

# Web-mediated counseling to counteract the emotional impact of COVID-19 for women with interstitial cystitis/bladder pain syndrome

G. MARANO<sup>1,2,3</sup>, E. GAETANI<sup>4</sup>, M. MARTURANO<sup>5</sup>, G. SANI<sup>1</sup>,  
A. GASBARRINI<sup>4</sup>, G. SCAMBIA<sup>5</sup>, M. MAZZA<sup>1</sup>

<sup>1</sup>Institute of Psychiatry and Psychology, Department of Geriatrics, Neuroscience and Orthopedics, Fondazione Policlinico Universitario A. Gemelli IRCCS, Università Cattolica del Sacro Cuore, Rome, Italy

<sup>2</sup>U.P. ASPIC Università Popolare del Counselling

<sup>3</sup>Bocconi Sport Team, Milan, Italy

<sup>4</sup>Division of Internal Medicine and Gastroenterology, Fondazione Policlinico Universitario A. Gemelli IRCCS, Università Cattolica del Sacro Cuore, Rome, Italy

<sup>5</sup>Division of Gynecologic Oncology, Department of Woman and Child Sciences, Fondazione Policlinico Universitario A. Gemelli IRCCS, Università Cattolica del Sacro Cuore, Rome, Italy

**Abstract.** – **OBJECTIVE:** Interstitial Cystitis (IC) is a chronic and rare disease, more frequent in women. Symptoms of continuous pain can produce psychological disorders, such as anxiety and depression. The spread of COVID-19 pandemic added to distress experienced by patients with IC emotions, such as fear, sadness, boredom, frustration and anger.

**MATERIALS AND METHODS:** A research on very recent literature outlines the necessity for patients facing the complexity of IC during the COVID-19 outbreak to prevent the temporary crisis, to broaden perspectives, to deal with confusion, to support in struggling with unpleasant and unexpected events.

**CONCLUSIONS:** People affected by IC have a psychological vulnerability that needs tailored support interventions, particularly in the COVID era. A multidisciplinary approach offers a personalized treatment through a web-mediated counseling intervention for patients and their caregivers: a space for continuous discussion and reflection can favour a relationship-based process of change aimed at an improvement in quality of life.

*Key Words:*

Interstitial cystitis/bladder pain syndrome, COVID-19, Distress, Counseling, Personalized medicine, Multidisciplinary approach.

## Introduction

### *The COVID-19 Pandemic*

The COVID-19 epidemic began to manifest in December 2019 in the city of Wuhan, the capital of the province of Hubei, in central China, where a cluster of cases of atypical pneumonia of unknown etiology occurred. The pathogen responsible for the pneumonia outbreak is SARS-CoV-2, a virus that belongs to the Coronavirus family. These viruses are known to cause conditions of various severity ranging from the common cold to more serious diseases, such as Middle Eastern Respiratory Syndrome (MERS) and Severe Acute Respiratory Syndrome (SARS)<sup>1</sup>. The transmission speed of this new virus is high: within a few weeks it has spread all over the world, prompting the World Health Organization to officially declare the pandemic state.

There is a growing body of literature that brings together the puzzle of clinical manifestations of COVID-19. The disease caused by SARS-CoV-2 can determine an asymptomatic or pauci-symptomatic course where the most recurrent symptoms are fever, dry cough, a general feeling of discomfort and fatigue. Less common symptoms include: sore throat, headache, conjunctivitis, loss of taste or smell, gastrointestinal manifestations, such as diarrhea and nausea. In severe cases, the infection can provoke more pronounced symptoms and higher fever and in this phase bilateral interstitial pneumonia arises

## Abbreviations

BPS: Bladder Pain Syndrome; PBS: Painful Bladder Syndrome; HBS: Hypersensitive; Bladder Syndrome; IC: Interstitial Cystitis.

causing a worsening of respiratory capacity<sup>2</sup>. Lung Coronavirus infection can leave a chronic legacy on respiratory function. The reason can be found in lung fibrosis, which leads to the stiffening of the tissue affected by the infection, with consequent reduction in the functionality of gas exchange<sup>3</sup>.

The interhuman transmission modalities of the Coronaviruses can occur by air, direct close contact, or fecal-oral route. It has been ascertained that aerosol particles can enter not only through the airways, but also through the conjunctival and oral mucous membranes. The incubation period has been estimated between 2 and 14 days, with an average of 5 days<sup>4</sup>.

There is no specific remedy for the disease caused by COVID-19. Treatment is based on the patient's symptoms and supportive care can be very effective. In order to avoid the expansion of the virus, several measures to mitigate the risk of contagion have been put in place: social distancing, active surveillance, early identification of cases and prompt isolation following appropriate management and containment procedures, and accurate trace of close contacts to prevent further propagation. The categories of patients most exposed to Coronavirus infection are people affected by chronic diseases, hypertension, dyslipidemia, diabetes and heart disease<sup>5,6</sup>. In addition to the elderly, fragile or immunosuppressed subjects and people with previous pathologies are at risk of major complications and the lethality rate increases exponentially for them.

Beyond the Severe Acute Respiratory Syndrome and other medical complications produced by COVID-19, there are effects that can profoundly touch the psychological well-being of individuals: recent research<sup>7</sup> has investigated the psychological impact of this delicate and globally shared condition. During the lockdown due to epidemic, the mental health level is influenced by various vulnerability factors and stressors: living in limited spaces with various people, holding school-aged children at home, having lost job or closed activities often add to inadequate information, shortage of supplies of basic necessities, frustration for deprivation of liberty, fear of infection<sup>7</sup>. One of the most evident psychological consequences of Coronavirus is the terror of being infected, but also boredom, hopelessness, catastrophic thinking can increase in an epidemic context as well as anger, frustration and impulsive behaviors that may additionally deter-

mine social risks<sup>8,9</sup>. Moreover, people affected by psychological or psychiatric disorders can suffer even more in this context<sup>7</sup>.

### ***Interstitial Cystitis During the COVID-19 Pandemic***

Bladder Pain Syndrome (BPS) or Painful Bladder Syndrome (PBS) or Hypersensitive Bladder Syndrome (HBS) or Interstitial Cystitis (IC) is a disabling condition of unknown etiology. IC is often associated with other "functional" disorders in extra-pelvic districts, such as irritable bowel syndrome, temporomandibular joint syndrome, fibromyalgia and many other invalid conditions. IC is largely characterized by chronic pelvic pain, a sense of tension or pressure at the suprapubic level, particularly related to the bowel filling phase and associated with symptoms, such as dysuria, nocturia, daytime urination urgency, pollachiuria through day or night. Whether this condition is associated with gastrointestinal manifestations from gut-brain axis disorder and/or iatrogenic disorders, such as narcotic bowel syndrome or opioid-induced hyperalgesia, the quality of life is bound to deteriorate further, as the daily life of these patients is dominated by the management of sphincter functions and pain.

An epidemiological study<sup>10</sup> has highlighted different prevalence rates of IC, both for the lack of specific biological markers, and for the different methods of methodological approach applied to the conducted studies. McKernan et al<sup>10</sup> showed a growing prevalence and incidence of IC, as well as an increased diagnosis at an earlier age, probably due to a greater attention and interest paid to this condition. IC has been recognized as a rare disease in 2001, considering that it affects the population with low incidence, more frequently women than men in a variable proportion between 9:1 and 5:1. Koziol et al<sup>11</sup> described that the diagnosis in men is late, since initially confused with prostate diseases. In fact, in the absence of a valid marker, it is often difficult to distinguish IC from chronic pelvic pain syndrome such as non-bacterial prostatitis, prostatodynia, which most frequently affects men. This would suggest that the percentage of men with IC could actually be higher<sup>11</sup>.

The pathology usually begins as subacute, and then, completely develops within months or a few years. Although it is a chronic disease with an evolutionary character, there is not necessarily a progressive worsening. In general, the clinical picture reaches the stage of greatest symptomatic

intensity within five years from its onset<sup>12</sup>. The causes that lead to the development of the pathology, to date, are unknown. Symptomatology is likely to be the result of the combination of multiple etiological factors: activation of the immune system, increased permeability of the urothelium for urinary dysfunction and defect in glycosaminoglycans, inhibition of proliferation of urothelial cells of the bladder, autoimmune mechanisms, infections, hyperexcitability/neurological cross-talk, urinary toxic agents and genetics. There is a symptomatological set which defines the disease, although it greatly varies from patient to patient and from episode to episode. The 100% of patients report bladder pain, constant in severe cases, otherwise associated with bladder filling and attenuated by emptying. Other frequently encountered symptoms are urinary urgency and frequency, nocturia and pollachiuria. Bladder pain can be accompanied by vaginal pain and sexual problems, progressively extended to the whole genitourinary system up to the entire pelvis and to the abdomen<sup>13,14</sup>. It may possibly be associated, in a smaller number of patients, with urinary incontinence.

Overall, the pathology profoundly limits the performance of daily work, social and leisure activities, and compromises physiological functions, such as sleep and sexual activity, causing a profound decline in the quality of life. This determines a clear prevalence of anxiety, depression and stress, which is associated with a chronic reduction in coping capacity and the endurance of pain and fatigue<sup>15</sup>. People affected by IC therefore have a psychological vulnerability that needs personalized support interventions, particularly in the COVID era<sup>16,17</sup>.

Emotional and sexual relationships at the time of COVID change both for couples and singles: the need to rethink the “grammar” of the body and affectivity emerges in a scenario of “nameless terror”, as defined by the psychoanalyst Bion<sup>17</sup>. Massive use of the internet for virtual sex can have a defensive effect aimed to protect oneself from depressive anxieties or self-disintegrating fears, but it can also worsen or create disturbances in the affective area. The libido that fails to follow its course can sublimate itself, fixate on perverse satisfaction or generate anguish. The curbed sexual desire can be directed towards possible non-erotic goals, can regress towards partial instinctual drive, can slip into the modes of compulsion and addiction or can get stuck in frustration and aggression<sup>18</sup>.

A person suffering from IC lives in contact with his own subjective experience which is not always understood by others. This experience involves the patients but also their caregivers: the stories of people affected by a rare disease often display a sense of disorientation. Patients and families experience a feeling of exclusion, because their syndrome is rare, little known and for this reason, despite the progress made by medicine, diagnostic techniques, and new therapies are often still unsuitable or insufficient. With the spread of Coronavirus further emotions, such as anxiety, fear, sadness, boredom, frustration, anger, are experienced by patients with IC. Various defense mechanisms can be engaged, such as splitting, intellectualization, removal, displacement, repression, denial and trivialization. Each of these defensive solutions tends to stem but also hide the anguish that derives from the difficulty in confronting a danger that cannot be immediately circumscribed, therefore, there is a possible regression to the Kleinian schizo-paranoid position and a risk to remove value from any action<sup>19</sup>.

### ***Counseling for Patients Suffering from Interstitial Cystitis During COVID-19 Pandemic***

The counseling process can be a precious resource for deepening the understanding of the internal mechanisms of individuals and communities during the COVID-19 epidemic<sup>20</sup>. Counseling can intervene to prevent the temporary crisis, to broaden the person’s narrow perspective about a problem, to support him in facing an unpleasant and unexpected event, to deal with confusion. The life of a person suffering from IC unfolds like everyone else’s, within a world of relationships and bonds, but also in a context that has to cope with an unexpected and unwanted reality, indeed strongly feared as an unnamable spectrum. It has been added to all this the contagiousness of the virus which can be experienced as inescapably deadly. The anticipatory mourning and the risk of withdrawal of the affection from the objects perceived as damaged or damageable can determine a psychic condition expressively showed as apathy<sup>21</sup>. The declination of Bionian no-thing<sup>22</sup> and the Kleinian concept of projective identification<sup>23</sup> can be configured as an exhortation to face the vicissitudes of existence, accepting their uncertainty and complexity, avoiding the uneconomic illusion of thinking that it is possible to govern what is not completely governable.

IC influences couple life: many patients have pain caused by coital sexual intercourse or orgasm, which can lead to a consequent decrease in desire and tension in the relationship. Sexuality is not something that belongs only to the terrain of genitality, but promotes the sense of self, the feeling of being there, of existing as an increasingly defined subject. The presence of a disease that impairs sexual functionality, in a moment in which relationships take on an even more intense value, entails fluctuating perceptions on sexuality that make feel the sense of pleasure and at the opposite side pain, vitality and pathology. The body injured by chronic damage, in the COVID era, instead of representing a place of positive sensations sufficient to guarantee the basis of well-being, becomes the place of damage, altered function, and diversity.

## Conclusions

Our model of care for patients, especially for women with IC places the subject at the center of the care process, looking for solutions to improve the person's functionality and allow a right social participation and a good quality of life through a multidisciplinary approach that also includes the possibility of web-mediated counseling during the COVID-19 outbreak. The counselor's tasks are to be with the other, to read his narratives, to enhance his story, to listen to feelings at to stake and to grasp all the difficult engagements that each individual experiences. As Kaës<sup>24</sup> suggested, it is important to manufacture tools that permit to think again and temporarily about the relationship with the unknown who has been chosen as the way of being in the world, to react to fear and to discover hidden energies, with the aim to use new strategies for oneself and to make them available to others. In particular, during the COVID-19 pandemic, the relationship-based process of change for patients affected by IC aims to a personalized treatment and an improvement in quality of life.

## Conflict of Interest

The Authors declare that they have no conflict of interests.

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