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Biopsychosocial Aspects in Management of Scleroderma Patients

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Abstract

Systemic sclerosis (SSc) is a rare, chronic connective tissue disease with characteristic fibrosis of the skin, musculoskeletal system, and internal organs. It is a heterogeneous and polymorphic disorder, in which fatigue, sleep disturbances, stiffness, and joint pain are among the most significant clinical symptoms. However, the presence of stiffening and thickening of the skin usually has a negative impact on the appearance of these patients, and the degree of self-dissatisfaction can fundamentally interfere with their personality. Self-consciousness and self-conception of the patient, accompanied by depression, can also be affected. Thus we cannot regard this disease and approach it only from a biomedical point of view and should not underestimate the approach to the psychosocial nature of the treatment. Biological, psychological, and social factors are interconnected, and imbalances in their complex interactions disrupt health and cause or worsen the disease. That is why it is necessary to create a so-called biopsychosocial comfort of an individual with SSc and to develop a number of activities in the sense of a complex treatment. This chapter focuses on the psychosomatic approach to health and illness and the development of the biopsychosocial model in medicine just as it should be used in patients with SSc.

Keywords: systemic sclerosis, biopsychosocial aspects, psychosocial aspects, psychosomatics, stress, non-pharmacological interventions

1. Introduction

Systemic sclerosis (SSc) is a disease in which fibrosis is one of the dominant pathological processes which affects the connective tissue, resulting in the involvement of the skin, musculoskeletal system, and internal organs. It is a very heterogeneous and polymorphic disease, and in each individual the course and extent of the involvement is different. Most of the characteristic visceral organ involvement, such as interstitial lung disease, pulmonary arterial hypertension, and cardiac and gastrointestinal involvement, has a significantly negative effect on physical fitness and condition. This decreased level of physical condition neither benefits from the thickening and rigidity of the skin nor from muscle and tendon contraction and stiffness of the joints accompanied by pain and an ever-worsening range of motion in the joints [1, 2]. Furthermore, the mind itself, as a result of such a physical condition, is not helping these individuals, and together with the body condition, they aggravate the quality of life of SSc patients in a mutually interacting fashion. In line

with these principles, the healthcare professional's approach should be also targeted toward the body and mind (or soul) of the individuals with SSc, and only then can the treatment be successful.

2. Systemic sclerosis and its impact on the body and soul

Systemic sclerosis is a rare, chronic, and potentially lethal disease characterized by microvascular disorder, immune system activation, autoimmunity, and increased deposition of extracellular matrix components in the skin and internal organs [1–3]. To date, many mechanisms involved in the pathogenesis of SSc remain unclear, but there is increasing evidence suggesting that it is a complex pathological process, i.e., the interaction of the environment and genetic factors together with regulatory epigenetic mechanisms [1, 2, 4, 5]. Visceral organ involvement is responsible for increased mortality; however, in SSc patients, who are still alive, involvement of the lung, heart, skin, and musculoskeletal system poses a significant burden in terms of physical fitness and condition, as well as impairment of functional ability and quality of life [6, 7].

Non-pharmacological care for patients with SSc is becoming an increasingly important part of the interest of clinical research in SSc and is likely to reduce disability and improve the quality of life while contributing to the reduction of the burden of the disease. Overall, such care is predominantly focused on the musculoskeletal system and the skin [8]. Besides the physical component in the treatment of SSc patients, we must not forget the psychological (emotional) component (i.e., soul or mind) and the social components. These components are greatly and very often underestimated in the treatment, considerably subjective and different every other day, and therefore very demanding in research setting, but very useful in routine clinical praxis, if we, physicians or healthcare professionals, address them.

Every day, the organism is exposed to the effects of various stressors against which it is trying to resist and adapt to, such as viruses, bacteria, toxins (heavy metals), drugs, physical and psychological stress and the resulting lack of sleep, infection, responsibility, sadness, hunger, injury, the disease itself, etc. Each of us has a different ability to resist these stressors and thus to train the organism in the fight against them. However, if the burden of stress exceeds the effort of our organism, it leads to maladaptation, which results in negative consequences. It affects the psychological and physical state as well as the basic regulatory systems (hormonal, immune, and nervous) and leads to the onset of the disease or exacerbation of the disease itself. At the same time, we need some degree of stress to keep these regulatory mechanisms in place, for which we have to compensate with a certain degree of rest. Balance is the basis of good physical and mental health. Inability to rest to a right extent and form is one of the major factors in the development or worsening of a disease. Unfortunately, this is usually underestimated in clinical routine, where the treatment approach often deals only with the physical consequences of the disease. The patient is regarded as an object, not an entity that has its own way and means to help itself. And to better understand this principle, it is vital to explain two main concepts: movement and stress [9, 10].

2.1 Movement—the pillar of life in health and illness

Movement is a basic feature of life, and its disorder is a source of both somatic and psychological difficulties and significantly influences the motor behavior of a person regarding its physical, mental, and social aspects. The metabolic, digestive,

excretory, hormonal, respiratory, and cardiac functions as well as reproductive organs also have a significant influence on movement behavior. However, the free movement itself is controlled by the nervous system [11]. Biocybernetics is a scientific discipline dealing with the description of these control processes. Its main purpose is to include different levels of living system information into a model enabling the understanding of the function of the living organism under physiological and pathological conditions, i.e., to split a human organism that is a complicated biological system into simpler parts that can be more easily described and interpreted so that the organism can be readily understood as a whole rather than an isolated organ or subsystem [12]. Thus, a two-way exchange and processing of information is being conducted between the brain and the executive motor and internal organs. This constitutes a psychophysiological correlate that cannot be divided. To put it simply, the brain sends information to the muscles as motor instructions, and the executive body sends sensory information back to the brain to assure that the instructions were executed. Nevertheless, the state of mind and the way of thinking also influence the course of the whole movement [11]. It is said that all living organisms have the ability to perceive and respond to changes in the external and internal environment by sensory and motor sensors. These changes are being continuously read by our brain, processed, integrated, and interconnected with our emotions and then, at the cortical level, allow us to become conscious of them and understand them. In addition to all this, the connecting nociceptive component is also important, e.g., painful inputs, which in most pathological conditions are associated with disorders of emotional and cognitive pain processing [9, 11]. Thus, every type of physical movement develops a specific type of reflective bodily consciousness that has a significant influence on how we feel our body and how we perceive the outside world. In other words, what we do with and to our bodies shapes the way we see and experience the world [13]. It is therefore important for contemporary science to perceive a person as a whole, i.e., as a functional unit, his soul (mind) and body, and in unity with the environment in which he lives. Furthermore, current science should limit the shortcomings in the sense of Descartes dualism, which is anchored in the history of medical knowledge and can be visible to this day [14, 15]. These two prevailing viewpoints in the treatment of an individual, body and soul, if they are apart from each other, are very limited. From the physical-mechanical point of view, it is a healing process that focuses on the physical structure of the organism and on the mechanics of movement at the site of the structure, and less attention is paid to other well-preserved structures. In this view, the mental influence on movement (caused by the developed disorder), considered to be a subjective accompaniment of movement, is neglected in the objective analysis of the mechanics of motion. On the other hand, from a psychological point of view, it is a treatment procedure focused on the evaluation of the movement function affecting the formation of the organ structure, as well as on the personality character and its influence on the movement behavior, which can cause motor failure [11]. Both viewpoints during treatment emphasize a certain component of movement and do not separately meet the condition of a comprehensive treatment approach. Such a holistic treatment approach and procedure should include both of these components. In the treatment of an individual, it should be very beneficial to both sides, to the patient and the healer, and eventually to the whole system and economy. We are no robots, thus we should neither divide “soma” from “psyche” nor “psyche” from “soma,” neither in treatment nor in prevention.

2.2 Stress, our friend and foe

However, in order to maintain balance and life (movement, “psyche” and “soma”), it is important to adapt to various stressors acting on the living organism.

Despite the fact that ancient philosophers knew about stress and its effects, Hans Selye is considered to be the “father of stress.” His well-known concept of general adaptive syndrome (GAS) refers to three levels of biological response to stress: (a) alarm reaction stage (fight or flight), (b) resistance stage (adaptive), and (c) exhaustion stage [16]. In his study of stress, Selye noted that patients with different illnesses had many of the same non-specific symptoms that were a common response to stressful stimuli and that long-term stress exposure led to adaptation disorders. Although the GAS hypothesis was subsequently shown to be incorrect, it has put stress on the map and also emphasized that stress has a major impact on the immune system and on the adrenal glands [17–19]. In addition, epidemiological studies dealing with stress confirm the association between fetal malnutrition or poor nutrition in early life and coronary heart disease and constant changes in glucose metabolism, resulting in the development of diseases of civilization such as type 2 diabetes and myocardial infarction [20, 21]. Similarly, advances in studying genes, which increase the vulnerability of individuals to stressful life events, have attracted considerable research interest. For example, polymorphism in the monoamine oxidase A (MAOA) promoter that reduces MAOA expression affects vulnerability to environmental influences. This biological process can be initiated by childhood abuse. Furthermore, polymorphism in the serotonin transport gene promoter can also make individuals more prone to stressful life events [22–24]. At the same time, neuroendocrinology research revealed that the autonomic nervous system and hypothalamic–pituitary–adrenocortical (HPA) system serve as means of the afferent and efferent limbs of the stress response in vertebrates and are also central for maintaining homeostasis and allostasis [19]. Nevertheless, there is no unambiguous definition of stress but different perspectives depending on the studied field and different conditions. Stress is based on two basic concepts: physiological, non-specific (based on general knowledge), and psychological, specific (based on the specifics of each individual). Thus we can say that stress is a universal concept that denotes any burden and any stress response leading to a violation of integrity, may it be supposed or true [25, 26]. According to Selye, stress is a non-specific (i.e., occurring stereotypically after a variety of stresses) physiological response of the organism to any requirement applied to the organism. He argued that stress is not identical to emotional excitement or nervous tension because stress can occur during anesthesia in humans or animals and may also occur in plants and bacteria that do not have the nervous system [27, 28]. Criticism of this definition has been subjected to an experimental test that has shown that each stressor has its own specific neurochemical signature. Since these stress indexes are limited to only two neurohumoral systems and since most stressors have at least some overlapping responses, it is not clear that this approach degrades Selye’s definition. In addition, regardless of these limitations in the definition of Selye, cellular response to stress (in all living cells) is at molecular level represented by stress-induced synthesis of stress proteins or heat shock proteins (Hsps), of which molecular chaperones and proteases represent two well-characterized families. Many studies have shown that the response to heat shock is ubiquitous and highly conserved in all organisms from bacteria to plants and animals. It is a necessary defense mechanism for protecting cells (cytoprotection) from a wide range of stressors, including heat shock, alcohols, ischemia, energy metabolism inhibitors, heavy metals, oxidative stress, fever, or inflammation that, depending on amplitude and duration, can cause cell death by apoptosis or necrosis. Hsps also serve as modulation signals for immune and inflammatory responses and may play a role in the production of cytokines [19].

Selye also assumed that if the psychosocial aspect is as important to a human being as a biological aspect, its influence will have the same strength and consequences for the organism as biological factors. This has been later confirmed by new findings which demonstrate that psychological trauma has, in principle, analogous

consequences to physical trauma. Thus the stress model has become an important tool of psychosomatic approach [29].

Nowadays, there is a lot of research and growing interest in stress research focusing on interactions between gene and environmental factors and the role of epigenetics and other mechanisms of gene control (e.g., RNA interference) in stress. This is also very important for research on rheumatic diseases, especially systemic sclerosis.

Systemic sclerosis is a disease, as we have indicated, where motion and locomotion are restricted, and the disease itself is a stressor. Let alone the disease itself could be triggered by a stressor in a genetically predisposed individual.

So now it can be clear that the presence of tissue fibrosis in patients with SSc may adversely affect the transmission of information from receptors in the skin, muscles, joints, intestines, blood vessels, etc. This can consequently adversely affect the perception of internal and external changes, i.e., transmission, processing, and integration of information from internal and external environments, and the subsequent response of the patient with SSc, which is usually accompanied by pain and emotionally narratively experienced by the patient on an individual basis. Such a physical state can have a negative impact not only on the motor behavior of the SSc patient but also on the state of mind and the way of thinking which, conversely, have an impact on the course of movement, self-perception, and the surrounding environment. Adaptation of the organism in such a diseased condition is then weakened by various stressors, and its perceptions and interpretations may be unfavorable. The extent of dissatisfaction with a visibly changing person, not only for the patient but also for other people in his surrounding, the reaction of which the patient perceives very negatively, basically interferes with the personality of the patient and interpersonal relationships, self-esteem, self-image, self-efficacy,

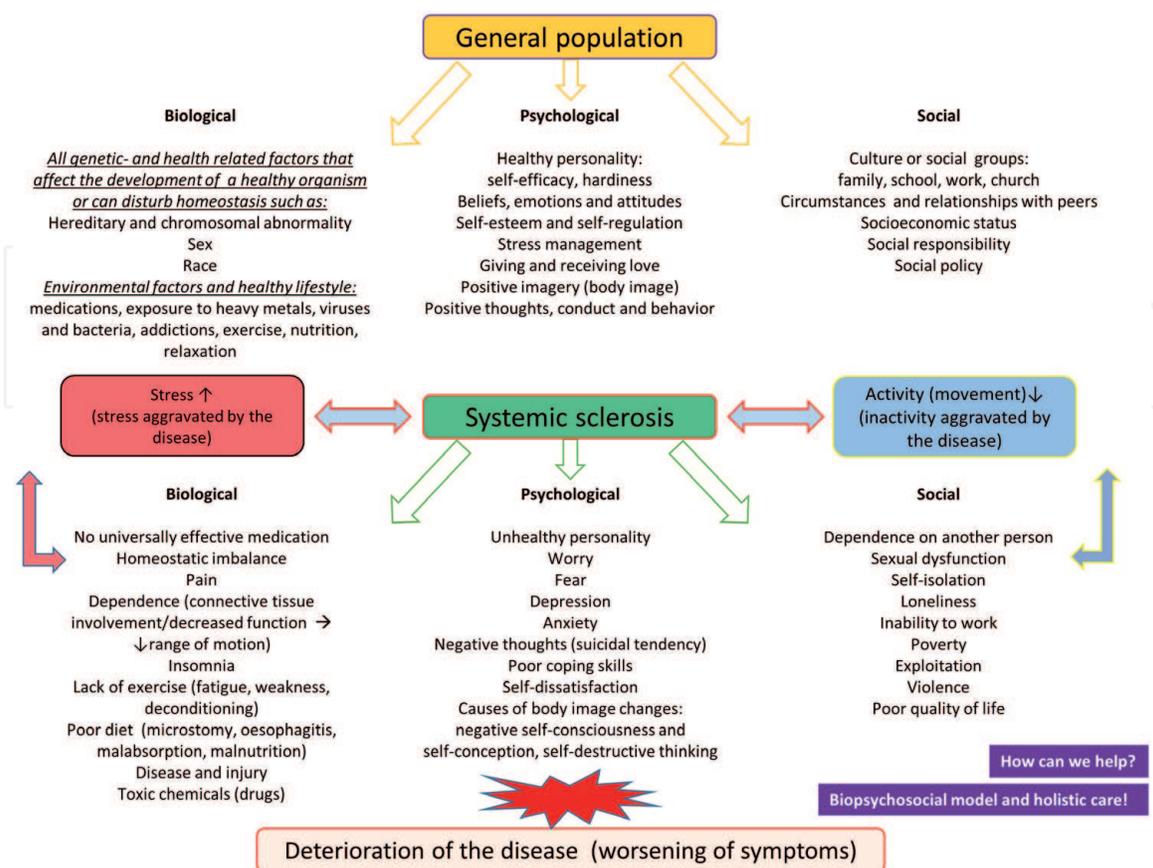


Figure 1.
 Biopsychosocial interactions in general population and systemic sclerosis.

and socioeconomic position. To make the situation even more complicated, chronic fatigue; pain; disease-specific features, such as disease progression, severity, and related organ involvement; and subsequent reactive depression or anxiety greatly reduce the quality of life in SSc patients, as depicted in **Figure 1**.

2.3 Quality of life and its areas affecting the general condition of patients with SSc

As stated in the previous paragraph, there are a large number of symptoms accompanying SSc patients that affect the quality of life and are variably present on an individual basis, i.e., to a greater or smaller extent and with varying intensity and time course. All of them, however, have a negative impact on the entire biopsychosocial personality of the individual and are influenced by a number of physical, psychological, and sociocultural factors. A recent analysis of a large Canadian study found that the most frequently reported symptoms (out of 65 possible symptoms with moderate to severe impact on activities of daily living) by SSc patients (more than 450 in total) are fatigue (89–72%), Raynaud's phenomenon (86–72%), hand stiffness (81–59%), joint pain (81–64%), and sleep disorders (76–59%). Nevertheless, decreased hand function and joint and muscle pain have often been associated with a moderate to severe impact on daily activities. Fever, loss of appetite, weight loss, and reactive depression were also listed in the constitutional symptoms [30].

In a 2013 review of the studies on psychosocial aspects of SSc that were published in the literature following the publication of the Consensus Research Program in 2010, which reflected the limitations of available studies in this area, researchers used structured interviews to determine the prevalence of clinical mood disorders in SSc. It has been found that anxiety remains understudied, and distress may be a useful outcome to consider. Predictors of fatigue and sexual dysfunction in men and women with SSc have been identified. Furthermore, body image distress suggests the importance of changes in the facial skin and hands, and breathing problems and fatigue predicted workplace disability. The study also found the importance of multidisciplinary care for the quality of life related to health. The truth remains that after the publication of this Consensus Research Program in 2010, the research methodology in the SSc psychosocial area has improved; nevertheless, there is still no prospective study in this field. Interventions need to be developed and tested through randomized controlled trials with the power to detect clinically meaningful changes [31].

Evidence-based medicine (EBM) of factors and symptoms subjectively experienced is always very limited due to the complexity and reliability of its research. This is especially true for rare diseases such as SSc. However, the subjective experience of any disorder plays an important role in the subsequent projection of the symptoms of the disease. When searched for in scientific databases, published studies are often evaluating the quality of life, depression, fatigue, or pain in SSc patients. Yet, we all, physicians or healthcare professionals, if we have listened to patients and had that holistic approach, have certainly met many patients who complained not directly about depression or the quality of life but especially on pain, fatigue, sleep disturbances, a certain movement, functional limitations and inability, fear of the future, suicidal tendencies, shame in the circle of their friends, mouth opening problems, inability to work, sexual dysfunction, issues associated with pregnancy, etc. In addition, their psychosocial problems resulting from this disease could even somatize. We are well aware of several other issues that may play a role: anxiety that is not just a feeling but a whole range of chemical processes; presence of larval depression; variability of pain and its perception based on every individual experience; some forms of pain that are also mediated by the so-called

<p>My fingers curl and I cannot properly close the fist, thus everything is falling out. I cannot open a bottle of water</p>
<p>At work, I do not want to shake the customer's hand. I could, but he would immediately notice and recognize that there is something wrong with my hands. That is why I am so ashamed of shaking people's hands</p>
<p>When someone squeezes my hand, then it hurts, and I make a painful grimace. Then he immediately knows that there is something wrong with my hands and I am ashamed</p>
<p>I cannot point at someone with the raised index finger, or point up the thumb to show someone thumbs up, or to make high five with somebody</p>
<p>I cannot scratch my back, but at least I can still wipe my behind</p>
<p>My ability to write with a pen has deteriorated, and my signature is constantly changing, which has been noticed by the staff in the bank</p>
<p>My face feels like a mask, and I feel that people around me realize that there is something wrong with my face. I can also tell the difference from the reactions of men: earlier, when they met me, they changed their behavior, straightened up, and tried to make a contact with me. Now they look like they do not see me at all</p>
<p>My mouth and tongue are becoming tightened, therefore it is more difficult for me to articulate, and sometimes I am being misunderstood. I cannot stick my tongue out at anyone</p>
<p>My eyelashes are falling out, thus I cannot apply paint to my lashes</p>
<p>To go out with friends for a dinner? I could, but I usually do not order any food because I know I would feel sick. I cannot have a wine because of heartburn. When I drink a beer, it comes back and I have a full mouth of bubbles. However, I can still do shots. Thus I mostly look like a fool, because I can only order still water, and everyone is asking me with sympathy, why I cannot eat. And then they feel sorry for me. Sometimes a piece of food falls out of my mouth</p>
<p>When on vacation, I have a problem eating at the hotel. Since my lungs are affected I cough every morning. When I go for a breakfast and start coughing, everyone looks at me and thinks I have tuberculosis or at least a contagious infection. Similarly, I get the same awkward feeling when traveling by a subway, bus or airplane. Usually I cannot eat much for dinner</p>
<p>I am not fit and able to climb a small hill</p>
<p>I cannot drink using a straw, whistle or lick my lips</p>
<p>My dentist is hysterical when he sees me. My teeth never used to decay easily, but now, even if I clean them very carefully, they do. I still have all four wisdom teeth and the dentist is afraid of repairing or extracting them since he cannot access them properly</p>
<p>When I had my picture taken for a new ID, I smiled a little. The clerk was making fun of me. I did not know why. Then he showed me the photo, if it was okay. I had a skewed smile. I told him that I always have a symmetrical smile, and that he should take a new photo. However, it was the same. When he did it once again, I eventually believed I looked this way</p>
<p>Because my esophagus is affected by scleroderma, I have to sleep in a semi-seated position, which is hard to organize in a hotel, which usually has a problem to get so many pillows for me. Thereafter, in the morning I walk hunched over from back pain</p>
<p>It annoys me when my friends, who have not seen me for a week, ask me, how I am doing. If my illness has improved. It bothers me when they feel sorry for me. I'd rather never have to meet anyone</p>
<p>I do not like to go anywhere, although prior to my illness, I could not stand it being without other people</p>
<p>My boyfriend left me because I could not satisfy him manually, orally, or vaginally. I'd rather die</p>
<p>Will my disease get worse when I deliver my baby?</p>
<p>I do not trust the doctors. I blame the contraception pills for triggering my illness</p>
<p>I have no friends anymore, because my physical condition is not what it used to be. They do not want to wait for me. When we should go outside for a walk, they rather say that they do not want to burden me, and that I should stay at home</p>
<p>I have two little children and I am afraid I will not be able to take care of them sooner or later. My husband left me</p>
<p>I am unable to work and am not financially secure. When I say I have a disease, no one wants to hire me</p>

I have an affected esophagus and lungs, and digestive problems too. Other than that I do not look as a sick person. My biggest problem is fatigue, due to which I cannot normally function. Everyone thinks I am malingering. I have no support and I am in it on my own, and thinking about committing suicide
People are avoiding me
My breasts are gone
My skin is itching terribly and my face is full of small red spots
My skin color is changing, I look terrible
I cannot look in the mirror at myself anymore. It is not me.
There are only few specialists dealing with this disease and my doctor is very passive. I have to tell him what to prescribe
I live in countryside, and there is no physiotherapist available who could help me
I am not interested in any groups of patients with this disease. On one hand, they scare me, on the other hand, I feel alone. I want my normal life back. Will I ever have my old life back? Can I be healed?
I have researched this disease in the internet, where I found information that I would die within next 5 years. Is that true? If yes, I'd rather kill myself right now
On Facebook, I have read that stem cell transplantation can heal my disease. Is that true?
Do you think that alternative methods can help me? I have spent a lot of money already, and nothing has changed. What should I do? I do not want to die
I am unable to catch a bus or tram, since I cannot run, my lungs do not allow it. I am stiff, in pain and slow
What, do you think, would help you most in the treatment of your disease? Patients' answers: rest, option, freedom, peace, absence of introversion, contact with other people, experience, divorce, etc. (none of the patients said or thought about any potential new or existing drug!!!)

Table 1.

List of a few selected authentic sentences from the point of view of patients with SSc, which emphasize the need for a biopsychosocial model of the treatment of patients with SSc (from the author's own long-term experience with approximately 150 patients with SSc).

hidden central nervous system defects; chronic pain which always accompanies a change in behavior that often complicates and prolongs the course of the disease; some emotional or social problems which cannot be read well and are erroneously processed by a patient and then they are experienced in a physical form, etc. [9].

From my own experience, I particularly depict a few points of subjective experience in a few selected sentences articulated by the majority of more than 150 SSc patients during my 7-year practice that can be exhaustive for us healthcare professionals, but, on the other hand, they depict the everyday nightmare of patients with SSc (**Table 1**). This suggests that, aside from the EBM, SSc patients, if we listen to them, have psychological, emotional, social, and socioeconomic problems that should not be overlooked, because if they are not addressed, each of our treatment approach is wrong and we will not achieve the desired result. Thus, it is not enough just to direct the treatment in a biomedical manner, but it is necessary to aim, more extensively and as soon as possible, for the so-called biopsychosocial comfort of an individual. Therefore, interdisciplinary cooperation and the development of a number of activities in the area of complex rehabilitation are necessary in order to bring its significance to the attention of the wider medical community so that it becomes a necessary part of the treatment of patients with SSc in clinical practice.

3. Biopsychosocial model of the treatment of patients with SSc

Contemporary medicine should evolve to the ideal of a biopsychosocial (BPS) approach, i.e., psychosomatic treatment of patients, let alone its research. Because

not just one, but all three factors (not separating emotions either), as we have suggested, precede some malfunction, experience, progression, and prognosis. In other words, “psyche” and “soma” form an integral and functional inseparable unit. Although in 1977 the World Health Organization (WHO) adopted a BPS model of illness involving biological, psychological, and social factors, which aims to extend the vision of a physician to psychosocial contexts, and to apply its practical use in everyday practice, there is still a long journey to a BPS model of treatment. It is due to the fact that one of the factors of increasing imbalance disfavoring psychosocial factors in ailing, besides its considerable complexity, can be the EBM methodology itself, which still favors biological factors in obtaining evidence of the correctness of the treatment [32]. The need for the BPS model of treatment was pointed out by Engel in the 1970s and 1980s [33, 34], who argued that the biomedical model of treatment does not take into account the psychosocial aspects of health and illness. He explained it by the fact that other factors (such as subjective experience of illness) that affect social, psychological, and cultural variables also interfere with biochemical responses and they need to be assessed in a view of their interaction with each other. Engel did not deny the importance of biomedical research in medicine, but criticized the too narrow (biomedical) focus of leading clinicians who see patients as objects and ignore the possibility that subjective patient experience is accessible to a scientific study. He promoted his ideas not only as a scientific proposal but also as a basic ideology that tried to reverse the dehumanization of medicine and the disarmament of patients. Furthermore, his research in psychosomatics has pointed to an integrative view, showing that fear, fury, neglect, and attachment have physiological and developmental effects on the whole organism [35]. According to him, the BPS model is a complex and systemic view of relationships that affect both health and illness both inside and outside the individual [36].

On the contrary, critics of the Engel’s BPS model support Grinker’s approach, which highlights biological factors that were otherwise ignored, especially in mental illnesses [36]. According to Monet and Lazarus, the BPS model is based on a stress theory that has a psychological and physiological level including the level of the environment [37]. And, according to Junne and Zipfe, there is a need for an interconnected biomedical and biopsychosocial approach and interdisciplinary cooperation [38]. Some authors think that the BPS model has helped patients to make better use of existing knowledge than the science itself in medicine [35]. Nevertheless, in 1977, the BPS model of illness was adopted by the WHO, which at the same time defined health as “a state of complete physical, mental and social well-being, and not merely the absence of disease or infirmity” [39].

Indeed, the definition is clearly indicated by the fact that if we want to heal or approach a healthy condition, an individual with SSc (or any other individual) must concentrate on maintaining a balance between these mutually affecting factors, which also jointly influence the onset, progression, and prognosis of the disease, its outcomes, and mortality of SSc patients. Biological factors in SSc comprise microvascular involvement of unknown etiology, immune activation, and progressive tissue fibrosis against which there is no universal effective drug available to date. In addition, more and more evidence points to a close link between environmental factors and the pathogenesis of SSc, i.e., the complete pathological process of interacting with the environment and genetic factors that corresponds to epigenetic mechanisms [3].

At the same time, fatigue, depression or anxiety, body image distress, pain, functional limitation, decreased quality of life, and disturbance of sleep patterns were noted among the main psychosocial factors influencing the adaptation to this chronic illness [31, 40–46]. Furthermore, from our own experience, in the history of patients, we can identify factors that precede the onset of the disease, namely, exposure to stressors and environmental factors, poor lifestyle or social support

(family, society, and community), personality, emotional incompetence, etc. The question remains: Who is responsible for the treatment and resolution of these factors? The physician? Physiotherapist? Psychologist? Gynecologist? Sexologist? Occupational therapist? Social worker? Or some other healthcare professional? In the BPS model of treatment, the answer is clear—interdisciplinary cooperation which is very demanding but beneficial. And if there is no interdisciplinary cooperation, all of these factors (because these patients usually have them) fall into the care of one expert, who can experience a burnout or ignorance syndrome from exhaustion and great exertion and misunderstanding of all the components.

Unfortunately, the current concept of medicine addresses most of the patients (let alone patients with a rare and incurable disease like SSc) as an object from a biomedical point of view, assuming the linear relationship between the pathophysiology of the disease, its course, the patient's involvement, and disability, whose usual means of treatment are insufficiently effective. This is also the case if healing does not take place in a multidisciplinary team and the psychosocial factors affecting the ability of patients with SSc to face their disease are neglected and underestimated due to the idea that they belong to other professionals competent in this area. In addition, possible somatized psychosocial problems caused by this disease in SSc patients, who respect a physician who performs a social role for them which equals the position of God, strengthen this biomedical model most of the time. On the other hand, the psychosocial model assumes that the interdependence between the bio-, psycho-, and social variables is rather complex and therefore the SSc can be understood as a significant predictor of a mental condition. This is how we can say that such an integrated BPS model of SSc includes both the effects that contribute to the progression of the disease but also the influences involved in the disease behavior. However, none of the processes is linear but involves circular cycle and feedback with a repeating process over time [47–49].

From my own experience, I can point out that during the diagnosis process and subsequent treatment, the patient with SSc suffers from several stages of disease acceptance: from shock upon diagnosis, detection of its prognosis on inadequate web sites, anxiety states at the time of first physical symptoms and increased follow-up, inappropriate expectation of the results of further examinations to a depressive state of varying intensity. Another response is deciding whether to undergo treatment at all if there is no universal effective drug, and the drugs used to suppress the symptoms of the disease have many other undesirable and potentially toxic effects on the body. Consequently, some even experience maladaptation, refusal of treatment, and accompanying deep depression with suicidal thoughts. Nevertheless, the patient is constantly confronted with the reality of decreased life expectancy (70% of SSc patients survive for 10 years), the fear of pain, change in appearance, functional limitation, dependence on another person, loneliness, lack of social support, cessation of many activities, fear of treatment side effects, death, etc. Cognitive assessment of threats created by stressors and other possible sources has a central role in the effects of stressors on psychosocial and somatic outcomes.

In a 2014 study, where a personalized approach was used for modeling biopsychosocial features in relation to SSc-associated pain, the results indicated that psychosocial functioning is the basis for understanding the pain in this population, and physicians should apply the holistic approach and, if appropriate, recommend pain management in specialized centers [49].

And such a complex BPS model in SSc patients offers a comprehensive approach to diagnosis and treatment of its manifestations, including pain that mostly leads to suffering. However, suffering through somatization can also create pain, influenced by cognitive and emotional factors. This means that for a SSc patient, social and psychological impairment as a result of painful experience can be as difficult as somatic injury.

4. Conclusion

In conclusion, we can say that without the need to investigate EBM, an individual complex of biopsychosocial factors influences the onset, progression, treatment, and survival of SSc patients. In addition, besides the biological factors, the psychological and social factors play a significant role in negatively affecting the quality of life of patients with SSc and their interpersonal relationships, disruption and change of their personality and behavior, and coping with the illness. Since the illness and the consequences of treatment are reflected and manifested not only at the somatic level but also at psychological (emotional) and social levels, we should consider all these components in the treatment and approach in a multidisciplinary fashion. Since fatigue is one of the most prevalent symptoms which is adversely affecting the SSc patients, future research should investigate whether such a disease-associated depressive condition negatively promotes fatigue or whether effective pain management could reduce fatigue or explore other possible causes of fatigue and then find adequate strategies for its effective management. In any case, anyone involved in the treatment of SSc patients should have that twenty-first century holistic approach, take a proper medical history, and listen to patients' own opinions about their quality of health, which could help to spread the knowledge about psychosomatic correlations of the disease and adequate modification of the therapy for the patient. Nevertheless, proper education and awareness of the patient's illness is essential in managing the illness according to the best practice available.

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