

Psychological consequences of multiple sclerosis and assistance possibilities

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Abstract

Multiple sclerosis (MS) is an inflammatory and demyelinating disorder of the central nervous system. It is a chronic, unpredictable and pleomorphic disease, with a variety of symptoms and diverse course, which changes the life of the patient, their family and relatives. Therefore, the analysis of the nature and individuality of psychological issues in MS has become an important aspect for health professionals. Psychological consequences may occur before, during, or after the diagnosis. The adaptation process, mental changes observed in patients and how they live their lives with a chronic disease are very individual in character. The disease and its sequelae are so stressful that they cause dramatic changes which are contrary to the previous development, to the image of self. The quality of life in MS patients is conditioned not only in physical but also in psychological terms; thus there is a necessity to seek treatment, support, and specialist rehabilitation of patients in relation to psychological help. The full rehabilitation program should represent a holistic approach to the patient and include physical, cognitive, emotional, personal, and social aspects.

Key words: multiple sclerosis, psychological consequences, chronic disease, image of self, psychological help

‘And this is the reason why medical practitioners in Hellas cannot treat a plethora of diseases; they ignore the whole that has to be considered because the part shall never be healthy if the whole is not.’
Socrates [1]

What is multiple sclerosis

A vast amount of information about the mechanism, symptoms, and treatment of multiple sclerosis (MS) (Latin *sclerosis multiplex*, SM) has been acquired since Jean-Martin Charcot managed to describe the disease scientifically 1868 for the first time. However, the clear-cut cause or effective treatment of MS have not been discovered as yet [1].

MS is an inflammatory and demyelinating disorder of the central nervous system, in which the white matter of the nervous tissue is focally damaged under improper immune responses that are determined genetically. MS is considered an autoimmune disorder because the patient’s own immune system treats myelin cells as foreign and fights them, thus leaving nervous cells without their sheath, which causes the disruption of transmitting nerve impulses. The disease is characterised by chronic inflammatory, degenerative, and demyelinating conditions, usually occurring in exacerbations, which lead to multifocal damage to the nervous tissue and may gradually cause severe disability [2]. The disease may exhibit symptoms depending on what areas of the brain or spinal cord undergo changes. Therefore, the essence of MS involves the occurrence of neurological symptoms while their intensification is traditionally referred to as ‘the exacerbation of the disease.’ Its course may vary widely in terms of exacerbation frequency and the speed at which neurological

failure increases [3]. The onset of the disease may be monosymptomatic or polysymptomatic, and the first symptoms may appear suddenly or develop slowly.

The most common initial symptoms include optic neuritis (40% of cases) and sensory disorders (21–55% of cases) [4].

MS deficiencies may be divided into: motor, sensory, affective, and cognitive. Symptoms mainly concern: vision disorder, brainstem and cerebellum function disorder, spinal cord function disorder, vegetative disorders, cognitive function disorder, and mental symptoms [4].

Owing to the variable nature of the disorder course, the following clinical types of MS may be distinguished: relapsing-remitting and secondary progressive (70–80% of cases), primary progressive (15% of cases), and mild (1–5% of cases) [5].

The aetiology of the disease is still unknown. MS is a chronic and immune-mediated condition, whose development is caused by exogenous, environmental, and genetic factors [1].

The total of 2.5 million people are estimated to suffer from MS in the world [1]. Studies show that its incidence rises along with the increase of latitude and lowers when approaching the equator [6]. Thus, MS usually affects white people. Women suffer more often, with a ratio of 2:1. The disease may be diagnosed at any age, but it is most frequently identified at the age of 20–40. If the symptoms are displayed at the age of 16 years or less, MS is usually referred to as paediatric. Late-onset MS is diagnosed when the first episode of the disease occurs after the age of 50. The average life expectancy after the start of the disease is 25–35 years. It has been calculated that the disease shortens life expectancy by an average of 6–7 years, which is most often a result of neurological complications and immobilisation [5].

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In Poland, over 40,000 people suffer from MS [1]. Given that the disease predominantly affects young people and lasts for their entire lives, the high quality of life becomes a significant objective for health professionals and the patients themselves. Compared with other neurological diseases, MS features the biggest unknown in terms of aetiology, diagnosis, symptoms and their intensification, as well as the development rate. Thus, the population of MS patients is very diverse. In addition, 75% of them suffer from various mental disorders on top of neurological conditions and symptoms [7]. To that end, particular emphasis should be placed on the psychological aspect of MS, which presents a great challenge both with regard to diagnosis and therapy.

Psychological consequences of MS as a chronic disease

MS is a chronic, unpredictable, and pleomorphic disease, with a variety of symptoms and diverse course, which changes the life of the patient, their family and relatives. One may claim that there are no two identical cases of MS; therefore, there are as many disease courses as MS patients. It seems that this individualism and the unpredictability of the disease have a great impact on the nature and uniqueness of mental changes in patients.

Psychological consequences, and, therefore, mental changes in MS patients may occur at the time of diagnosis and have a chronic nature. Providing the patient with the diagnosis and MS knowledge alone bears psychological implications and may take one of the three forms of a physician-patient relationship [4].

The first relationship type may be called paternalistic: the physician has a decision-making authority; the second type is consumeristic: the physician somewhat 'sells' the information and the patient is to decide. On the other hand, the third relationship type – partnership – occurs when the physician and the patient collectively talk and decide the treatment process. Each of these relations has its pros and cons but the research shows that giving the patient an opportunity to have some impact leads to positive consequences in terms of their mental health, provided that the patient is provided with sufficient information and psychoeducation [8].

By observing psychological responses of patients, three periods may be distinguished: before telling the diagnosis to the patient, telling the diagnosis to the patient, and after the patient is provided with the diagnosis [4]. The phase before the diagnosis is made is very difficult for both the physician and the patient. As the set of symptoms may be ambiguous, making a diagnosis of MS is difficult and time-consuming, which causes additional stress for the patient. Regular discussions with patients about the MS diagnosis criteria may significantly contribute to trust strengthening on the basis of a partnership contract, which in turn will reduce emotional tension within the course of the diagnostic process, and also may inhibit adverse responses associated with telling the diagnosis [4].

Therefore, the key, in a broader sense, is communication with the patient, the listening attitude, and trying to answer the patient's questions. This phase may pose a challenge to health professionals because the time when the diagnosis is made is associated with massive chaos, confusion, a mixture of thoughts and whirlpool of emotions that the patient has to experience, and they all may be focused on health professionals [9].

The phase after the diagnosis is made is often 'a struggle with the road to the unknown' for the patient. The response

is very individual, dynamic and may depend on many factors, such as the general image of the disease created by the mass media and contact with other people, the general image of the medical service, individual emotional reaction, both natural and acquired, or individual ways of dealing with stress [4].

Being diagnosed with MS is a shock for many people and they compare it to being diagnosed with cancer or AIDS, as the term 'chronic disease' is confused with that of 'fatal disease' [10]. In such a case, patients and their relatives go through a gamut of emotions ranging from fear, anxiety, distress to anger and depressive disorders. A sense of relief may also occur. Recent studies confirm the hypothesis that there is a connection between stressful events and MS exacerbations; therefore, huge stress caused by making the diagnosis may contribute to the occurrence of another exacerbation in a short time [11]. It is widely known that the disease has a negative impact on the mental state, and the mental state itself also has a major impact on the disease course and its symptoms [4].

MS is a chronic disease that affect all aspects of the patients' lives. The diversity of clinical symptoms cause patients to evaluate the disease in terms of loss, danger, or challenge [12]. This cognitive evaluation has a huge impact on the selection of methods to cope with MS. The previous results of studies concerning the adaptation to living with the disease are rather ambiguous. The specific nature of MS patients' responses, as well as the resulting consequences, cannot be indicated on the basis of the above-mentioned results. The main reason of these research difficulties is the essence of MS, which is progressive and unpredictable in terms of its course and effects; as a result, the population of MS patients is rather dispersed [13]. Thus, one may claim that there are as many diagnosis responses as MS patients but practitioners who deal with MS on a daily basis attempt to classify the process in a certain way.

A psychological theory of the patient's response to the diagnosis of an incurable disease by Elisabeth Kübler-Ross, an American physician [14], seems to be of help in this case. The stages that Kübler-Ross distinguishes may be regarded as some clues or information concerning what patients think and feel and what consequences their thoughts and emotions may bear in the context of their behaviour, decisions, environment, or relationship with the physician. It should be remembered that MS is an unpredictable disease not only because the physical state of the affected may change overnight. The unpredictability also concerns moods: from euphoria, when the patient manages to do something seemingly impossible, to despair, associated with failure. The emotions that the patient has to go through may be difficult to stand by nearby relatives and friends, especially because they result from imperceptible changes connected with fatigue or attenuation, for example [4].

The first phase distinguished by Kübler-Ross [14] is denial. The patient, having been told the diagnosis, experiences the so-called mental shock. In this stage, the patient is struck with thoughts such as: 'it cannot be really happening,' 'I cannot believe it, the diagnosis must be wrong, I do not have MS, I am not sick or disabled after all.' This may lead to a number of diverse consequences: starting from disclosing the diagnosis and ending with aversion to treatment.

The next phase is anger. The patient is characterised by emotional dysregulation, a sense of pain, solitude, fear, and overarching anger at the injustice of the world, environment, relatives, or the patient themselves. It is a hard time for the patient's environment, as well as for health professionals.

Then the bargaining stage occurs. The patient experiences the so-called wishful thinking and thoughts such as 'it is impossible, it is a nightmare, if..., it is all the fault of..., ' as well as fear, sense of guilt, anger, despair, or the need to seek for new, alternative, sometimes 'miraculous' treatment.

The next stage that the patient may go through is the depression stage, characterised by despair, feeling of inner emptiness, hopelessness, longing for the pre-diagnosis life, reduced confidence in oneself, fear of rejection and uncertain future.

The fifth Kübler-Ross stage is acceptance. The depression phase is followed by adaptation to the current life, change of behaviour, entering into relationships with other people, taking up new activities, reconciliation, and inclusion of the disease in the patient's life [14].

Some researchers decide to include a sixth stage of adapting to the chronic disease: the development stage [15]. In this case, the disease becomes an opportunity to discover new values, seek appropriate lifestyle, and look at the purpose of life from a different perspective.

It should be kept in mind that these stages do not have to appear in the presented order, the patient does not have to experience them all, and the nature of the stages is variable and dynamic.

The life attitudes in patients with a chronic disease such as MS and, therefore, mental changes are very individual. Despite the support of the environment, some patients cannot accept disability. On the other hand, studies prove that those who know about their diseases and understand their mechanisms have an easier time adapting to the life with a chronic disorder [4]. Thus, psychoeducation of patients and their families turns out extremely important in terms of MS diagnosis and treatment.

MS is a social disease. On this basis, it is also worth to look at the stigma associated with a chronic disease. According to the stigma theory by Erving Goffman, an American sociologist [16], both the mind of the sick and the healthy plant a belief that the disease carries a punitive stigma. Through atypical physical signs and the association with a stereotype, the disease is interpreted as a punitive consequence of something bad, e.g. an unhygienic lifestyle or negatively appraised biographical events. The researcher explains that healthy people are not taught how to deal with patients; additionally, perceiving the patient as bad and the disease as their fault is an easier way of thinking [16]. This leads to enormous psychological and social consequences for chronically ill people, who may even experience symptoms of social exclusion in extreme cases. The society takes a dichotomous approach as for the phenomenon of health and disease. A person diagnosed with MS enters the role of a patient and usually assumes a passive approach, which has its consequences in the process of struggling for health and broadly understood rehabilitation. In addition, the mechanism of a self-fulfilling prophecy may be triggered and, as a result, the patient will meet all expectations of the environment and behave within the specific 'patient's role' framework, including, for example, an attitude of alienation, professional or social inactivity [17]. The patient's knowledge of their disease and the consequences of the social reception of discrediting symptoms associated with it primarily have a decisive effect on the understanding of the patient's disease [16]. The image of self, self-evaluation, and self-esteem, which are so important in the context of mental changes

in the disease entity under discussion, are also dependent on the knowledge level and consequences.

In the case of a chronic disease such as MS, the psychological and psychosocial situation is even more sophisticated because the disease stigma is carried invisibly for a long time. It is up to the patient whether the disease should be revealed, which may lead to enormous stress, fear of rejection, misunderstanding, or changing life, especially in terms of relationships. Patients are afraid of being labelled and stigmatized while shame and a sense of guilt, additionally reinforced by the Polish and Catholic awareness, often prevent them from revealing their disease [17]. Therefore, the change in the patients' psyche is chronic stress and constant alertness and readiness to be attacked from the outside, as well as an internal conflict between being honest (a chronically ill person) and playing the appropriate role of a so-called normal person [17]. Thus, psychoeducation at the social level should be vital and strongly emphasised, as well as the attempt to challenge the stereotype that associates the disease stigma with punishment. The role of professionals should also be to shape a psychological response to the disease of the MS-diagnosed person so that it helps in their lives rather than does harm.

MS patient's self-image

In the context of the analysis of psychological changes associated with MS, it is impossible to ignore what happens with the patient's self-image as a sick person. The subject literature defines an image of self as a set of qualities that a person recognizes as their own and unique. It is formed throughout the whole life on the basis of experience and concerns e.g. own appearance, physical condition, mental ability, aptitude, skill, activity, social position, individual needs, or value system [18].

The disease and its sequelae are so stressful that they cause dramatic changes to the self-image, which are contrary to the previous development [19]. In such a case, MS becomes a kind of cataclysm that turns the patient's life upside down. Meeting the needs for balance and proper functioning, such as the need to preserve identity, self-esteem, or control over the environment, is undermined. Patients are forced to change their image and incorporate new, often unfavourable knowledge of their own health status. The result may include reducing self-evaluation and self-esteem, which can affect not only personal suffering, but also the daily functioning and social roles.

On the basis of the studies conducted so far, one can describe some characteristics of the way patients suffering from MS perceive themselves. Negative self-evaluation, low self-acceptance, feeling of isolation, passivity, an increase in anxiety, decrease in ambitions and creativity, resignation attitude, or lack of self-confidence are just a few of their features [18]. The feeling of being inferior, avoiding interpersonal contact, and lack of motivation to execute the plans and life goals lead to a withdrawal from active shaping of one's destiny. In addition, motor deficits or fear of their appearance result in the rise of helplessness and lack of control. Therefore, the patients' lives start to focus on the disease symptoms, which additionally causes anxiety and a sense of threat, amplified by a precarious prognosis. Similarities can be found to the phenomenon of learned helplessness, observed in patients with depressive disorders [18]. In addition, MS patients have a tendency to suppress emotions, as well as feel unable to overcome stress, and in the long run to deal with reality, which all deepen adaptive difficulties.

The attitude of resignation and passivity causes the appearance of a higher (compared with the previous period) need for support and healthcare; the tendency to depend on other people does not always go hand in hand with the degree of disability [18]. Studies also show that negative feelings associated with the person themselves are aggravated by periods of relapse [20]. The process of self-image change affects the majority of chronically ill patients, but it is worth remembering that the onset of MS significantly decreases self-esteem and releases a tendency to depreciate oneself, which can change later on in the process of disease adaptation [18].

The correction of self-image among patients with MS should be an important therapeutic task [18, 21]. According to the research, the disability itself is not an explanation for such a profound change; therefore, therapies which, by re-defining the self-image, would allow to formulate tasks and life goals accurate for the patients' abilities, would be of usefulness. As a result, the patients' self-esteem, self-acceptance, and daily life would benefit. It is a very difficult process, often impossible without the help and support of the environment and the professionals who accept the patients as they are and teach them this acceptance.

Psychological help for MS patients

MS is a disease that changes the life of the patient and their family. The psychological changes that accompany the disease affect different areas of psychosocial and occupational functioning, thus reducing the patient's quality of life. From among more than 60 outpatient clinics of MS registered in the system of the National Health Fund in Poland, only a few offer a psychologist's support. Given the multitude of psychological changes and the analysis of the patients' expectations concerning psychological aid, one can say that this is an especially unmet need [4]. The professional help of a psychiatrist, psychologist, or psychotherapist is not necessary for each patient but it is postulated that everyone should have the opportunity to take the advantage. Many authors indicate the benefits of a so-called multi-dimensional, comprehensive rehabilitation, regarding man as a whole, with their body, psyche, and mind [1]. The quality of life in MS patients is conditioned not only by physical but also by psychological factors; therefore, there is a necessity to offer patients treatment, support, and specialist rehabilitation in the psychological context. Latest scientific research indicates that psychological interventions can have a significant and beneficial effect on both the mental and physical aspects of MS, improving fatigue, sleep disorders, pain, and general vitality, as well as the quality of life and well-being [22].

Therefore, more broadly understood support for MS patients is aimed at reducing stress, managing the psychological crises, offering psychological help for patients in need of company, sense of security, hope, belonging, and autonomy. The support may be professional or unprofessional, and may take different forms, such as emotional, informational, instrumental, material, spiritual, or motivational [23]. Patients with MS can also seek comprehensive support in a variety of movements, organisations, or associations. The patients who meet in such places often give support to one another, build a network of mutual help and create a platform for sharing information and experience.

However, the role of a psychologist may be to accompany the patient by entering into their world, to enrich their knowledge and to cope with the loss of efficiency (improve

self-awareness), to create conditions for revealing difficult emotions, to understand the present situation, to help make adequate decisions (support in realism), as well as to shape or rebuild the sense of life or find new values (improve acceptance) [23]. Many patients also need outplacement, which is frequently a requirement to participate in professional and social life for as long as possible, especially when the abilities and opportunities are altered as a result of the disease.

MS patients frequently suffer emotionally because of both a biological brain disorder (e.g. depression, apathy) and numerous psychological problems associated with the difficult, often dramatic life situation. Thus, the therapy of mental changes in this patient group is a very important aspect of rehabilitation. Understanding the rehabilitation and treatment process carried out on the interdisciplinary level and its supplementation with the psychological aspect, both in relation to patients and their families, have been gradually improving on the medical service market. People are more aware of the fact that the full rehabilitation program should represent a holistic approach to the patient – not only in physical terms, but also in the cognitive, emotional, personal, and social context.

Summary

MS is a chronic, unpredictable, and pleomorphic disease, with a variety of symptoms and diverse course, which changes the life of the patient, their family and relatives. Therefore, the analysis of the nature and individuality of psychological issues in MS has become an important aspect for health professionals.

The quality of life in MS patients is conditioned not only in physical but also in psychological terms; therefore, there is a necessity to seek treatment, support, and specialist rehabilitation of patients in relation to psychological help. The full rehabilitation program should represent a holistic approach to the patient and include physical, cognitive, emotional, personal, and social aspects.

In broadly understood therapeutic work, the patients' way of perceiving reality and the interpretation of stressors seem to be crucial. Psychological and psychotherapeutic help, both individual and in a group form, should focus on the importance of chronic illness in the patient's life, cognitive evaluation, emotional consequences, and coping strategies. Already in 1891, medical doctor Sir William Osler noted that knowing who the suffering patient was seemed far more valuable than knowing what the disease was [1].

The recently growing popularity of positive psychology gives the researchers a chance to focus not only on the patients' deficits in perceiving themselves and their reality, but also on exploring their resources. Studies on factors like self-esteem, optimism, satisfaction with life, or meaning in life, which have a close relationship with a positive attitude to life, might be helpful in the reversal of unpleasant experiences associated with MS. Therefore, it is important to develop the patients' interpersonal skills and their potentials in order to help them cope with stressors related to illness and improve their quality of life.

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