

Functioning in the emotional sphere and ways of coping with chronic connective tissue disease

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Abstract

Chronic illness is a strong stressor, and its occurrence in human life forces the individual to make adaptive changes. The aim of the study was to evaluate the reactions, behaviors, and emotional states of a person in the face of systemic connective tissue disease and ways of coping with this difficult situation. The method of choice was an individual case study. The subject was a 41-year-old patient, diagnosed with diffuse systemic sclerosis (dSSc) 8 years previously. The patient was characterized by lowered self-esteem, the presence of depressive symptoms, low level of hope for success, a reduced sense of competence, a tendency to use stress coping strategies focused on emotions and dominance of anxiety and tension. Emotional stress coping strategies, low level of hope for success, and non-acceptance attitude predispose the person suffering from systemic sclerosis (SSc) to exhibit depressive symptoms.

Key words: systemic sclerosis, self-esteem, acceptance of the disease, emotional functioning.

Introduction

Chronic disease is a problem for every human, due to the fact that it is associated with its progressive course, which is accompanied by a constant struggle with the burden of symptoms and the treatment process. The disease state disturbs the relative homeostasis of the body and causes malaise, thereby reducing the quality of life. Awareness of the progressive process, and sometimes even approaching death, is an additional aggravating factor, reducing the perceived satisfaction and sense of life [1].

Research in the field of medicine and psychology of health proves that the relationship between illness and stress is mutual – on the one hand stress is sometimes one of the factors contributing to the disease, while on the other, the disease itself generates stress situations that evoke emotions that overlap the clinical picture of the disease [2].

The main problem of patients is coping with losses incurred as a result of the disease, changes associated

with it, and a sense of threat in the future. The basic aspects of the loss are lost ability to function properly, including social activity, which is connected with inefficiency to perform their previous roles in professional and private life. They are accompanied by pain and suffering which intensify the feeling of fear.

Disease may be a difficult test, which may sometimes break a person and plunge them into despair or motivate them to undertake new ventures that previously appeared to be abstract [3]. The consequences of the disease will be more pronounced in people who have difficulty in accepting their condition and are accompanied by negative emotions [4]. One of the chronic diseases, having a large impact on the functioning of the patient in the field of bio-psycho-social and life-threatening conditions, is systemic sclerosis (SSc), which affects women 3–4 times more often than men, at age 30–50 years [5]. Patients suffering from SSc struggle with the loss or serious limitation of basic functions, constant suffering from pain, secondary consequences of illness, mortality

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risk, significantly limited ability to perform social roles, and lowered self-esteem [6].

Systemic sclerosis is characterized by progressive fibrosis of the skin and internal organs, leading to their failure, abnormal morphology and dysfunction of blood vessels and the immune system. It is a disease that cannot be fully predicted [7]. The severity of changes resulting from the involvement of internal organs affects the prognosis. The disease process leads to abnormalities of the esophageal motility, pulmonary and kidneys fibrosis as well as conduction disorders in the myocardium [8]. Systemic sclerosis is characterized by peripheral or central sclerodactyly, depending on the SSc type. Raynaud's phenomenon (RP) leads to ischemia of the fingertips or tips of the toes (RP also applies to internal organs). In the course of the disease, the fingertips and calcification are also ulcerated [9]. The appearance of patients' faces (telangiectasia, microcoria) also changes and they become more and more similar. This affects the negative and pessimistic perception of one's own disease, causing deterioration of functioning in the main areas of existence, i.e. psychological, social relations, professional work and satisfying needs [10].

The main purpose of this study is to reveal the determinants and the model of human life with the diagnosis of a chronic disease, including ways to deal with difficulties, a system of values and attitudes towards disease. It is also interesting to learn about the organization of the patient's life within the emotional and social functioning as well as the struggle with the problems of everyday life.

In the article a description of the course of the disease is presented, because only an in-depth analysis and a multi-aspect approach to the functioning of the individual with a chronic, progressive disease can reflect the nature of the struggle of the person with suffering. As a result, it is easier to understand the problems of a person suffering from a severe, life-threatening disease.

Case report

The subject was a 41-year-old female patient with SSc diagnosed 8 years ago (SSc classification criteria from 2013 EULAR/ACR), under the care of the Department of Rheumatology and Internal Diseases, Medical University of Białystok. The tests were conducted during the patient's stay at home. The patient was residing in the city, had secondary education (she graduated from a medical high school), was working as a nurse, and was married, with two children. Before being diagnosed with SSc, she did not suffer from other serious somatic diseases. The family has no burden of autoimmune diseases.

The research was aimed at obtaining answers to the following research problems:

- How does the diagnosis of a chronic disease affect its assessment and level of acceptance?
- How does a chronic disease affect various aspects of human self-esteem?
- What emotions does the sick person experience?
- What is the state of illness, the possibilities of a person's functioning influence coping with possible life problems?

The description of emotional functioning takes into account such aspects as experienced emotions, mood, the degree of adaptation to the current state, level of fear and anxiety. The following indicators were used to describe the social aspect: attitude to social contacts and to other people, and the level of assertiveness. Strategies for coping with difficult situations were also assessed.

The following research methods were used in the study: psychological interview, gathering case history, free observation and standardized psychological methods – the Multidimensional Self-Esteem Inventory (MSEI) [11] measuring the internal diversity of self-evaluation aspects; Questionnaire of Hope for Success [12], used to assess the hope of success understood as a belief in having a strong will and beliefs about the ability to find solutions, that is, having appropriate competences; Mood Adjective Checklist (UMACL) [13], based on which the current mood of the subject is assessed; Beck Depression Inventory (BDI) [14], measuring the intensity of depression; Coping Inventory for Stressful Situations (CISS) Questionnaire [15], which is a tool for studying conscious styles of coping with stress; The Scale for the Assessment of Own Disease [16], which reveals the attitude towards the disease being examined, and the Acceptance of Illness Scale (AIS) [17], which allows one to illustrate the stigma reflecting the disease in the daily functioning of the subject.

The applied research tools were obtained from the Psychological Test Laboratory of the Maria Curie-Skłodowska University in Lublin. Due to the psychological education held by the author, there was no need to apply for additional permits to use the above-mentioned questionnaires. Before the commencement of the diagnostic procedure, the subject was informed about the purpose and course of the tests, and the possibility of stopping them at any time, without incurring any costs. The patient gave informed and voluntary consent to participate in the research.

Course of the study

Analyzing the course of the disease based on medical records and the interview, it was noted that in the initial period of the study the patient reported pain in the joints, swelling of hands and feet, and had problems with movement, mainly in the morning. Well-being

gradually deteriorated along with the development of the disease – she felt constant fatigue, decreased activity, loss of interest, lack of appetite and significant loss of body weight (over 10 kg within 6 months) as well as periodic sleep disorders and emerging thoughts of resignation. Clinical symptoms, elevated IgM and IgG, allowed for the diagnosis of Lyme disease.

In the further diagnostic stage, a preliminary diagnosis of scleroderma (morphea) was made based on the histopathological examination of the skin. The subject at that time was found to have clear swelling of the skin around the wrists, and small joints of the hands and feet, knee joints and ankle joints. The skin in the areas of the above joints was red and tense. The patient complained of pain and stiffness in the joints. ANA antinuclear antibodies and Scl-70 antibodies were detected in blood serum tests. The capillaroscopic examination showed widened loops, shortened, congestive megacapillaries, single extravasations and small areas of malfunction. Due to the dynamic course of the disease, immunosuppressive therapy and organ-specific therapy were included. Another problem in the course of SSc was recurrent episodes of palpitations and general weakness. Physical examination found smoothing and thickening of the skin of the face, hands and forearms, scars after ulcerations on the fingertips, and disturbed heart activity. The pulmonary X-ray showed the presence of scar lesions. Left ventricular relaxation was impaired, which was likely due to myocarditis.

Eighteen months after the diagnosis of SSc, the patient continued to complain about general weakness and the feeling of reduced exercise tolerance. Physical examination revealed smooth and thickened skin around the forehead, cheeks, fingers, microstomia, atrophy of the nose, and single telangiectasias. Single crackles were heard at the base of the right lung, as well as individual additional contractions over the heart. At a later stage, the patient suffered from pain in the shoulder, knee and ankle joints, general weakness, decreased exercise tolerance, and swallowing disorders. The physical examination revealed thickening of the skin of the face, arms, forearms, hands, chest, abdomen, redness of the labium, microstomia, contractures in the metacarpophalangeal and palmar joints of both hands, scars after ulcerations on the fingertips, and crepitations in the subcutaneous region. The gastrointestinal tract X-ray showed widening of the esophagus and abolition of the peristaltic wave with features of contrast and air retention.

Five years after SSc diagnosis, the patient had been diagnosed with esophageal hernia, gastritis, and progression in lung function tests.

After 14 years of struggling with severe, progressive connective tissue disease, the patient died.

Observation, history and psychological examination were conducted within the test period of 8–9 years of duration of SSc.

Attitude towards the disease

The subject perceived the disease primarily as a threat; it was a life event for her that disrupted the current balance and sense of security. The situation exposed the woman to destabilization of her life situation, violated plans, but also aroused fear and anxiety about her health, social situation and family life. The analysis of the Own Disease Rating Scale also proves that the disease was a kind of value for her, with a deeper meaning, a way to appreciate the value of life, helping to find its meaning and appreciate it to a deeper extent. The disease also opened the woman to the transcendent dimensions of life. The patient tried to treat the disease as a challenge, an enemy who had to be faced, fought and defeated. In a certain dimension, the disease was interpreted as harm, injustice, undeserved punishment (Table I, Fig. 1).

On the scale measuring the degree of acceptance of the disease (AIS), the woman obtained a low score (10/40 points), which stands for an attitude of acceptance and adaptation to the situation. She felt psychological discomfort, her self-esteem was significantly decreased, she felt unnecessary, dependent on others. Periodically she had the feeling of being a burden to her own family.

Self-assessment

Characteristic for the subject was dissatisfaction with her appearance, and doubts appeared about sexual attractiveness. The woman thought that by her appearance she discouraged others. Her physical condition (Multidimensional Self-Assessment Questionnaire) was

Table I. The attitude towards connective tissue disease

Dimension name	Raw result	Items number	Average
Evaluation factor of own disease			
Threat	38	8	4.75
Benefit	9	7	1.29
Obstacle/loss	19	7	2.71
Challenge	21	6	3.5
Harm	23	7	3.29
Value	22	6	3.67
Meaning	10	5	2.0

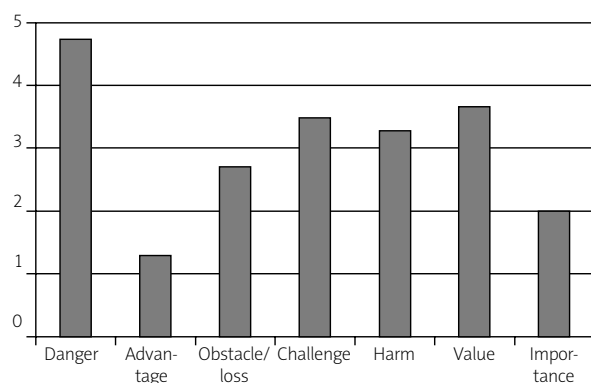


Fig. 1. Attitude towards the disease – intraprofile comparison.

assessed as very poor compared to other people in the same age category.

At the time of the study, she thought she was clumsy, awkward, and watching others made her feel uncomfortable. In terms of her own competences she was willing to judge herself as unable to present her skills and incompetent. As a result of the intensification of her symptoms, she assessed herself as physically and intellectually unfit. The general self-esteem was definitely lowered – the woman was dissatisfied with herself, she had doubts about success in life and the inclination to lower her value. In terms of leadership skills, she assessed herself as a person who could be used and easily intimidated. She believed that she could not show enough love and affection to others, but she also felt herself unsatisfied in being loved, and she felt rejected.

High scores in moral self-acceptance indicate behavior consistent with generally accepted standards, socially approved (Table II).

Functioning in the emotional sphere

The patient had symptoms of mild depression, measured on the basis of the Beck Depression Inventory (BDI = 14 points – mild depression) [14]. An event (illness – SSc) took place in the life of the subject which made her feel helpless and lost at times. The Analysis of Mood Adjective Checklist (UMACL) showed that the patient, in comparison with other women aged between 16 and 44 years, obtained average results in the field of Hedonistic Tone, Voltage Curvature and Energy Arousal.

In the intraprofile comparisons, the result of the Voltage Arousal appears to be the most significant, reaching an above-average level. This pattern is characteristic for malaise and can be described as a bad mood. It can be concluded that the situational factors, especially the disease, have a decisive influence here (Table II).

Coping with stress

The subject was characterized by a low level of finding solutions, weak will and low hope of success (Questionnaire of Hope for Success) (Table II). Negative emotions and fatigue of the disease, also caused by the awareness of approaching death, could probably have a significant impact on the reduction of the above-mentioned indicators. The results of the Coping Inventory for Stress Situations (CISS) showed that the subject did not look for social contacts in difficult situations and did not engage in substitute activities. From the intraprofile comparisons it appears that she had a tendency to focus on her own emotional experiences, which was confirmed in the interview (Table II).

Discussion

Chronic illness is a strong stress factor, and its occurrence in human life forces one to make adaptive changes [4]. It is widely believed that the disease multidimensionally disrupts the functioning of humans, affecting the emotional and social spheres and ways of coping with stress. It also involves pain and suffering. In the case of diseases, especially progressive, adaptation to changes caused by the disease state, mental and physical disability, is very difficult for many patients. Increased somatic complaints, decreasing tolerance to treatment, adverse effects of therapy, or the threat of co-morbidities, affect various aspects of human functioning [18]. Changes in the current functioning force the body to employ strategies to cope with the disease and the challenges it poses [19].

In patients with SSc there is a significant decrease in quality in the general perception of health and somatic functioning. It has been found that the limitation of the ability to perform daily activities secondarily affects the emotional state of the patient as well as the level of social functioning [20]. Scientific research of, among others, Georges indicates that in people suffering from SSc, in addition to lowering the level of somatic functioning, the quality of mental functioning also decreases. Sandqvist et al., however, believe that patients suffering from SSc have the most difficulties in the field of manual activities, requiring precise movements of hands and fingers, such as using cutlery, buttoning, and sewing [21, 22]. The examined patient, as the disease progressed, had more and more difficulties in manual activities.

Another problem that constantly affects patients is pain, which mainly affects the musculoskeletal system – bones, joints, muscles. The skin of the hands, in particular, gives the impression of a “tight glove”, atrophy of the nails occurs, and it is often impossible to bend the hand [18, 23].

Table II. Subject self-esteem, functioning in emotional aspect, coping with stress

Dimenson name	Raw result with confidential intervals	Stens with confidential intervals	Interpretation
General self-esteem	22 (23–25)	2 (1–3)	Low
Competence	26 (22–30)	3 (1–5)	Low
Beeing loved	32 (28–36)	4 (3–6)	Lowered
Popularity	25 (22–28)	2 (1–3)	Low
Leadership skills	22 (18–26)	3 (2–4)	Low
Self control	30 (26–34)	5 (3–6)	Average
Moral self acceptance	45 (41–49)	10 (7–10)	Very high
Physical attractiveness	15 (11–19)	1 (1–2)	Very low
Vitality	15 (11–19)	1 (1–2)	Very low
Identity integrity	30 (26–34)	5 (3–6)	Average
Defensive self-esteem increasing	49 (43–55)	5 (3–6)	Average
Mood Adjective Checklist			
Hedonistic tone (HT)	31 (29–33)	5 (4–6)	Average
Tension stimulation (TS)	18 (15–21)	6 (5–7)	Average
Energetic stimulation (ES)	30 (27–33)	5 (4–6)	Average
Hope for Success Questionnaire			
Finding solutions	17	2	Low
The Power of Will	17	3	Low
Hope for success	34	2	Low
General result		58 points	
Coping Inventory for Stressful Situations			
Concentrated on task style	53 (49–57)	5 (4–5)	Average
Emotions concentrated style	48 (43–53)	6 (5–7)	Average
Engaging in substitute activities	10 (6–14)	2 (1–4)	Low
Looking for social contact	15 (12–18)	5 (3–6)	Average
Avoidance concentrated style	31 (25–37)	3 (1–4)	Low

Angelopoulos et al. [24] report that people with SSc undergo constant psychological pressure, resulting from fear of environmental reactions, intensifying symptoms, aggravating pain and fear of death – it is often the result of depressed mood and anxiety. In addition, patients manifest a feeling of guilt and a high level of interpersonal sensitivity [24]. In the case of the examined patient, the above results were reflected in the present work. The patient expressed numerous fears about how she would be perceived by others, and she was ashamed of her appearance, which often hindered her easy interpersonal contact.

The experience of chronic connective tissue disease affects the current self-image, i.e. self-esteem, in which we distinguish, among others, sense of physical attractiveness, mood and interpersonal relations. During the illness, self-evaluation may be significantly reduced [25].

In our research it was confirmed that the sense of physical attractiveness and general self-assessment were at a low level.

The examined patient manifested symptoms of depressive disorders. This is confirmed by research, among others, Roca et al. [26], proving that a patient suffering from SSc reacts with increased susceptibility – tends to experience negative emotions: fear, dissatisfaction, anger, guilt, reactivity in stressful situations. Studies by Benrud-Larson et al. [27] based on the Beck Inventory also indicate that in almost 50% of patients with SSc, symptoms of depression are present. The risk of depression also depends on the severity of the disease symptoms and its duration [28]. Difficulties in swallowing, more and more severe, chronic joint pain limiting self-care, and respiratory and cardiovascular disorders, cause the person to experience psychological distress,

which is associated with depression. Research indicates the presence of a “vicious circle”; i.e. the feeling of severe pain causes mood depression and depressive states, and on the other hand, depression itself exacerbates pain [24].

Conclusions

The awareness of the consequences of the disease of SSc causes inferior physical and mental functioning. Changes in appearance and increasing difficulties in everyday functioning result in a low sense of physical attractiveness, reduced self-esteem and diminishing hope for success. It is difficult for a patient to accept a chronic, life-threatening illness, which causes anxiety, depressed mood and depression. Knowledge of the course of SSc and its possible effects allows one to take specialized therapeutic actions, focused on improving the mental state of the patient.

The basis of therapeutic activities is effective communication with the patient, as well as the attitude of the therapist himself, characterized by openness, empathy and understanding. Unpleasant feelings and emotions, feelings of helplessness and frustration may be minimized by thorough psychoeducation of the patient about the disease and effective coping strategies. It is also worth taking into account the possibility of patient participation in support groups and making contact with people with similar health problems [29, 30]. Research shows that patients suffering from SSc expect understandable information and effective communication at every stage of treatment. Lack of information causes deterioration of physical and mental functioning [31].

The authors declare no conflict of interest.

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