

QUALITY OF LIFE IN PATIENTS WITH SCLEROSIS MULTIPLEX

Dagmar MASTILIAKOVÁ¹, Ján BIELIK^{1*}, Ivana HOLBOVÁ¹, Iveta MATIŠÁKOVÁ¹,
Katarína GERLICOVÁ¹

¹ Faculty of Healthcare, Alexander Dubček University of Trenčín in Trenčín, Študentská 2,
911 01 Trenčín, Slovak Republic

*Corresponding author E-mail address: jan.bielik@tnuni.sk

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Abstract

Quality of life of patients with sclerosis multiplex (SM) is the central point of this paper. The authors focus on the prevalence, diagnostics, symptom and course of the disease, and on the possibilities of treatment remitters. The paper examines the impact of the disease on the individual domains of quality of life. Presented information was obtained from the patients through the questionnaire SF-36. The results are statistically evaluated and presented in our work. We hypothesized that the quality of life focused on components of physical health and mental health component is higher in patients receiving biologic therapy than of the other ones not treated with biological therapy, which we confirmed by statistical processing. We also found out that a component of overall physical health is increasingly influenced by the SM as a component of the overall mental health observed in both files.

Keywords: sclerosis multiplex, quality of life, physical health, mental health

1 Etiology and epidemiology

Sclerosis multiplex (SM) is a demyelination disease in which the fatty myelin sheaths around the axons of the brain and spinal cord are damaged, leading to demyelination and scarring as well as a broad spectrum of signs and symptoms. SM mostly occurs as a result of some combination of genetic, environmental and infectious factors and possibly other factors like vascular problems. SM is believed to be an immune-mediated disorder mediated by a complex interaction of the individual's genetics and as yet unidentified environmental insults. Damage is believed to be caused by the person's own immune system attacking the nervous system. Possible targets of the immune response include myelin basic protein (MBP) and proteolipid protein (PLP). Even so, the role of MBP in MS is controversial; it is buried within the myelin sheath (rather than on the surface), where immune cells would not be able to recognize it [1].

Disease onset usually occurs in young adults, and it is more common in women. It has a prevalence that ranges between 2 and 150 per 100 000 inhabitants. The prevalence in Slovakia is estimated between 100 till 150 cases per 100 000 inhabitants [1, 2].

2 Clinical picture

Almost any neurological symptom can appear with the disease, and the disease often progresses to physical and cognitive disability. Psychiatric symptoms may also occur. SM takes several forms, with new symptoms occurring either in discrete attacks (relapsing forms) or accumulating over time (progressive forms). Between attacks, symptoms may go away completely, but permanent neurological deficits often occur, especially as the disease advances [3].

3 Diagnosis

SM can be difficult to diagnose since its signs and symptoms may be similar to other medical problems. Currently, the McDonald criteria focus on a demonstration with clinical,

laboratory and radiologic data of the dissemination of SM lesions in time and space for non-invasive SM diagnosis. Magnetic resonance imaging of the brain and spine shows areas of demyelination (lesions or plaques). Testing of cerebrospinal fluid obtained from a lumbar puncture can provide evidence of chronic inflammation of the central nervous system. The cerebrospinal fluid is tested for oligoclonal bands of IgG on electrophoresis, which are inflammation markers found in 75–85% of people with SM. The nervous system of a person with MS responds less actively to stimulation of the optic nerve and sensory nerves due to demyelination of such pathways. These brain responses can be examined using visual and sensory evoked potentials [4].

4 Clinical courses and disability

MS is recognised as a disease in four courses (subtypes):

1. relapsing remitting (80% all causes),
2. secondary progressive,
3. primary progressive, and
4. progressive relapsing.

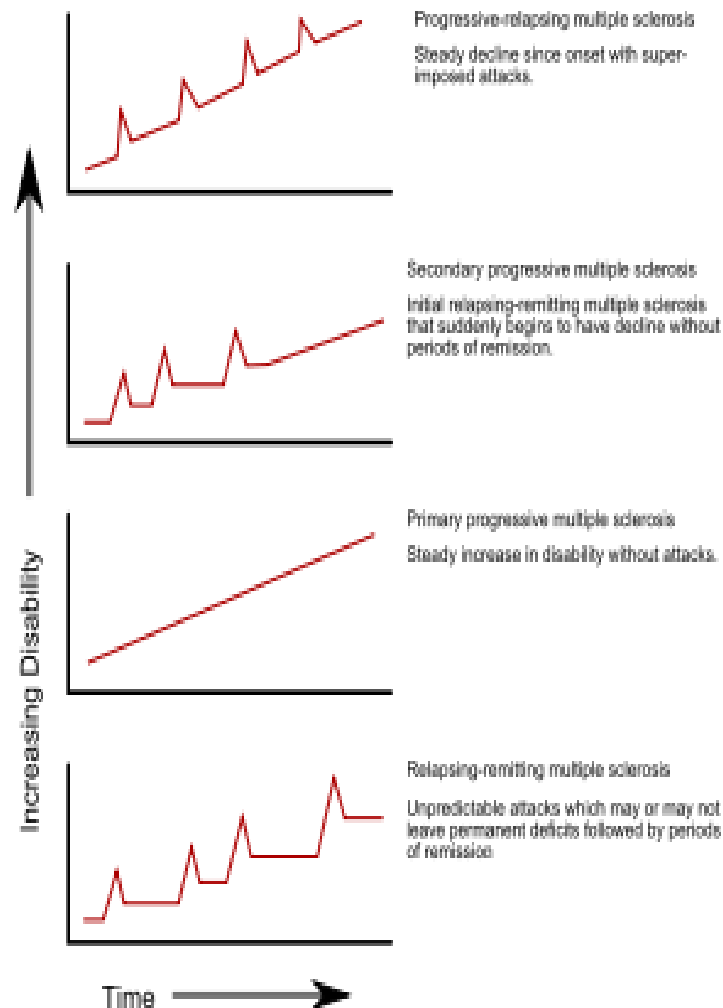


Fig1: Association of MS progression and disability

The main clinical measure of disability progression and symptom severity is the Expanded Disability Status Scale or EDSS. Progression of SM subtypes is shown in the Fig.1.

5 Treatment

Although there is no known cure for SM, several therapies have proven helpful. The primary aims of therapy are returning function after an attack, preventing new attacks, and preventing disability. During symptomatic attacks, administration of high doses of intravenous corticosteroids, such as methylprednisolone, is the routine therapy for acute relapses, while oral corticosteroids seem to have a similar efficacy and safety profile. Consequences of severe attacks which do not respond to corticosteroids might be treated by plasmapheresis.

6 Disease-modifying treatment

Disease-modifying treatments are expensive and most of these require frequent (up-to-daily) injections. Others require IV infusions (pictured) at 1–3 month intervals. As of April 2013, eight disease-modifying treatments have been approved by regulatory agencies of different countries. The approved drugs are interferon beta-1a, interferon beta-1b, glatiramer acetate, mitoxantrone, natalizumab, fingolimod, teriflunomide and dimethyl fumarate [5, 6].

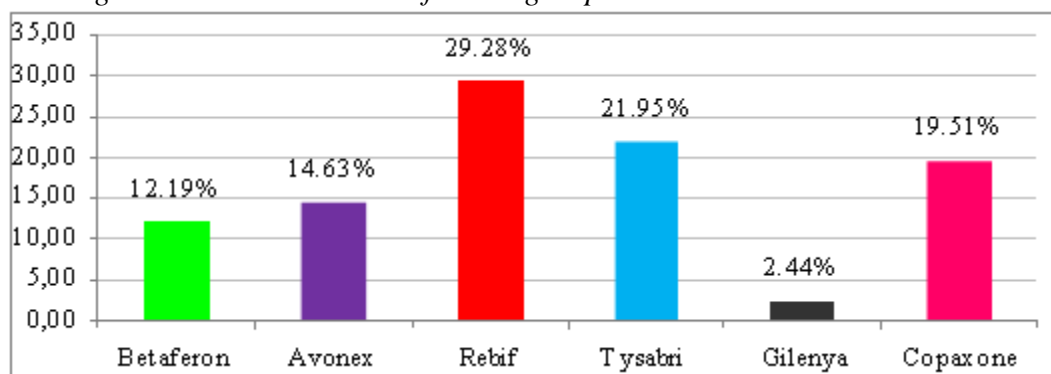
Disease-modifying treatments reduce the progression rate of the disease, but do not stop it. As SM progresses, the symptomatology tends to increase. The disease is associated with a variety of symptoms and functional deficits that result in a range of progressive impairments and disability.

The disease evolves and advances over decades, 30 being the mean years to death since onset. The life expectancy of people with MS is 5 to 10 years lower than that of unaffected people. Almost 40% of people with MS reach the seventh decade of life. Nevertheless, two-thirds of the deaths in people with MS are directly related to the consequences of the disease. Although most people lose the ability to walk before death, 90% are still capable of independent walking at 10 years from onset, and 75% at 15 years [7, 8].

7 Group of patients

The group of patients consisted from 82 patients. Group A: 41 (29 women, 12 men) patients were treated by conventional therapy. Group B: the 41 (32 women, 9 men) patients were treated by moderns disease modifying treatment and biological therapy (Betaferon, Avonex, REbif, Tysabri, Gilenya, Copaxone). The proportion of drugs is shown in the table 1.

Table 1 Drugs used in the treatment of SM in group B



There were asked total 120 patients originally, but 38 returned questionnaires were wrong or incompletely fulfilled. The average age in the group A was 50.59 years and in group B it was 41.82 years [9].

The socio-economic characteristics of incomes have shown these results in following categories:

Group A.: 300-500€ - 26 patients (63.41%), 501-800€: 13 pp. (31.71%), 801-1600€: 2 pp. (4.88%). Disability was 9.39 months per 1 patient in average. Loss of incomes was 123.17€ per person. The expectations in the future were indexed on 2.39 (1-bad, 5 excellent).

Group B.: 501-800€: 20 patients (48.78%), 300-500€: 16 pp. (39.02%), 801-1600€: 5 pp. (12.20%). Disability was 5.02 months in average. Loss of income was 165.85€ per person. The expectations in the future were indexed on 2.41 [9].

8 Methods

The nonparametrical statistic methods were used (Mann-Whitney test). The value of statistical significance was less than $p < 0.05$.

The questionnaire SF-36 was incorporated in the total questionnaire. The results obtained by the items of SF-36 were summarized in two categories - summary of physical component (PCS) and summary of mental component (MCS). These summarized outcomes are seen in the table 2 (below). The difference between group A and B was statistical significant ($p < 0.05$) [9].

9 Results

Group B possessed higher level of quality of life (QoL) compared to group A, in PCS and MCS, too (Table 2).

Table 2 Results from SF-36

Group	Parameter	n	Median	Minimum	Maximum	X	SD
A	PCS	41	21.87	1.25	62.50	28.23	19.76
	MCS	41	30.83	2.81	95.00	33.01	22.58
B	PCS	41	45.63	20.63	73.44	45.65	15.59
	MCS	41	54.48	6.25	73.43	51.65	13.36

Legend: X – average, SD - standard deviation, PCS – physical komponent summary, MCS – mental component summary, B – group B, A – group A

Table 3 Actual QoL

Level	0	1	2	3	4	5	6	7	8	9	10	Average
Group A	0	0	1	2	8	13	8	8	1	0	0	5.29
Group B	2	2	2	8	6	8	8	4	1	0	0	4.34

The second evaluation of QoL was evaluated by patients themselves and so in four categories: 1. - Actual QoL (e.g. during the „full“ treatment). 2. – QoL in the time of diagnosis of SM (in the time of advanced disease). 3. - QoL without disease. 4. – QoL in the time by feeling of excellent health. The scale from 0 to 10 was used (0 – the worse, 10- the best) (Tables 3-6) [9].

Table 4 QoL in the time of diagnosis of SM

Level	0	1	2	3	4	5	6	7	8	9	10	Average
Group A	8	9	5	4	3	2	1	1	4	3	1	3.29
Group B	3	9	13	13	1	2	0	0	0	0	0	2.15

Table 5 QoL without disease

Level	0	1	2	3	4	5	6	7	8	9	10	Average
Group A	0	0	1	1	0	0	2	5	4	8	20	8.68
Group B	0	1	1	0	1	1	0	3	10	14	10	8.17

Table 6 QoL in the time by feeling of excellent health

Level	0	1	2	3	4	5	6	7	8	9	10	Average
Group A	0	0	1	0	0	0	1	4	2	3	30	9.24
Group B	0	0	1	1	0	1	0	0	2	16	18	8.29

10 Discussion

QoL is a new phenomenon in the evaluation of the treatment impact on patient feeling his own health. Some methods are used mentioned as valuable to evaluate the effectiveness of the treatment or the whole health care by patient. This method is more used by the chronic diseases with a great impact on disability e.g. on QoL, too. SM is a degenerative disease of brain occurred mostly in the age of 20 to 40 years. The associated parameters with QoL in patients with SM are the age and intensity of disease, leading to disability of patient. The QoL in our group – 0.48 is in satisfied correlation with the outcome from Kobelt – he found out the QoL on the level of 0.56 [10].

Disorder of moving is mentioned as the parameter with the most influence from physical parameters on physical health. Opposite to this fact was discovered the treatment by biological therapy has a significant impact on this physical health [11].

Kantor's paper is in correspondence with our results. The difference of PCS in patients of group A and group B is significant better for patient with disease modifying treatment.

The biological therapy has a significant impact on the mental health, mostly oriented in familial relationships, fatigue, depression. It has increased the personal energy, motivation, concentration, etc. too [12]. These findings were confirmed in our paper, too, and so on the significant difference. The physical QoL was more disturbed than mental health. The difference was statistical significant. This is in concordance with fact, that in the beginning of the disease is more disturbed mental health but with the progression of the disease is more disturbed physical health.

11 Conclusion

SM is chronic degenerative disease of central nervous system. This disease had a great impact on patient's QoL. The treatment by conventional or disease modifying therapy (DMT) had a significant impact on QoL. The modern DMT had the higher statistical influence as on physical health so on mental health in comparison with the patients treated by conventional therapy. In any case, as conventional so DMT did not reached the level of QoL before beginning of SM. That offer incentives for better management of SM from the part of patients and from the part of treatment (mostly compliance of patients).

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Marián Kaščák*