).

Table 2: Showing major perceived causes of IC/PBS (n=159).

Table 3: A univariate logistic regression analysis of illness perception items as predictors of IC/PBS severity (n=159).

Table 4: A multivariate logistic regression analysis of illness perception items as predictors of IC/PBS severity (n=159).

**Figure 1:**



**Figure 2:**

**Figure 3:**



**Figure 4:**

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