

# PSYCHOLOGICAL FUNCTIONING OF PATIENTS WITH INFLAMMATORY BOWEL DISEASES: CROHN'S DISEASE AND ULCERATIVE COLITIS

## PSYCHOLOGICZNE ASPEKTY FUNKCJONOWANIA OSÓB Z CHOROBYMI ZAPALNYMI JELIT – CHOROBA LEŚNIEWSKIEGO-CROHNA I WRZODZIEJĄCYM ZAPALENIEM JELITA GRUBEGO

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### ABSTRACT

The most common inflammatory bowel diseases are Crohn's disease (CD) and ulcerative colitis (UC). The impaired digestive system function due to ulceration or other GI tract epithelium dysfunctions causes unpleasant symptoms that can affect patients' emotional state.

The present paper contains a review of the latest empirical findings and literature about the correlations between people's emotional states and their experience of living with a disease. Patients' responses to health problems are described.

High neuroticism, low self-esteem and negative perception of reality increase the risk of depression in somatic diseases and inhibit the healing process. Individuals with a more positive attitude towards fighting their disease, motivated and hopeful with respect to prognosis and recovery achieve better outcomes.

**KEYWORDS:** ulcerative colitis (UC), Crohn's disease (CD), emotional states.

### STRESZCZENIE

Najczęściej występujące choroby zapalne jelit to choroba Leśniewskiego-Crohna (ChLC) oraz wrzodziejące zapalenie jelita grubego (WZJG). Zaburzone funkcjonowanie układu trawiennego spowodowane występowaniem owrzodzeń lub innych dysfunkcji nabłonka przewodu pokarmowego powoduje nieprzyjemne objawy u pacjentów, które wpływają na ich stan emocjonalny.

W niniejszej pracy dokonano przeglądu najświeższych wyników badań oraz publikacji naukowych dotyczących korelacji między stanem emocjonalnym człowieka a sposobem przeżywania choroby. Opisano reakcje pacjentów w obliczu zagrożenia zdrowia.

Wysoka neurotyczność, niska samoocena oraz negatywne postrzeganie rzeczywistości sprzyjają występowaniu depresji w chorobach somatycznych i pogarszają proces leczenia. Lepsze efekty terapeutyczne osiągają osoby pozytywnie nastawione do procesu walki z chorobą, zmotywowane oraz mające nadzieję na dobre dalsze rokowania i wyleczenie.

**SŁOWA KLUCZOWE:** wrzodziejące zapalenie jelit, choroba Leśniewskiego-Crohna, stan emocjonalny.

### Introduction

Chronic inflammatory bowel diseases include Crohn's disease (CD), ulcerative colitis (UC) and indeterminate inflammatory bowel diseases. These conditions are characterized by the presence of segmental lesions in the gastrointestinal tract, such as abscesses, ulcers, inflammatory lesions, anal fistulae and rhagades of unknown aetiology. As these are autoimmune diseases, a significant role is played by genetic factors, with positive history findings in some patients suffering from CD. Similarly, with respect to monozygotic twins, both siblings are affected in 50% of cases. Besides genetic predispositions, there are important external factors, such as viruses, bacteria, and smoking, as well as unhealthy diet and lifestyle [1, 2].

In the majority of patients, inflammation occurs towards the terminal segment of the intestine, but mouth and other parts of the GI tract can also be affected. In CD, inflammatory lesions usually occur in the colon, caecum, stomach, oesophagus, segments or the whole length of the ileum, with all mucous membrane layers involved, while in UC usually only the colon is involved. The disease usually starts at a young age, with 30 years being a typical age of onset.

Diagnosis is based on GI endoscopy with biopsy for histopathological examination, and a GI scan. The mucosa in CD shows characteristic cobblestone appearance on endoscopy or lower gastrointestinal series. Laboratory findings include elevated ESR, ischaemia, leucocytosis, and high CRP levels in 95% of patients.

More detailed diagnostics of affected intestinal segments involve imaging, with the preferred method being CT or MRI enterography. Diagnosis should be based on physical examinations combined with detailed history including lifestyle and coexisting symptoms (headaches, skin lesions, ophthalmological problems, and other diseases, e.g. primary sclerosing cholangitis – PSC) [2–4].

Treatment includes topical anti-inflammatories (salicylic acid derivatives), followed by oral or intravenous glucocorticosteroids. Supplementary treatments include immunosuppressants, e.g. azathioprine, mercaptopurine derivatives. In later stages of treatment, monoclonal antibodies and biologic agents should be considered.

There is no causal treatment; pharmacotherapy is symptom-driven. Diarrhoea and vomiting are treated with antidiarrheals and bile acid sequestrants, such as cholestyramine.

A definitive indication for surgery is ileus, perforation or peritonitis. These are conditions for which surgery is a lifesaving procedure. Affected segments are sometimes resected; the size of lesions can be reduced over time. Unfortunately, sooner or later surgery is unavoidable. Patients with multiple intestinal resections or large lesions and those resistant to pharmacotherapy are given enteral nutrition with formulas specifically designed for patients with inflammatory bowel conditions, while in clinical cases of complications from bowel resections some patients require temporary or permanent parenteral nutrition in the home setting [2–4].

Patients should be placed in the care of the treatment team that includes, apart from the treating physician, a dietician and a psychologist. Patients with chronic, non-specific bowel inflammation, due to accompanying symptoms, such as diarrhoea, vomiting, and abdominal pain are at risk of malnutrition due to abnormal intestinal absorption and also have increased risk of depression. Patients with UC are 40% more likely to suffer long bone fractures, peritonitis, and toxic megacolon [1, 5].

### **Low stress tolerance threshold as a risk factor in somatic bowel diseases**

One of the risk factors contributing to the inflammatory bowel disease is stress. Stress has negative effects on digestion and peristalsis. When dealing with prolonged stress, the body responds a number of defence reactions that can cause organ dysfunctions.

The first stage of response to stress is the release of corticotrophin from the hypothalamus, followed by the release of ACTH from the anterior lobe of the pituitary gland and elevation of cortisol secreted by the adrenal cortex. Prolonged high cortisol levels result in decreased immunity as evidenced by the low natural killer cell, cytotoxic T cells and macrophage counts [3, 6].

A gut-associated lymphoid tissue (GALT), present in the GI tract, along with the mucosa is part of the immune system. Immunoglobulin A, responsible for the initial contact with the pathogen, provides protection against food-related antigens and neutralizes toxins. This is the body's first line of defence, and the mechanism is part of the acquired immune system. Abnormal immune response negatively affects GI tract function due to impaired activity of mucosa upon contact with pathogens [7].

Intestinal bacteria ensuring the integrity of intestinal epithelium are involved in the process of regulating the acquired immune system and eliminate pathogens in the body. Prolonged stress and increased tension cause imbalance in the natural gut flora. The result is dysbiosis and growth of pathogenic bacteria in the intestines. The dominant species are *Escherichia coli* and *Bacteroides*; there is an overrepresentation of gram-negative and anaerobic bacteria. Gut dysbiosis leads to increased intestinal permeability, which significantly increases the risk of inflammatory bowel diseases and secondary symptoms, such as interloop abscesses.

There is a strong correlation between the severity of bowel inflammation and increased psychological stress. Individuals with low self-esteem, neurotic traits or exposed to stressors are at a much higher risk for a variety of diseases, particularly inflammatory bowel conditions [6–9].

### **Emotional responses in patients with inflammatory bowel diseases**

Being ill is a challenging condition, pushing patients out of their established comfort zone. This leads to the activation of compensatory mechanisms in order to adjust to the new situation. Inflammatory bowel diseases are associated with worsening of the quality of life, chiefly due to uncomfortable somatic symptoms. In addition, frequent tests and, initially, the diagnostic procedures themselves, such as colonoscopy and proctoscopy, cause intense stress, anxiety and fear of uncertain future in patients. At this stage of the disease patients usually have low self-esteem and self-approval, emotional lability and resistance to lifestyle changes. Patients can also experience a sense of guilt, blaming themselves for having neglected their health in the past [9, 10].

The defence mechanisms typically mobilized against the emerging threat are automatic, habitual ways of reducing unpleasant emotional tension, such as fantasizing about the disease, revaluation, externalization of negative emotions or general changes in emotional profile that sometimes precede the disease process. Moreover, diagnosis may be repressed or its validity questioned as a way to conceal anxiety. Patients may

exhibit emotional responses inadequate for the progress of the disease. Emotional responses may result in enhanced motivation to fight the disease and resolve to actively participate in the treatment or in low mood and lack of energy [11, 12].

The disease affects three areas of life: reactivity and behaviour, emotionality, and personality. Patients are often forced to give up their career or life plans because the disease impairs their ability to perform their job or play the role of parent, guardian or partner. Patients become insecure and the fact that their way of living may need to change is a source of intense psychological stress [13, 14]. Worsening of health upsets the equilibrium of life. Values that were central for the individual may now become marginalised; patients may feel abandoned and hurt by their social circle. It should be mentioned, however, that the disease may have a positive impact by enhancing social contacts, giving the patient a new appreciation of his/her achievements and life before falling ill, as well as satisfaction with the current level of functioning. The reaction to a disease process, diagnosis, symptoms of a given condition depend on personality, character traits and the environment in which the individual was raised and currently lives. Still, most patients associate the disease with loss and the traumatic experience of diagnosis. At the beginning patients often show apathy, decreased activity, and they withdraw from social contacts and professional career. Then, once they come to terms with the diagnosis, patients often require more interest and care from friends and family. Due to changes in behavioural reactivity, patients expect compassion and comforting. Chronic illness is associated with personality changes, inhibited emotional expression and often reduction of interests [15,16]. Additionally, patients often complain of headaches, insomnia, loss of appetite, which leads to attention deficits, increased anxiety, higher excitability threshold, loss of previous tolerance for other people's behaviour and depression. There may be an increase in the embarrassing symptoms associated with stress and depressed mood, such as diarrhoea and vomiting. Support from experienced medical staff and therapists are very important for the way patients deal with the disease [17, 18].

### **Patients' adjustment to their new health status**

The process of adjustment to and acceptance of a disease depends on personality and attendant's psychological status. Adjustment to the disease is considered not to be dependent on the stage of the affliction, but primarily on the length of time, number of complications and personality traits. Patient's clinical status may deteriorate due to stress and emotional lability during the

initial stage of the disease. High neuroticism, emotional withdrawal and failure to engage in coping activities increase the probability of this type of the somatic response [8, 12].

Deterioration in the functioning of a previously healthy body is a significant stressor, which is why coming to terms with limitations resulting from the disease or with disability and the need to depend on other people significantly enhance the treatment process. Traits that are very important when dealing with a chronic somatic disease include the ability to control emotions, stable mood, resistance to emergent stimuli and willingness to overcome adversity.

In a previously published study, the purpose was to establish the emotional approach of patients and its effects on treatment (which was the same in all subjects). The study included 41 patients with CD and 34 with UC. Patients were aged from 18 to 75 years; 35 subjects had active disease and 40 were in remission. The results of previous studies have shown that patients during a relapse phase demonstrate stronger neurotic traits than healthy individuals. A positive correlation was found between low agreeableness, maladjustment to the disease and high neuroticism and low disease acceptance. Participants tended to perceive reality in a negative light. No such behaviours were seen in patients during remission: on the contrary, their different attitude towards the disease had a positive impact on their health [8, 14].

There are 5 different types of behaviour that patients demonstrate in the course of the disease process while adjusting to their new circumstances:

- Responsive-combative behaviour – patients believe that the disease will become milder and therefore, they have little impact on everyday functioning, but at the same time they are motivated to fight and overcome the disease;
- Projective-aggressive behaviour – patients demonstrate negative emotions, such as self-loathing and aversion towards others, including the medical staff; the dominant feelings are aggression, suspicion, spitefulness;
- Resignation-passivity – characterized by complete consent to patient care provided by the medical staff; patients want to be dependent on those who take care of them;
- Rationalization of the disease – patients repress the fact that they are sick;
- Partial or complete denial – repressing the disease from consciousness, negative attitude towards treatment and suggested therapy, disbelief towards and rejection of the diagnosis [15].

According to Shontz [19], patients go through the following stages when facing their disease:

- The moment of diagnosis, accompanied by shock, disbelief and temporary detachment from the situation;
- Encountering the problem – at this stage patients start to understand the situation and the fact that their health has deteriorated, are pessimistic about treatment and prognosis, demonstrate helplessness and refuse treatment;
- At the third stage of adjustment patients repress the existence of the disease, suppress negative emotions by denying undisputable facts at the cost of later being less well adjusted to living with the disease;
- Reorientation towards reality is the final phase of adjustment. Patients start to see their disease in a new light, they mobilize their strength to fight and start treatment. Values that have previously been ignored now become important, patients establish better relations with others, their outlook on life changes [19].

Among the many adaptive responses of the body to the dysfunctions caused by the disease, literature describes the cognitive effort patients make to gather information about the course of their affliction, its signs and symptoms, and potential complications. They rely on the knowledge of the medical staff, who become the primary source of trusted information. At this point it is vital that the medical staff pay close attention to symptoms reported by the patient, while the patient in turn is expected to accept the changes his/her body has already undergone or will undergo in the course of treatment [14].

Another strategy patients use to shield themselves from negative emotions is a positive reappraisal, whereby they find positives in their condition. Some patients compare themselves to people in worse situations and find consolation in that tactic. Others yet use relaxation techniques to draw their attention away from negative environmental stimuli. The abovementioned behaviours give patients a sense of being in control of the disease and their bodies, which translates to better responses to treatment [17, 18].

### **Quality of life of patients with inflammatory bowel disease**

One possible outcome of inflammatory bowel disease is the need for parenteral nutrition, which is associated with a long list of contraindications and dietary restrictions that must be observed to avoid mistakes leading to complications. Being unable to ingest food orally is highly stressful to patients, lowering their quality of life and often leading to mood swings and depression. Patients with non-specific inflammatory bowel conditions

are also at risk for malnutrition due to impaired absorption of nutrients in the course of the disease [20].

Studies have shown that people who are lonely are worse at coping with the disease and have a much lower quality of life compared to those who can rely on their family or support group. Personality plays a significant role in the disease process. Traits such as neuroticism and a pessimistic view of the world increase susceptibility to mental diseases. Available data show that people living in cities cope with the disease better than those in rural areas [20]. This can likely be attributed to better access to healthcare and paramedic services, and a more accepting attitude in urbanized areas for the dysfunctions of the human body.

Many patients (between 50 and 70%) report experiencing pain in the course of inflammatory bowel disease. In addition, 20% of patients experience pain even during remission. Pain carries significant information for the human body and may signal a potential health problem. Visceral pain causes stimulation of the sympathetic nervous system; the sensation is highly unpleasant, the pain can often be chronic, diffuse and difficult to locate precisely. It tends to be accompanied by symptoms such as nausea, vomiting, and dizziness. The body's defence response in the form of chronic pain also causes significant cellular stress and affects nitrogen metabolism [21].

The experience of each individual should be considered subjectively due to variation in excitation thresholds and resistance to pain. There is a theory that pain is experienced as being worse when people are alone compared to being in a group. Sometimes a small discomfort causes incommensurably intense sensations due to the body's prolonged exposure to unpleasant symptoms [6, 9, 10, 21, 22, 23, 24].

### **Conclusion**

The scope of this paper goes beyond the course of the disease itself, its diagnosis and treatment, to analyse the emotional experiences of and psychological approaches to patients. A number of emotional issues associated with health impairment are identified that can disrupt everyday functioning and require the presence and assistance of qualified individuals trained in paramedic procedures. There is a positive correlation between the psychological approach to patients and a positive attitude towards the disease on the one hand, and a better prognosis and more effective treatment on the other.

Patient's cooperation with the treating team is crucial. Psychologists play a significant role in the course of somatic diseases, and in the case of IBD a dietician



also needs to be involved. A diet suited to the patient's condition can help avoid persistent discomforts such as diarrhoea, bloating, headaches, nausea, and vomiting. Talking to a psychologist may change the perception of the disease. There is a definite need for support groups and organisations for people suffering from a given ailment. People have a chance to discuss their disease-related experiences, share practical advice on how to cope with everyday life, and find in fellow patients the empathy that can sometimes be missing in relationships with healthy people. Each patient should receive multidisciplinary specialist care to ensure the highest quality of health services and proven treatment efficacy.

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