



Interstitial Cystitis/Bladder Pain Syndrome [IC/BPS]: Assessment of Knowledge and Awareness in General Population of India

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Abstract

Introduction: Interstitial Cystitis/Bladder Pain Syndrome (IC/BPS) is a chronic and incapacitating disorder marked by ongoing bladder pain, discomfort, and increased frequency of urination, which greatly undermines the quality of life for affected individuals. Despite being widely acknowledged in Western countries, IC/BPS is still not often diagnosed or reported accurately in India.

The objective of this study is to evaluate the extent of understanding and consciousness of IC/BPS among clinical practitioners and the general population in India.

Objectives: The primary objective of this research is to evaluate the awareness and understanding of IC/BPS among medical professionals, including urologists, gynecologists, and general practitioners, as well as to assess the level of awareness among the Indian population. Furthermore, the study aims to ascertain the obstacles and impediments to precise diagnosis and efficient treatment of IC/BPS in the healthcare setting of India.

Methods: Data was gathered from a representative number of clinical practitioners in key urban areas of India, as well as from a diverse demographic of the general population. The survey quantified knowledge, diagnostic procedures, treatment preferences, and perceived obstacles.

Results: Initial results suggest that both clinical practitioners and the general community in India have a limited level of awareness and understanding of IC/BPS. A significant number of healthcare professionals indicated little familiarity with IC/BPS cases and inadequate training in its diagnosis and treatment. A considerable segment of the general populace harboured limited knowledge of the disease, frequently conflating its symptoms with those of more frequently diagnosed urinary tract infections (UTIs). Furthermore, the study revealed that cultural stigma, absence of defined diagnostic criteria, and restricted access to specialized treatment are significant obstacles to the successful management of IC/BPS in India.

Conclusion: The results emphasize the immediate requirement for focused educational programs aimed at enhancing awareness and comprehension of IC/BPS among healthcare professionals and the general Indian community.

Keywords: Interstitial Cystitis (IC); Bladder Pain Syndrome (BPS)

Introduction

The existence of this disease happens to be there since 19th century and it has been listed in English literature by Joseph Parrish. In 1938, he had described this condition as "tic douloureux of bladder", which means a patient is suffering from extremely painful urinary symptoms, despite of not having stone in bladder [1].

Century passed by and the term IC/BPS had been evolved through many names; from ulcer – non ulcer, from Hunners ulcer to Hunners Lesion to finally be named as PBS 'painful bladder syndrome' [1] by 'ICS [International Continence Society]' in 2002 and described it as "the complaint of suprapubic pain related to bladder filling, accompanied by other symptoms such as increased daytime

and night-time frequency, in the absence of proven urinary infection or other obvious pathology” [2] and later by ‘NIDDK [National Institute of Diabetes and Digestive and Kidney Diseases]’ in 2003 as PBS/IC ‘painful bladder syndrome/interstitial cystitis’ [1].

Epidemiological studies have reported a variety of findings about the prevalence of IC/PBS. This can be the result of imprecise sample methods, inconsistent criteria for diagnosing IC/PBS, and a lack of conclusive diagnostic investigations. According to traditional data, women are nine times more likely than men to receive an IC/PBS diagnosis. Moreover, the only proven risk factor for this illness is being a woman. The female to male ratio in a managed care population drops to 5:1, suggesting that male patients may not be receiving enough diagnoses for their conditions [9].

Reports on the prevalence of interstitial cystitis conflict, depending on the country of origin and the criteria used for diagnosis. In addition, there is significant overlap with conditions such as urinary tract infection, pelvic pain syndromes, and overactive bladder [10].

There have been variable reports on the prevalence of IC. The prevalence of IC/BPS is around 45 out of 10,000 in women and 8 out of 100,000 in men [11].

The prevalence of IC is also found to be variable, and it ranges from 52 to 500/100,000 in females compared to 8–41/100,000 in males, and its incidence is reported to be increasing globally [9].

In women, the incidence of clinically proven probable Interstitial Cystitis (IC) was 230 per 100,000 (95% confidence interval 100 to 360), while the incidence of likely IC was 530 per 100,000. Based on the limited data available on patients experiencing urinary symptoms, the revised estimates were 300 per 100,000 (95% confidence interval 120 to 770) for males and 680 per 100,000 (95% confidence interval 360 to 1,300) for women. Moreover, the data obtained from the clinically verified diagnosis suggest that IC is far more prevalent than previously believed [12].

IC onset is subacute rather than insidious, with classically full-blown disease occurring in a relatively short time. Another study has shown that IC reaches its final state quickly, and there is less chance of further deterioration in symptom severity [15].

Interstitial cystitis (IC) does not commence as a terminal condition; it initiates with milder, intermittent symptoms that are often misinterpreted. Most individuals with sexual activity-related symptom flares have intermittent IC. Later symptoms include pain and urgent incontinence. When IC flares, UTI is most often misdiagnosed. A history of UTI is twice more likely in patients with IC as compared to controls. Most IC patients have symptoms before 30, although diagnosis is usually delayed until 40. Genetics appear important. These aspects should be considered while assessing women with “early IC” to ensure proper diagnosis, treatment, and lower health care expenditures [16].

Methodology

The research project was conducted in a survey-based model where the objective of the research project was to evaluate the level of awareness of the disease IC/BPS among the general population of India.; A validated questionnaire was shared with participants, with whom the survey was conducted. The Questionnaires was developed with the help of available literature and by understanding the issues and bottlenecks in the awareness and knowledge of IC/BPS.

Survey was conducted among the general population of India ranging from 18 – 60 years.

Results

Awareness of IC/BPS has been poor based on the understanding from literature, the participants responded to the question asking if they were aware of Interstitial Cystitis/Bladder Pain Syndrome [IC/BPS]. It was not so surprising as the disease comes under Rare/Orphan/Unserved category, 18.18% [70 of 385] stated that they are aware of what is IC/BPS and 81.82% [315 of 385] stated that they were not.

Next the participants were asked “What treatment options you are aware of to treat IC/BPS?”. To this Majority of the participants 71.43% [50 of 135] stated that they are aware of Oral Medication, whereas 21.43% [15 of 135], 24.29% [17 of 135], 35.71% [25 of 135], 30.00% [21 of 135] stated that they were aware of Probiotics, Hydrodistension, cystoscopy, intravesical instillation respectively. 10.00% [7 of 70] stated Others wherein the answers received to others were Pelvic health physiotherapy, Botulinum in some resistant cases, Pain blocks, surgery, PRP, Yoga etc.

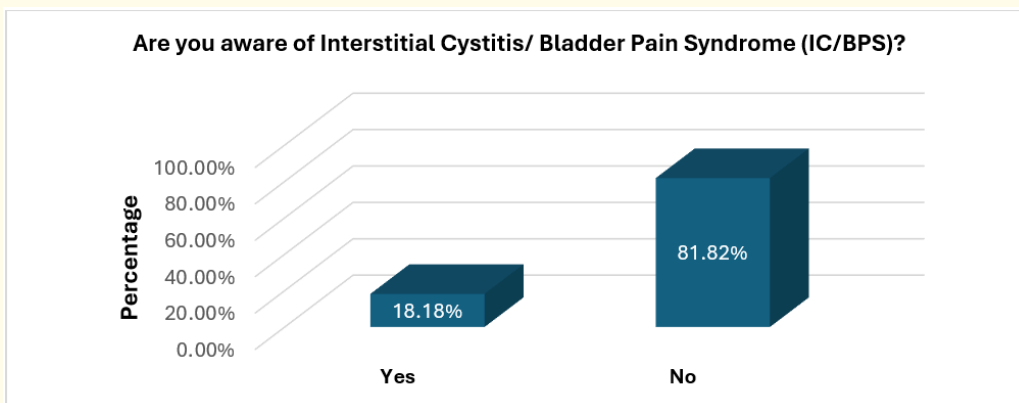


Figure 1

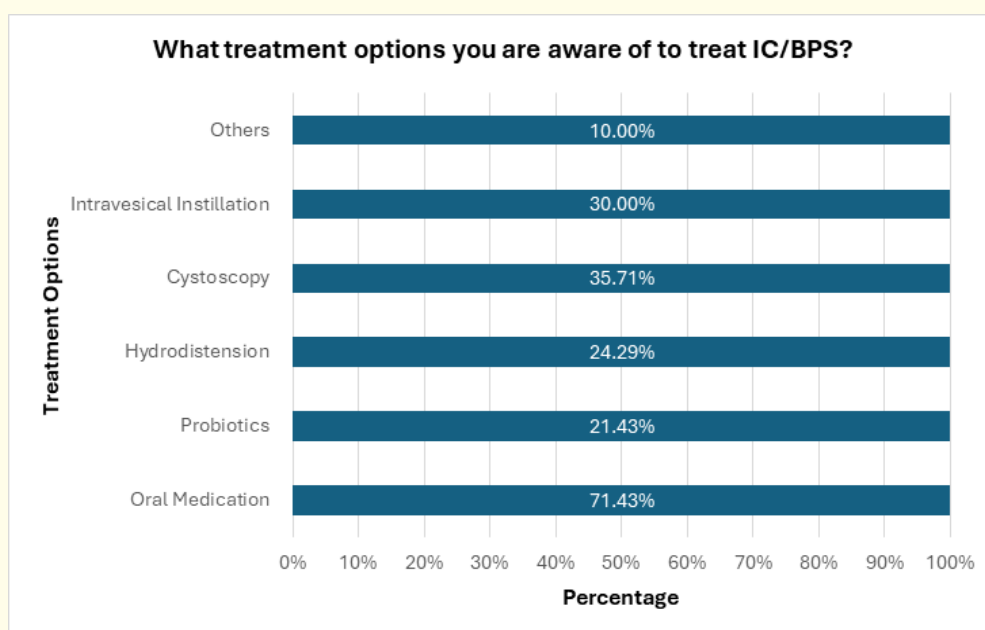


Figure 2

“Do you think Nocturia [the need to get up at night on a regular basis to urinate] would be one of the sign/symptoms of IC/BPS?”, this has been a major misconception. To which 80.00% [56 of 70] stated Yes and 20.00% [14 of 70] stated No.

Next the participants were asked “if they think IC/BPS is Curable/Treatable/Manageable”. To which 45.71% [32 of 70] stated that it is manageable whereas 28.57% [20 of 70] and 25.71% [18 of 70] stated that it is Treatable and Curable respectively.

The participants were then required to answer the question “Under what circumstances do you think a patient can have IC?”. In response, most of the participants (67.14%) stated that Pain while voiding can be one of the circumstances where a patient can have IC, while 62.86% stated that frequency of urination can be one of the circumstances where a patient can have IC. 57.14% stated that urgency of urinating and irritation and burning sensation can be one of the circumstances where a patient can have IC. 10.00% stated others wherein they stated dyspareunia or Lower abdominal discomfort or pain relieved on voiding can be one of the circumstances where a patient can have IC.

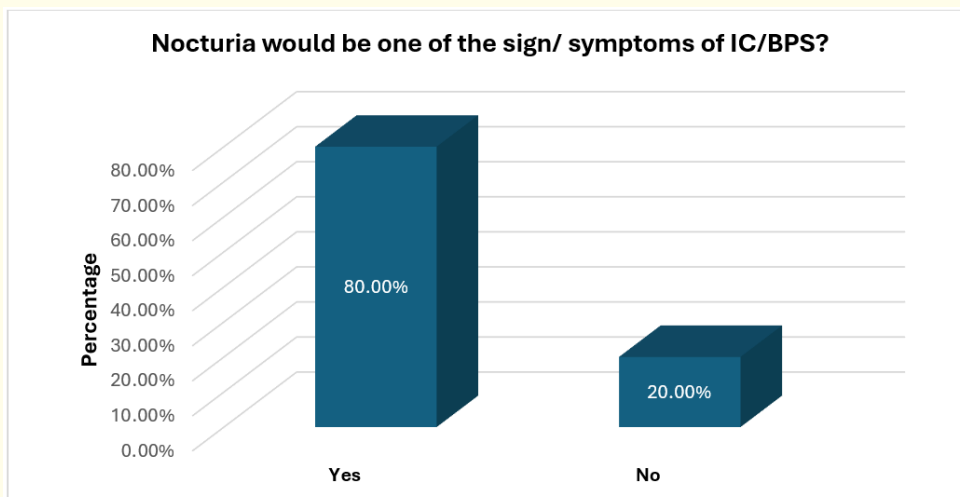


Figure 3

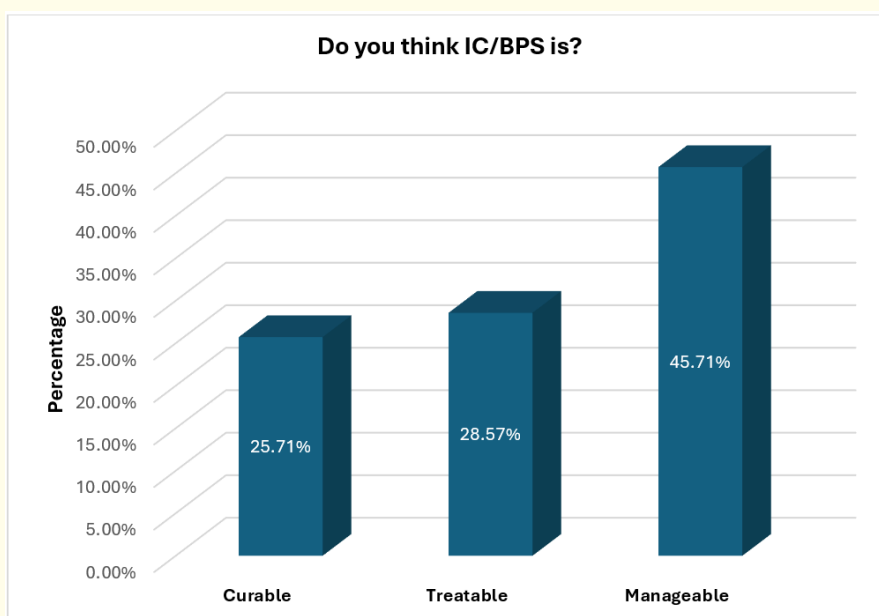


Figure 4

Discussions

The present research was conducted to study the knowledge and awareness of Interstitial Cystitis/Bladder Pain Syndrome (IC/BPS) in Indian society. Current research findings indicate a significant insight. In Indian society, many people strongly describe the chronic condition and exhibit some critical areas in which health practitioners, legislators, and researchers should pay attention. These are discussed in the discourse as it relates to an even broad-

er context in which the international health trends and challenges of controlling IC/BPS are presented.

Degrees of awareness

It was observed in the survey that the general population had low levels of understanding concerning IC/BPS within certain healthcare communities. Example: Only 32.86% of the respondents know that IC/BPS is considered a discontinuation of diag-

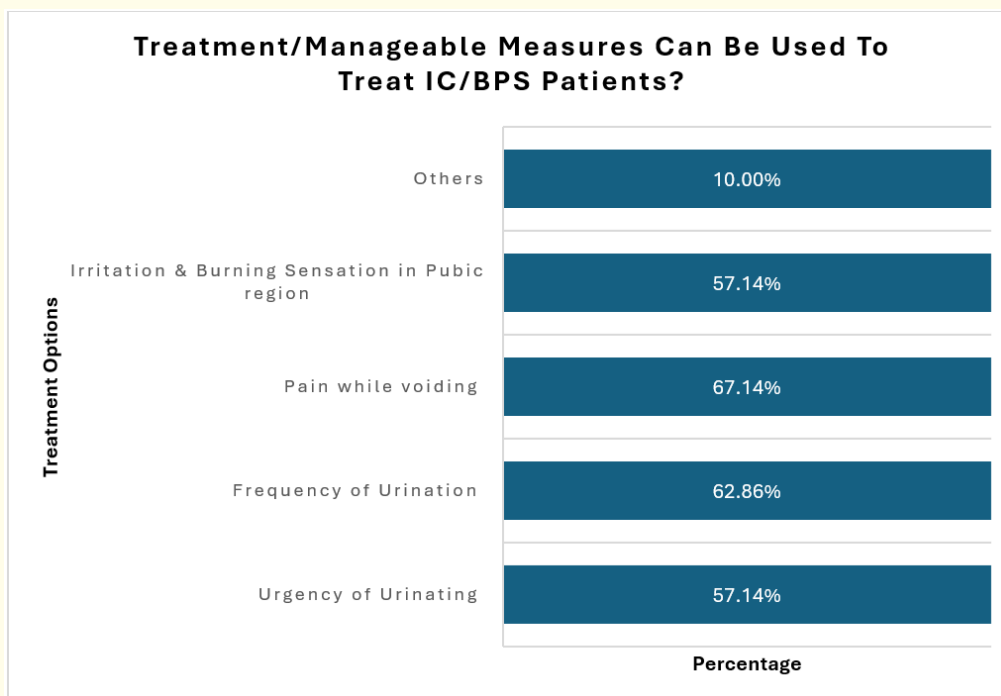


Figure 5

nostic tests. Such a finding corresponds to global trends; IC/BPS is generally considered underdiagnosed and poorly understood (Hanno, *et al.* 2015). It may settle within that gap and delay diagnosing and treatment for such stigmas attached to understanding bladder and pelvic health in India.

The lack of public conversation even concerning pelvic health makes it more difficult for individuals to move toward the medical advice, especially in conservative areas where urological symptoms are taboo topics. Breaking through this barrier requires a holistic strategy that will combine education, community involvement, and having bladder health become a normal conversation topic. Awareness programs may also include local languages and culturally relevant narratives to make conversations about IC/BPS easier. In addition to this, community health workers might be in a position to serve as the main agents in disseminating knowledge and driving individuals toward medical advice with minimal fear of judgment.

Conclusion

It is imperative from this study for the overall population that there is marching toward awareness and understanding of IC/BPS.

Although there’s a considerable quality of life impairment due to IC/BPS, most Indians do not even know about the illness as a well-acclaimed medical illness. Only 18.18% of the sample population who were surveyed confirmed awareness of the disease. Awareness would have to include culturally sensitive ones more targeted at the younger and rural populations so that the taboos could be liberated around bladder health. Furthermore, it would include community health workers and be able to harness the advantage of digital technologies to inform, encourage timely medical visits, and reduce stigma. People understand the facts well so that the gap in awareness is eventually reduced with an earlier diagnosis that maximizes positive outcomes among those affected by IC/BPS.

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