

Psychological consequences of multiple sclerosis and assistance possibilities

Jolanta Neustein¹, Joanna Rymaszewska²

¹ Vratislavia Medica in Wrocław

² Division of Consultation Psychiatry and Neuroscience, Department of Psychiatry, Wrocław Medical University

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“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]

Summary

Multiple sclerosis 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 as well. The adaptation process, mental changes in patients and how they live their life 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 development until now, to the image of self. The quality of life in MS patients is conditioned not only in physical terms, but also in psychological; therefore, there is a necessity to seek treatment, support and specialist rehabilitation of patients in relation to psychological help. The full rehabilitation program should have a holistic approach to the patient – not only in physical terms, but also in cognitive, emotional and personality, and social terms.

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

What is multiple sclerosis

A vast amount of information about the mechanism, symptoms and treatment of multiple sclerosis (Sclerosis multiplex, or SM in Latin) have been acquired since 1868 – it is when Jean-Martin Charcot managed to describe the disease scientifically for the first time.

However, the clear-cut cause or effective treatment of MS have not been discovered as yet [1].

Multiple sclerosis is an inflammatory and demyelinating disorder of the central nervous system (CNS), in which the white matter of 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 nervous tissue, and may gradually cause severe disability [2]. The disease may exhibit such 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].

Due to the variable nature of the disorder course, the following clinical types of multiple sclerosis 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. Multiple sclerosis is a chronic and immune-mediated disease, the development of which is caused by exogenous, environmental and genetic factors [1].

2,5 million people on the world are estimated to suffer from MS [1]. Studies show that its incidence increases along with the increase of latitude. On the other hand, it decreases when approaching the equator [6]. Thus, it usually affects white people. Women are affected by MS more often, with a ratio of 2:1. The disease may be diagnosed at any age, but it is most frequently diagnosed at the age of 20–40. If the disease symptoms are displayed at the age of 16 or less, then MS is usually referred to as pediatric. 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].

Over 40,000 people in Poland suffer from MS [1]. Given that the disease predominantly affects young people and last their entire lives, a high quality of life becomes a more significant objective of health professionals and the patient itself. Compared with other neurological diseases, multiple sclerosis features the biggest unknown in terms of aetiology, diagnosis, symptoms and their intensification, as well as in terms of development rate. Thus, the population of MS patients is very diverse. In addition, 75% of the above-mentioned population 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 multiple sclerosis, which presents a great challenge both in diagnostic and therapeutic terms.

Psychological consequences of multiple sclerosis as a chronic disease

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. One may claim that there are no two identical cases of MS; therefore, there are as many disease courses as MS patients. So, it seems that this individualism and the unpredictability of the disease have a great impact on the nature and individuality 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 – is 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 when the patient is given the opportunity to have some impact, such an action has positive consequences in terms of their mental health provided that the patient is given 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 patient. As a set of symptoms may be ambiguous, making a diagnosis of MS is difficult and time-consuming, which causes additional stress for the diagnosed patient. Regular discussions with patients about the MS diagnosis criteria may significantly contribute to trust strengthening based on partnership contract, which in turn will reduce emotional tension within the course of the diagnostic process, and also may reduce the development of adverse responses associated with telling the diagnosis [4].

Therefore, the key, in a broader sense, is communication with the patient, 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 responses, 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 while the term chronic disease is confused with a 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].

Multiple sclerosis 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 how to adapt 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 multiple sclerosis, which is progressive and unpredictable in terms of its course and effects, and, as a result, the population of MS patients is rather diverse [13]. Thus, you may say that there are as many diagnosis responses as MS patients but practitioners who deal with multiple sclerosis on a daily basis attempt to classify the process in a certain way.

A psychological theory of the patient's responses about the diagnosis of an incurable disease by Elisabeth Kubler – Ross, the American physician [14], seems to be of help in this case. The stages that Kubler – 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 terms of patients' behaviour, decisions, environment or the relationship with the physician. It should be remembered that MS is an unpredictable disease not only because of the fact that the physical state of the affected may change overnight. The unpredictability also affects 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 these emotions result from imperceptible changes connected with fatigue or attenuation, for example [4].

The first phase distinguished by Kubler-Ross [14] is denial where 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”. It 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 where 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, which is characterised by despair, feeling of inner emptiness, hopelessness, longing for the pre-diagnosis life, reduced confidence in themselves or fear of rejection and uncertain future.

The fifth Kubler – Ross stage is acceptance. The depression phase is followed by the adaptation to the current life, change to the 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 is an opportunity to discover new values, seek an 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 this order, the patient does not have to experience them all, and that the nature of the stages is variable and dynamic.

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

Multiple sclerosis 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, the American sociologist [16], both the mind of the sick and the healthy plant a belief that the disease carries a punitive stigma. Through physical, atypical signs and the association with a stereotype, the disease is interpreted as a punitive consequence of something bad, such as the impact of an unhygienic lifestyle or negatively appraised biographical events. The researcher explains that healthy people are not taught how to deal with patients; additionally, this “patient is bad and the disease is their fault” way of thinking about the world is easier [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 in the aspect of health and the disease. A person diagnosed with multiple sclerosis enters into the role of a patient and usually takes a passive approach, which has 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 knowledge level 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 case of a chronic disease such as multiple sclerosis, 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 or disclosed, which may lead to enormous stress, fear of rejection, misunderstanding or changing their life, especially in terms of relationships. Patients are afraid of being labelled and stigmatised while shame and a sense of guilt, additionally reinforced by the Polish and Catholic awareness, often prevent patients from revealing their disease [17]. Therefore, the change in patients' psyche is a 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 the appropriateness of their role played (of the so-called normal person) [17]. Thus, psychoeducation at a 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 such person's life rather than does harm.

MS patient's image of self

Though the analysis of psychological changes associated with multiple sclerosis, it is impossible to ignore what is happening 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 recognises as their own and unique. It is formed throughout the whole life based on experience and concerns for example 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, which are contrary to the development until now, to the image of yourself [19]. In such a case, multiple sclerosis is a kind of cataclysm that turns the patient's life upside down. Needs for balance and proper functioning, such as the need to preserve identity, self-worth or control over the environment, are shaken. Patients are forced to change their image and incorporate a new, often unfavorable, knowledge of the state of their own health. The result may be the reduction of self-evaluation and self-esteem which can affect not only personal suffering, but also the daily functioning and social roles.

Based on 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 characteristics [18]. The feeling of being inferior, avoiding of interpersonal contact and the lack of motivation to execute the plans and life goals lead to an individual withdrawal from active shaping of one's destiny. In addition, motor deficit or fear of their appearance result in the rise of helplessness and lack of control. Therefore, patients' lives start to focus on the symptoms of the disease, 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, feel unable to overcome stress, and in the long run deal with reality, which all deepen adaptive difficulties. The attitude of resignation and passivity causes the appearance a higher (compared to the pre-term period) need for support, receiving a healthcare of among patients, as well as the tendency to depend on other people, which 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, despite its usually poor disability, significantly decreases self-esteem and release a tendency to depreciate oneself, which can change 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, disability itself is not an explanation for such a profound change; therefore, therapies, which, by redefinitions of the self-image, would allow to formulate tasks and life goals that are 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 and often impossible process without the help and support of the environment and the professionals who will accept patients as they are and will teach them this acceptance.

Psychological help for MS patients

MS is a disease that changes the life of the patient and his family. The psychological changes that accompany this disease affect different areas of psychosocial and occupational

functioning, thus reducing the quality of life of the patient to some degree. From among more than 60 Outpatient Clinics of Multiple Sclerosis registered in the system of the National Health Fund in Poland, only a few feature a psychologist. Given the multitude of psychological changes and the analysis of the expectations of the patients concerning psychological support, you can say that this is an especially unmet need [4]. It is not necessary to care for every patient by a psychiatric, psychology or psychotherapy professional but it is postulated that everyone should have that kind of opportunity. Many authors indicate the benefits of a so-called multi-dimensional, comprehensive rehabilitation, grasping a man as a whole, with his body, psyche and mind [1]. The quality of life in MS patients is conditioned not only in physical terms, but also in psychological; therefore, there is a necessity to seek treatment, support and specialist rehabilitation of patients in relation to psychological help. Latest scientific research indicates that psychological interventions can have a significant and beneficial effect both on the mental and physical aspects of multiple sclerosis. Improvements have been observed in fatigue, sleep disorders, pain and general vitality, as well as in the quality of life and well-being of the subjects [22].

Therefore, more broadly understood support for MS patients is aimed at reducing stress, managing the psychological crisis, psychological support for patients in need, by accompaniment, creating a sense of security, hope, belonging and autonomy. Support may be professional and 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 for each other, 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 his world, to enrich 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 them to make adequate decisions (improvement in realism), as well as shaping or rebuilding sense of life or finding new values (improvement in 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 after the abilities and opportunities are altered as a result of the disease.

MS patients frequently suffer emotionally due to both a biological brain disorder (e.g. depression, apathy) and numerous psychological problems associated with a difficult, and often dramatic, life situation. Thus, the therapy of mental changes in this patient group is a

very important aspect of rehabilitation. The understanding of the rehabilitation and treatment process that is carried out interdisciplinarily and its supplementation with a psychological aspect, both in relation to patients and their families, has been gradually improving on the medical service market. People are more aware of the fact that the full rehabilitation program should have a holistic approach to the patient – not only in physical terms, but also in cognitive, emotional and personality, and social terms.

Summary

Multiple sclerosis 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 terms, but also in psychological; therefore, there is a necessity to seek treatment, support and specialist rehabilitation of patients in relation to psychological help. The full rehabilitation program should have a holistic approach to the patient – not only in physical terms, but also in cognitive, emotional and personality, and social terms.

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

The recently growing popularity of positive psychology gives the researchers a chance to focused not only on 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 reversal of unpleasant experiences associated with MS. Therefore it is important to develop patients' interpersonal skills and their potential, which help theme to cope with stressors related to illness and improve their quality of life.

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