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## **SENSE OF COHERENCE IN PATIENTS WITH MULTIPLE SCLEROSIS**

### **INTRODUCTION**

Multiple Sclerosis (Latin: *sclerosis multiplex*, MS) is an acquired, chronic, neurologic demyelinating disease with a wide range of symptoms of rather vague aetiology. Its essence is a multifocal damage to the central nervous system (CNS), which causes the occurrence of various neurological symptoms<sup>1</sup>. MS is a chronic disease, that accompanies the patients for the rest of their life and results in disability. Multiple sclerosis affects various aspects of patient's life and thus the relatives. It is estimated that<sup>2</sup> there are over 2,300,000 people suffering from MS in the world, including around 700,000 in Europe, of which about 45,000 in Poland. Despite the high level of medicine and pharmacology, no effective remedy has been found. Only drugs that prevent the disease or slow its progression are used. A separate group are medicines that facilitate daily functioning.

For both the person who has just been diagnosed and the one who has been ill for a long time, it is important to accept the loss of health and to adapt to the changes resulting from the disease. According to our knowledge in the field of health psychology, one of the key immune resources, playing a major role in adaptation, is the sense of coherence. According to Aaron Antonovsky<sup>3</sup>, the author of the concept, the sense of coherence is a global human orientation, expressing the feeling of confidence that incoming

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<sup>1</sup> K. Selmaj, *Stwardnienie rozsiane*, Poznań 2006.

<sup>2</sup> Polskie Towarzystwo Stwardnienia Rozsianego [Polish Society of Multiple Sclerosis], 2017.

<sup>3</sup> A. Antonovsky, *Rozwikłanie tajemnicy zdrowia: jak radzić sobie ze stresem i nie zachorować*, Warszawa 2005.

stimuli from the internal and external environment are predictable and explicable (sense of comprehensibility); the resources are available to one to meet the demands posed by these stimuli; (sense of manageability); and that it is worth engaging and making efforts (meaningfulness). The sense of coherence indicate in which point on the health-disease continuum is the patient, and indentifies the ability to fight for the well-being. The sense of coherence in people suffering from multiple sclerosis has become the subject of interest of the authors of the presented study.

### MULTIPLE SCLEROSIS

**Aetiology and pathogenesis of multiple sclerosis.** Multiple Sclerosis (G35)<sup>4</sup> is a disease of young adults diagnosed mainly between the age of 20 and 40. It affects women more often than men (2:1). MS occurs most often in geographical areas of moderate climate, i.e. in northern European countries, in Canada, and in the northern states of the USA<sup>5</sup>. This disease is non infectious and cannot be genetically transmitted to the offspring<sup>6</sup>. Multiple sclerosis is not an inherited disorder, however, scientists see certain dependencies in genetic factors that predispose to its development.

The identification of a common morphological base, that is degeneration or damage of myelin around nerve fibres (axons) in the central nervous system, has enabled the identification of demyelinating diseases to which MS belongs. The pathological picture of demyelinating diseases is dominated by primary damage to the myelin sheath, i.e. not caused by other pathological factors. If the degeneration to the myelin is low, it causes a slowdown of the nerve impulses transmission. In the case of severe damage of the myelin sheath, scar tissue (sclerosis) occurs. The scar inhibits or blocks the transmission of nerve impulses entirely. Because that disorder can arise in many parts of the nervous system, the disease has been given the name *sclerosis multiplex*.

In the diagnosis of multiple sclerosis, three tests are used: magnetic resonance imaging (MRI), visual evoked potentials test (VEP) and cere-

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<sup>4</sup> According to International Statistical Classification of Diseases and Related Health Problems, (ICD-10) 2000.

<sup>5</sup> M. Wender, *Choroby demielinizacyjne*, [in:] W. Kozburski, R. Mazur, A. Prusiński (ed.), *Podstawy klinicznej neurologii*, Warszawa 1999.

<sup>6</sup> A. Gryżewska, 2017.

brospinal fluid examination (taken from a lumbar puncture). To diagnose multiple sclerosis, at least two pathological symptoms must be identified. However, in about 3/4 of cases, only one symptom occurs in the initial stage of the disease, which extends the time of diagnosis.

In magnetic resonance imaging in patients with multiple sclerosis pathological changes are visible within the brain and spinal cord. They are called demyelinating lesions or plaques. They are most often seen in the periventricular area, corpus callosum, as well as in the subcortical and supratentorial area, along with the brainstem and branches of the cerebellum, and in the spinal cord. Plaques are mainly located in the white matter. The number and size of demyelinating lesions is varied – the number can reach several dozens, while the size can reach up to several centimetres. In active lesions, the number of inflammatory cells gradually decreases and appear. Inactive lesions are transformed into scars<sup>7</sup>.

Basing on clinical observations, it is concluded that the mechanism of MS formation is associated with autoimmune processes. Pathologically, MS is an inflammatory disease that affects immunocompetent cells, e.g. lymphocytes and macrophages. Formation of plaque can probably be encouraged by the cross-reactivity of myelin antigens with certain bacterial and viral antigens and increased availability of myelin antigens. In a healthy human body, these antigens are well isolated but in case of infections of various origins they can get into the blood and lymph glands, stimulating autoreactive lymphocytes. As a result of the inflammatory process, neuronal axons undergo demyelination. In a situation where the lesion is small, their remyelination is possible by oligodendrocyte precursor cells. However, when the damage is very serious, there is no chance of repairing the damaged myelin and the axons are destroyed. At this point, the sclerosis of astrocytic glial cells arises in this place, and the disease process continues to progress.

**Clinical picture of multiple sclerosis.** The following forms of multiple sclerosis are distinguished in the clinical classification<sup>8</sup>: relapsing-remitting multiple sclerosis (RRMS), secondary progressive multiple sclerosis (SPMS),

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<sup>7</sup> L.A. Rolak, *Choroby demielinizacyjne*, [in:] A. Szczudlik (ed.), *Sekrety neurologii*, Wrocław 2008.

<sup>8</sup> Diagnostic and Statistical Manual of Mental Disorders; DSM-5, 2013.

primary progressive multiple sclerosis (PPMS) and progressive relapsing multiple sclerosis (PRMS). In the majority of patients, the relapsing-remitting form is diagnosed in the early stages. The relapse is defined as the appearance of new or exacerbation of already existing neurological symptoms. Symptoms of the relapse may last from several hours to several days or even weeks. Both the remission period and the frequency of flare-ups are individually differentiated. On average, 1–2 exacerbations may occur each year. It happens that they can appear more frequently, up to several per year. Usually, symptoms disappear partially or completely. After a period of 7 to 10 years, in approximately 65% of patients, the form of RRMS passes into the SPMS. Neurological symptoms no longer show a tendency to remission. In approximately 10–15% of patients, the primary progressive type (PPMS) is diagnosed. A person with this form of the disease has no relapses, and overall physical function from the onset of symptoms gradually deteriorates. The PPMS is diagnosed mainly after the age of 40.

The clinical disease activity of multiple sclerosis is individual. Symptoms do not depend on the number of demyelinating plaques, but from the place where they are located in the central nervous system. Patients with a large number of lesion in the magnetic resonance image (MRI) often show better neurological condition than those in whom a small number of demyelinating plaques are located in important structures of the central nervous system<sup>9</sup>.

The most common symptoms of multiple sclerosis include: pyramidal tract signs, spasticity, sensory disturbances, coordination disorders, tremor, sphincter disturbances, sexual dysfunction, depressive disorders, retrobulbar neuritis<sup>10</sup>.

Pyramid paralysis include upper and lower limbs. Lower limb paralysis are more common, more severe and appear much faster. The paralysis may be flaccid or spastic. Characteristic for multiple sclerosis is paraparesis, i.e. partial paralysis of both legs, however, you can also meet with tripareza and tetraparesis. Hemipareza, or hemiparesis, is less common<sup>11</sup>.

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<sup>9</sup> I. Czarnecka, (ed.), *Stwardnienie rozsziane, konsekwencja dla Ciebie i Twoich bliskich*, Warszawa 2009.

<sup>10</sup> Polskie Towarzystwo Stwardnienia Rozszianego [Polish Society of Multiple Sclerosis], op. cit.

<sup>11</sup> K. Selmaj, op. cit.

Spasticity, i.e. increased, uncontrolled muscle tension, appears just before or along with muscular paralysis. At the beginning of the disease spasticity occurs in the muscles of the hip and knee rectifiers. Spasticity appears much more rarely in the upper limbs. It mainly affects elbow and wrist joints. Patients may also have spasticity in the face, which is a consequence of central facial nerve palsy. It is manifested by the elevation of the corner of the mouth in the direction of paralysis and the contraction of the muscles of the lower part of the face<sup>12</sup>.

The sensory integration dysfunction are dominated by disturbances of temperature and pain perception, exteroceptive sensation (superficial sensation), and rarely loss of proprioception (deep sensation). Disorders of superficial sensation mainly comprise weakened sense of touch and paraesthesia. The deterioration in sensory processing mainly affects limbs and torso. Another characteristic symptom of MS is the Lhermitte's sign, which is a sudden unpleasant sensation resembling an electric shock that passes down the neck and into the spine. Sensory disorders are the first symptoms of the MS in approximately 35–40% of patients. The relapses of the disease that are related to the sense of touch usually disappear and have good prognosis<sup>13</sup>.

In patients with MS due to the damage to the cerebellum and the connections of the cerebellum with the brainstem, a coordination disorder appears. It usually takes the form of cerebellar ataxia, which is a lack of fine control of voluntary movements. The characteristic symptoms are action tremor and inability to perform the rapid alternating movements (adiadochokinesis). Ataxia affects upper and lower limbs and torso. It is one of the more troublesome symptoms because when intensified, it prevents independent functioning. In the case of strong ataxia of the hands, a person may not be able to perform simple self-service activities, and if the torso is affected, it may be difficult to sit without support<sup>14</sup>.

In terms of speech, the disorders of coordination of muscles involved in the vocal apparatus cause a characteristic, slowed, stuttering and intermittent speech, termed scanning speech or cerebellar dysarthria. Dysarthria is caused by damage to the centers and neural networks of speech organs, including muscles, cranial nerves and the extrapyramidal system. Dysarthria

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<sup>12</sup> C.H. Polman, *Stwardnienie rozsziane*, Warszawa 2011.

<sup>13</sup> K. Selmaj, op. cit.

<sup>14</sup> Ibid.

can cause problems within each of the components that make up the proper process of speech production: respiration, phonation, articulation resonance and prosody. Speech problems affect nearly 50% of people with MS<sup>15</sup>.

Postural and kinetic tremor are also a common symptoms in MS. However, they are not permanent, they activate in the moment of a greater than usual physical effort. Tremor can be enhanced when nervous or tired.

Sphincter control disorders are common in Multiple Sclerosis (MS), representing a large source of morbidity and burden for the patients. It is estimated that the problem of urinary incontinence affects about 70% of patients. Nearly 2/3 of them complain about disturbances of the large intestine function<sup>16</sup>.

Sexual dysfunction occurs in nearly 70% of patients. These problems affect men more often. Sexual problems in men are manifested, inter alia, by not maintaining an erection, in women by weakening or not feeling sexual arousal.

Many people with multiple sclerosis also struggle with mental disorders. The most common is depression, which occurs in nearly 70% of patients. It appears more often in women. About 13% of people with multiple sclerosis suffer from bipolar disorder<sup>17</sup>.

According to neuroscientists, retrobulbar optic neuritis (RON) is usually the first isolated symptom of multiple sclerosis, and the risk of MS varies between 30–70% of patients. RON manifests itself mainly in the deterioration of vision, pain while moving the eyeballs and the loss of colour vision. People affected with RON most often complain about the so-called „foggy” vision, photophobia and blindness. Others are struggling with reduced contrasting sensitivity, blurred vision, dyschromatopsia and have trouble seeing to the side. It is estimated that in 50–80% of patients in the course of optic neuritis pain occurs. Blurring or flashes of the image are less often observed. Retrobulbar optic neuritis usually develops very quickly and lasts an average of 4 weeks. The prognosis is generally good and in most patients the vision returns completely<sup>18</sup>.

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<sup>15</sup> M. Przeździeń, *Usprawnianie mowy w SM. Zestaw ćwiczeń logopedycznych dla osób chorych na stwardnienie rozsiane*, Warszawa 2011.

<sup>16</sup> C.H. Polman, op. cit.

<sup>17</sup> M. Siwek, *Zaburzenia psychiczne w stwardnieniu rozsianym*, 2017.

<sup>18</sup> K. Selmaj, op. cit.

**Treatment and rehabilitation of people with MS.** Multiple sclerosis is an incurable disease, but it does not directly threaten the patient's life. Treatment of MS is multifaceted. Pharmacotherapy, physiotherapy, psychotherapy and speech therapy are applied. During the relapsing phase, the most commonly is pharmacotherapy with glucocorticosteroids, which have very strong anti-inflammatory properties. Adrenocorticotrophic hormone (ACTH)<sup>19</sup> is also frequently used. In the event that treatment with steroids is not effective, the filtration of blood plasma (plasmapheresis) is performed, or intravenous immunoglobulin is administered<sup>20</sup>.

Physical rehabilitation is necessary to maximize the patient's potential. Different exercises are recommended, especially the ones enabling a full range of movement in the joints, strengthening, stretching, water sports and breathing exercises. Rehabilitation improves the quality of sleep, circulation, coordination, strength, prevents obesity<sup>21</sup>.

### AARON ANTONOVSKY'S THEORY OF THE SENSE OF COHERENCE

The sense of coherence is one of the components of the salutogenetic model according to Aaron Antonovsky. Salutogenetic orientation is a holistic approach to health. It involves searching for factors supporting human health and well-being as well as protecting it in harmful circumstances. It has challenged the traditional pathogenetic paradigm, aimed at searching for the causes of disease, however, the salutogenetic and pathogenetic paradigms are complementary. Using the pathogenetic and salutogenetic orientation, the possibility of rapid and accurate diagnosis and selection of adequate therapy is increased<sup>22</sup>.

The salutogenetic paradigm is based on the assumption that the primary feature of living organisms is heterostasis and entropy (decline into disorder).

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<sup>19</sup> M. Jackowska (ed.), *SM i ... rzuty*, Warszawa 2009.

<sup>20</sup> M. Gierasiumiuk, 2017.

<sup>21</sup> Specialist centers in Poland, designed mainly for people with multiple sclerosis, are in Borne Sulinowo – Centrum Rehabilitacji SM [Rehabilitation Center of MS] and in Dąbek – Krajowy Ośrodek Mieszkalno-Rehabilitacyjny [National Residential and Rehabilitation Center].

<sup>22</sup> I. Heszen, H. Sęk, *Psychologia zdrowia*, Warszawa 2007.



According to Antonovsky, the adoption of the salutogenetic paradigm (1) protects against focusing only on the aetiology of a specific disease, prompts us to become familiar with the history of human life – not the patient. The author indicates that (2) stressors are not only negative. They should be limited, nevertheless, they are not always pathogenic factors as may even sometimes contribute to health system strengthening, (3) dichotomic classification to healthy as opposed to ill should be rejected, (4) search for sources of negative entropy, (5) data from salutogenetic studies are more extended than those obtained in pathogenetic, (6) instead of focusing on stressors, one should find a way to cope with stress.

The sense of coherence is an important factor conditioning human health. The vast majority of research indicates that it is related to the ways of coping with stress. According to Antonovsky, the sense of coherence is a global human orientation, expressing the degree to which one has pervasive though dynamic sense of confidence that (1) the stimuli that come from the internal and external environment in the course of living are structured, predictable and explicable (2) the resources that allow to meet the demands of these stimuli are available, (3) and requirements are challenges worth the effort and engagement.

Antonovsky distinguished in his concept of three inseparable and necessary components: a sense of comprehensibility, manageability and meaningfulness. The sense of comprehensibility reflects the degree to which an entity receives information from the environment as consistent, clear, structured. Manageability is a one's conviction that he can deal with adversities and problems. The third component, according to Antonovsky, is the most important – meaningfulness – the conviction that the challenges are worth the effort and commitment. Meaningfulness determines motivational force and is a source of personal strength constituting the condition for one's development.

### SENSE OF COHERENCE IN PATIENTS WITH MS. EMPIRICAL RESEARCH

**Method.** The main objective of the empirical pilot studies was to understand the degree of the sense of coherence, i.e. the level of comprehensibility, manageability and meaningfulness in people with multiple sclerosis. The



aim of the research was to determine whether people with multiple sclerosis present a different sense of coherence from psychosomatically healthy people. There were also questions about the relationship between the level of sense of coherence according to sex and age of people, the length of time of illness, whether the respondents have family (spouse and children) and professional activity.

Aaron Antonovski's life orientation scale was used to measure the sense of coherence in relation to life and its challenges (SOC-29). The questionnaire consists of 29 questions, of which 11 measures a sense of comprehensibility, 10 sense of manageability and 8 sense of meaningfulness. The maximum possible test result is 203 points, the minimum is 29.

The research was conducted from September 2015 to April 2016, anonymously, electronically, on the portal [www.ankietaplus.pl](http://www.ankietaplus.pl). The research sample included 15 people suffering from multiple sclerosis from 3 to 31 years, with relapsing-remitting, primary-progressive and secondary-progressive forms. A comparative test was taken by 15 neurotypical persons. The age range in the studied population was 18–60 years old, gender: 16 women and 14 men. In the group of respondents, in equalized proportions, there were people who were professionally active and had a descendant / spouse and people who did not take up professional activity and did not have a family.

**Results.** The sense of coherence (SOC) in people with MS and health people was almost identical. The level of SOC in healthy and multiple sclerosis respondents was almost identical. The median of the results of people with MS was 126.1 points, healthy interviewees 124.5. The highest global result of the test among patients was 144 points, among healthy respondents 148 points. The lowest result in the group of patients was 96 points, healthy 95 points. Differences in the levels among components of the sense of coherence: the sense of comprehensibility, resourcefulness and meaningfulness in people with MS and healthy ones were minimal. Neither the sex nor the duration of the disease, having children or performing work did not differentiate the obtained results of sense of coherence levels in both groups. The outcome achieved by the examined persons differed on the irrelevant dimensions.

## CONCLUSION

The information obtained through the empirical study is unexpectedly optimistic – despite the serious disease, the subjects have a high level of sense of coherence. Individuals suffering from MS accept their special and difficult situation, try to prepare for the challenges that may be waiting for them, seeing the sense of fighting the symptoms of the disease. These data contradict the information provided by the Polish Society of Multiple Sclerosis (PTSR)<sup>23</sup>. According to PTSR, the multiple sclerosis is associated with a very high risk of depressive episodes, attempts to “rescue” by psychoactive drugs and attempted suicide. Moreover, every fourth patient significantly reduces social life, does not decide to have children. Some patients give up or lose their job. Most have the feeling of being dependent on others.

Of course, it is possible that the sense of coherence does not reflect the actual mental condition of patients. However, it seems more probable that those who voluntarily participated in the study were those who did not succumb to the disease. And these are the people who inspire reflection on the strength of the human psyche.

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<sup>23</sup> Polskie Towarzystwo Stwardnienia Rozsianego, op. cit.

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## SUMMARY

Multiple sclerosis (MS) is a demyelinating disorder with multifocal symptoms. The variety of symptoms of the disease is related to the different location of pathological changes within the central nervous system. MS is a disease for which no drug has yet been found. Strong sense of coherence, consisting of a sense of comprehensibility, manageability and meaningfulness, helps in the fight against difficulties and maintains faith in the meaningfulness of life in

spite of the illness. In order to determine the magnitude of the sense of coherence in people with multiple sclerosis, Aaron Antonovsky's scale was applied using the Life Orientation Questionnaire (SOC-29) in a form of empirical pilot study. The results did not reveal differences in the level of sense of coherence between people with MS and psychosomatically healthy respondents.

**Key words:** multiple sclerosis, sense of coherence, salutogenesis.