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Articles

Psychological distress in Interstitial Cystitis/Bladder Pain Syndrome: cross-sectional study on emotional pattern

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Abstract

Interstitial Cystitis/Bladder Pain Syndrome (IC/BPS) is a chronic condition well studied in the urology and gynaecology fields, but its psychological impact on patients' quality of life has been neglected. Our study prioritised the psychological impact of IC/BPS on the quality of life and wellness of patients in an effort to identify the emotional impact of this pathology on the sex lives of women. A cross-sectional study was conducted on sample composed of 132 women (aged 20-75 years). Statistical analysis evidenced significant differences in diagnosis time ($p<0.02$) associated with sexual distress and characterised by significant metacognitions, such as negative beliefs ($p<0.01$), cognitive confidence ($p<0.08$), stress ($p<0.00$), anxiety ($p<0.001$), and depression ($p<0.001$). This finding highlighted that women suffer significant psychological distress related to IC/BPS. Personalised treatments using an integrated clinical approach should be the innovative solution for co-morbid psychological distress in IC/BPS pathology.

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1. Introduction

Interstitial Cystitis/Bladder Pain Syndrome (IC/BPS) is a chronic condition characterised by pelvic pain and urinary storage symptoms such as persistent urge to void, nocturia, and urinary frequency. Its aetiology is unknown, and a multitude of therapies are currently available for its treatment (Davis, 2014). IC/BPS is a chronic debilitating condition and can have a severely negative impact on a patient's quality of life. Evidence suggests that psychosocial factors, such as comorbid anxiety, depression, quality of life, and trauma-related symptoms, accompany and intensify the illness (Goldstein et al., 2008; Watkins et al., 2011).

The psychological and social impacts of IC/BPS are well described as pervasive consequences of the condition. IC/BPS diagnosis is frequently associated with a significantly increased likelihood of anxiety or depressive disorders. Symptoms of anxiety, depression, generalised stress, and increased suicidal ideation are reported in the literature, and many individuals are more likely to engage in catastrophic thought processes, which globally worsen functioning (Lutgendorf et al., 2000; Rothrock et al., 2001; Zhang et al., 2013; Lai et al., 2015).

Clearly, IC/BPS has a significant impact on patients' quality of life, self-esteem, and social functioning. Moreover, in their review, McKernan et al. (2018) highlighted that the psychological consequences of an IC/BPS diagnosis can positively affect the efficacy of clinical treatments and also self-management interventions and strategies (such as guided imagery/self-hypnosis, mindfulness, and online health education).

Higher wellness was significantly related to better management of IC/BPS symptoms (significant reductions in pain and urinary urgency, greater perceived control of symptoms). Moreover, the authors highlighted the urgent need for integration of psychological assessment and management into care plans for IC/BPS.

Surprisingly, few studies have examined sexual distress and its emotional impact on quality of life in youth and adulthood among female IC/BPS patients, paying attention solely to the sexual dysfunction symptom. Tonyali and Yilmaz's review (2017) evidenced this aspect as a paramount domain in IC/BPS, but it is not yet well investigated;

randomised controlled studies are still needed. Almost all research have been conducted on small samples of adults, highlighting the emotional aspects (detecting urological and gynaecological symptoms);

however, a case-control study by Peters et al. (2007) verified the presence of sexual distress in IC/BPS patients compared to control women (without pathology), highlighting the need to explore multiple factors contributing to this symptom in IC/BPS. Borgat et al. (2010) confirming Peters' (2007) findings, investigated the sexual disfunction by large scale study design highlighting the association between severity of BPS/IC symptoms and individual features (younger age, worse depression, worse general health);

Borgat et al. (2010) highlighted the impact of pathology on the sexual behaviour and suggesting the need to plan integrated treatments conducted by interdisciplinary team of clinicians with expertise in urology, physical therapy, and sex therapy. More, women with BPS/IC seem do not seek help for sexual issues because of their being reluctant to tell about sexual disfunctions during medical sessions.

Following literature highlights, the lack of psychological investigations combined with the increased rate of IC/BPS diagnosis has favoured the emergence of this research topic.

The present study prioritised the psychological impact of IC/BPS on quality of life and the wellness of women affected by IC/BPS in an effort to identify the emotional impact of the condition on the sex lives of women.

The objectives of the study were to:

1) evaluate the emotional impact by comparing IC/BPS patients at different time points after diagnosis;

2) analyse the correlation between the levels of psychological and sexual distress in younger and older women affected by IC/BPS; and

3) examine the ability to manage IC/BPS in one's own daily life.

2. Materials and Methods

2.1 Ethics Statement

Informed consent was obtained from each participant, and the study adhered to the Declaration of Helsinki (2008). The IRB approval didn't need because was a preliminary screening committed by Italian Association of Interstitial Cystitis (AICI). Participants have been voluntary.

2.2 Participants

Participants were 132 Italian women aged 20–75 years old (M = 50.17, SD = 11.99). Participants were living in the North (N = 57; 43.2%), Middle (N = 49; 37.1%), or South of Italy (N = 26; 19.7%) in urban and rural areas. Using the median age (= 52 years old), participants were divided into two groups (Younger Group = G, Older Group = OG), both composed of 66 women. Farther, the distribution operated by the timing of diagnosis: a) T1 = 1-3 years since diagnosis (32.5% of the sample); b) T2 = 4-7 years from diagnosis (25.7%); and c) T3 = 8-11 years from diagnosis (41.6%).

Recruitment was carried out through social media, mainly by medical doctors. The inclusion criteria were: a) female; b) aged 20–75 years; c) Interstitial Cystitis/Bladder Pain Syndrome diagnosis; and d) signed informed consent.

Table 1 shows the demographical data.

Table 1 – Distribution frequencies and percentages of sample demographical data

Demographical Variables	**N°**	%
Relationship status		
Married/living with partner	98	74.2
Divorced/widowed	17	12.8
Single	17	12.8
Education		
Did not graduate	21	15.9
High school	63	47.7
Graduation	48	36.3
Occupation		
Housewife	33	25
Employed	52	39.3
Self-employed	28	21.2
Retired	19	14.3
Timing of diagnosis		
T1(1-3 years)	43	32.5
T2(4-7 years)	34	25.7
T3(8-11 years)	55	41.6

2.3 Measures

Standardised tests were applied to measure psychological variables (metacognitions, distress, depression, anxiety, sexual distress), and an experimental self-report questionnaire was used to analyse the psychological factor of adjustment to the interstitial cystitis diagnosis. Trained medical doctors collected the socio-demographic characteristics of the participants, such as age, residential area, and interstitial cystitis diagnosis, using a socio-demographics inventory.

The psychological battery was composed of three standardised measures (Metacognition Questionnaire-30; Distress Anxiety Stress Scale-21; Female Sexual Distress Scale) and an ad hoc self-report questionnaire.

Metacognitions Questionnaire-30 (MCQ-30, Wells & Cartwright-Hatton, 2004). The MCQ-30 is a brief multidimensional measure of metacognitions; individual differences in a selection of metacognitive beliefs, judgments, and monitoring tendencies are considered important in the metacognitive model of psychological disorders. Alpha reliabilities for the five subscales range from 0.72 to 0.89. The five subscales are: (1) positive beliefs about worry (POS), (2) negative beliefs about thoughts concerning uncontrollability and danger (NC), (3) cognitive confidence (assessing confidence in attention and memory) (CC), (4) negative beliefs concerning the consequences of not controlling thoughts (NEG), and (5) cognitive self-consciousness (the tendency to focus attention on thought processes) (CSC). Alpha reliabilities for the five subscales range from 0.72 to 0.89.

Distress Anxiety Stress Scale-21 (DASS-21). The DASS-21 is a self-administrated questionnaire that consents to measure the degree of severity of the core symptoms of depression, anxiety, and stress. It is composed of 21 questions with responses on a Likert scale (4 points).

Female Sexual Distress Scale (FSDS; DeRogatis et al., 2002). The FSDS is self-administrated questionnaire measuring sexually related personal distress in women. It consists of 13 questions with responses on a Likert scale (5 points).

Intimacy self-perception in IC/BPS (INTIMACY). The INTIMACY questionnaire is an experimental self-report for evaluation of IC/BPS patients' perceptions of their own intimacy in sexual activity; it is an *ad hoc* questionnaire aimed to detect women's positive or negative feelings towards their partners and sex. It is composed of eight items (Likert scale: 5 points). Figure 1 shows the questionnaire.

Figure 1 - Intimacy self-perception in Interstitial Cystitis (INTIMACY) and scoring system

Items	Never	Sometimes	Often	Always	No sex
1. I feel my sex life is lacking quality	4	3	2	1	0
2. Normally, my partner is quite sensible and aware of my problems concerning sexuality (i.e. pain in the genital area)	1	2	3	4	0
3. I'm satisfied with my sex life with my partner	1	2	3	4	0
4. I prefer to avoid sex because of discomfort/pain	4	3	2	1	0
5. How long have you perceived discomfort or pain during sex?	4	3	2	1	0
6. How would you describe the level of discomfort during or after sex?	4	3	2	1	0
7. How often do you worry about or fear pain during or after sex?	4	3	2	1	0
8. How comfortable do you feel with your sexual partner?	1	2	3	4	0

The INTIMACY questionnaire was applied in a previous pilot study composed of a sample of 30 IC/BPS patients; those patients were not included in the present research. The internal reliability of the scale was good (α=0.91).

2.4 Procedure

The individuals were recruited using the snowball sampling technique, a non-randomised method of sample selection. Participants were contacted on social media by the scientific collaboration with the Italian Association of Interstitial Cystitis (AICI, http://www.aicionlus.org).

First, we involved medical doctors in the study. They enrolled and recruited the eligible participants.

Research staff provided a digital form of the test protocol. Afterward, the self-report questionnaires were linked on the dedicated online website so that participants could access them and provide mandatory signed informed consent. The time for online form completion was about 20 minutes. The data were collected into a dedicated server, and data scoring was conducted by trained professionals, blinded to the study's objectives.

2.5 Study design

A cross-sectional study was conducted in order to evaluate the trend of emotional changes in IC/BPS patients; the age and timing of diagnosis variables were compared with the emotional indexes and the sexual distress classifications.

All data were carefully double-checked for possible miscoding, distribution of values, and updating of missing values prior to analysis.

Descriptive statistics, multivariate analysis of variance (MANOVA), and the least significant difference (LSD) test (as a post hoc test) were carried out using SPSS Statistics 22.0. The significance level was fixed at $\alpha < 0.05$.

3. Results

Statistical analyses were conducted on collected data.

Table 2 shows the raw scores (means and standard deviations) obtained by the psychological tests.

Table 2 – Raw scores of the psychological testing.

Psychological tests	**Raw score**	
	χ	**sd**
MCQ-30		
Positive beliefs	10.8	±4.0
Negative beliefs	16.0	±3.7
Cognitive confidence	13.4	±5.3
Need control	12.3	±3.9
Cognitive self-consciousness	15.8	±3.5
DASS-21		
Depression	17.5	±10.7
Anxiety	13.1	±8.3
Stress	21.8	±8.7
FSDS		
No sexual distress	4.6	±3.3
Sexual distress	32.3	±12.1
INTIMACY		

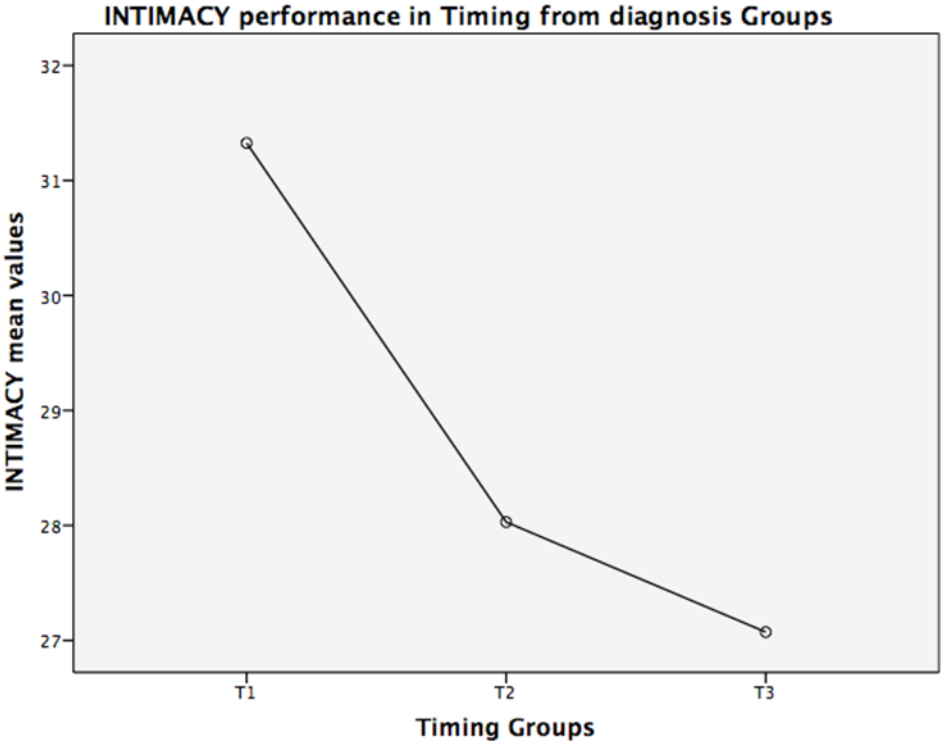
χ = mean value; sd = standard deviation

First, we analysed the aging effect on emotional patterns; a 2 (age groups) x 8 (emotional variables) MANOVA statistical analysis highlighted no significant differences. Age was not primary related to emotional changes in IC/BPS patients.

Then, a 3 (time since diagnosis: T1 = 0-3 years; T2 = 4-7 years; T3 = 8-11 years) x 8 (emotional variables) MANOVA statistical analysis highlighted a significant difference in the Intimacy index (F[228, 2] = 3,6; η =0.06; p<0.02); the post-hoc analysis (Bonferroni Test) showed that Intimacy seemed higher in the T1 group than the T3 group (p<0.02). The patients with more recent diagnoses did not report negative feelings and seemed confident in comfortably managing their own intimacy; on the contrary, women had gone longer since their diagnoses seemed more fragile in its managements.

In Figure 2 is reported the representation of differences.

Figure 2 – Representation of performance of timing of diagnosis groups on Intimacy test



We operated the distribution of participants into sexual distress classifications by applying the FSDS test. The sample was divided into two groups: 111 women with sexual distress (SD group) (84% of participants) and 21 women without sexual distress (ND group) (26% of participants). A 2 (SD/ND groups) x 8 (emotional variables) MANOVA statistical analysis showed significant differences according to metacognition variables, including negative beliefs concerning the consequences of not controlling thoughts (NEG: F[85, 1] = 6,4, η = 0.7, p<0.01), cognitive confidence (CC: F[190, 1] =

7,1, η = 0.7, $p<0.08$), negative beliefs about thoughts related to the uncontrollability (NC: F[168,1] = 12, η = 0.9, $p<0.001$), stress (F[1134, 1] = 16,7, η = 0.9, p< 0.00), anxiety (F[809, 1] = 12,6, η = 0.9, p< 0.001), and depression (F[1997, 1) = 19,9, η = 0,9, p< 0.001). The performance comparison of the SD/ND groups evidenced higher negative emotional impacts in the SD group in terms of higher depression, anxiety, and stress, together with negative thoughts about themselves and their physical conditions and the associated uncontrollability, as well as low levels of confidence and self-esteem. This data showed the co-morbidity IC/BPS and sexual distress, reflecting the complex psychological fragility of women. No significant effect was seen on the intimacy test between the SD/ND groups.

4. Discussion and Conclusions

Our study sought to analyse the emotional impact of interstitial cystitis on women throughout the lifespan. The cross-sectional study design highlighted the strong impact of sexual distress on quality of life among women in relation to their physical features, even if unrelated to the age or timing of diagnosis. Interstitial cystitis affects women's quality of life, especially in sexual terms, being strongly related to negative emotional impacts including (as expected) stress, depression, and anxiety, as well as negative beliefs concerning the consequences of not controlling thoughts, cognitive confidence (assessing confidence in attention and memory), and negative beliefs about thoughts concerning uncontrollability and danger.

Women experience significant psychological distress with chronic physical conditions. As expected, and as reported in the literature, our data confirmed the negative emotional impacts: women showed anxiety, depression, and stress symptoms. Most participants reported sexual distress and seemed to pay strong attention to their chronic conditions, developing awareness of the difficulty of managing their issues. Moreover, our data highlighted negative metacognitions, or the processes used to plan, monitor, and assess one's own understanding and performance. Our data better described the experience of patients' physical issues and evidenced their emotional weaknesses in their daily lives and, even more so, in their sex lives. Age and timing of diagnosis did not impact the emotional conditions much, and younger and older women did not show different patterns of behaviour in terms of feelings of intimacy. However, women who had been diagnosed for shorter periods of time seemed less affected in their feelings of intimacy, while women who had been diagnosed for longer periods of time (more time passed since diagnosis) perceived intimacy as being affected.

In conclusion, this study paved the way for understanding of the emotional impact of IC/BPS, a chronic physical condition related to the urinary area, on the sex lives of women. The findings confirmed the psychological distress but also dealt with and highlighted the consequences for women's sex lives. Women suffer physical weakness their sex lives, and this affects their wellness and quality of life. As suggested previously, psychological and sexual functioning should be introduced into clinical assessment and integrated with supportive services (medical and psychological), with personalised and tailored interventions proposed to apply an innovative emotion-centred approach to women's health. Personalised treatments should be the integrated clinical approach to the pathology; this could provide innovative healthcare for primary symptoms and prevent future implications while supporting co-morbid psychological distress in IC/BPS, boosting patients' mental and physical health.

Limits of the study is the lack of medical data, variety of symptoms and severity of pathology; we are planning to exploit medical data implementing the severity of pathology such as the symptoms in daily life as well as the recurrence of symptoms and the typology of them. Could be interesting to examine the psychological needs of patients along the BPS/IC developing and across the lifetime of women.

Authors' contributions

DDG supervised the research and was responsible for the intellectual contents, study design, and writing the paper. JR administered the online survey, and NL and SM conducted recruitment and data collection. FG performed the statistical analyses. DP contributed to the critical interpretation of the results and to writing the paper. All authors approved the final version of the manuscript.

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