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Original research article

Quality of life in patients with multiple sclerosis

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Abstract

Objective: Multiple sclerosis is characterized by a diverse clinical course and high disability of the disease. The aim of the study was to identify and analyse the quality of life of patients with multiple sclerosis.

Methods: The authors collected data using WHOQOL-BREF tool. The research sample consisted of 81.40% women and 18.60% men. In terms of age, the largest representation was recorded in persons aged 31–50 (56.98%). The research sample was divided into two groups: persons with a disease duration of up to 11 years (60.47%), and persons with a disease duration over 11 years (39.53%).

Results: We compared the research findings in each domain with the standard population Statistical significance was confirmed in the physical domain in the area of mobility ($p = 0.002^{**}$). Pain and discomfort were perceived more positively in both groups (M = 2.54 and M = 2.93) than in the population standard (PN = 4.03). We confirmed the statistical significance of survival in the area of concentration ($p = 0.045^{*}$). The availability of health services proved to be important ($p = 0.027^{**}$) in the environmental field. When comparing both groups in terms of disease duration, statistical significance was confirmed in the health satisfaction domain ($p = 0.049^{*}$).

Conclusion: Decreased ability to move independently represents the greatest correlation with decreased quality of life. For patients with multiple sclerosis, it is advisable to create checklists and rehabilitation programs to improve their quality of life.

Keywords: Duration of the disease; Multiple sclerosis; Population standard; Quality of life; Satisfaction with health

Introduction

Multiple sclerosis is a heterogeneous nosological entity with a variable clinical picture characterized by a spectrum of somatic changes with varying degrees of deficits in the patient's self-sufficiency. It is a disease that is often associated with quality of life and ranks among the most disabling neurological diseases. There is a high prevalence of MS in northern countries compared to the prevalence of the disease in Australia and New Zealand. The influence of environmental factors on the incidence of MS is unquestionable and confirmed by several epidemiological studies (Kakalacheva and Lünemann, 2011; Ramagopolan et al., 2010). Since the 1990s, the overall SPMS (Secondary Progressive Multiple Sclerosis) prevalence was on the rise, until the introduction of oral DMT (Disease Modifying Therapy) in the year 2010.

Multiple sclerosis (MS) has affected approximately 2.2 million people worldwide till 2016 (GBD 2016 Multiple Sclerosis Collaborators, 2019). This may be due to the possibility of the real MS prevalence being more than the reported prevalence, as no separate treatment interventions for SPMS patients were available until recently. The introduction of oral DMT (Disease Modifying Therapies) significantly influenced the overall pooled prevalence of SPMS ($p < 0.000001$). The prevalence of SPMS statistically correlated with that of MS. However, the extent of the increase in the SPMS prevalence did not correlate with that of MS (Vasanthaprasad et al., 2022).

Another risk factor is vitamin D deficiency in the individual's body. A third significant trigger for the development of MS is smoking (Ascherio et al., 2010). Multiple sclerosis is a chronic inflammatory demyelinating disease that significantly affects all areas of the patient's daily life and their immediate surroundings. It worsens the quality of life by increasing the neurological deficit, the ability to move independently, the self-sufficiency deficit, leads to the deterioration of cognitive functions and promotes the emergence of social isolation (Jankovičová and Kurča, 2016). The great variability in the course of the disease, as well as the individual response to treatment, is specific to patients with MS. The modalities of the pathological state are conditioned by the heterogeneity and complexity of the disease itself, as well as the dynamics of CNS changes over time (Kantorová et al., 2017). For these reasons, it is essential to monitor all areas of quality of life in patients with MS.

In this study, we wanted to investigate differentiations in various different domains of quality of life in patients with sclerosis multiplex in relation to the duration of the disease.

The aim of our work was to find out to what extent the duration of MS affects the quality of life in the physical, psychological, social and environmental areas in the group of people with a disease duration of up to 11 years and in the group of people with a disease duration of more than 11 years.

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We also wanted to monitor whether there were statistically significant differences across domains in the perception of quality of life in patients with MS.

Material and methods

Study design and research sample

In our paper, we used comparative research. The research was carried out in the months of April to July 2020. Questionnaires were distributed to the Multiple Sclerosis Patients Club in Presov in printed form (questionnaires delivered in electronic form were printed on site for time-management purposes). A total of 86 questionnaires were completed. 86 patients diagnosed with sclerosis multiplex participated in the study and were randomized on the following variables: age of the study sample, sex of the patients, and duration of the disease.

Characteristics of the questionnaire

We chose the standardized WHOQL-BREF quality of life questionnaire by Dragomirecká and Bartoňová (2006) The questionnaire consists of 26 items: two separate items assessing overall quality of life and health satisfaction, and 24 items grouped into four domains (physical health, emotional, social relationships and environment).

Nowadays, new specific questionnaires have been developed to measure the quality of life of MS patients: the MSQOL-54 questionnaire: Multiple Sclerosis Quality of Life and MusiQOL questionnaire: Multiple Sclerosis International Quality of Life. However, the WHOQL-BREF quality of life questionnaire has effective practical use and has good psychometric properties. Mikulášiková and Kačmárová (2014) investigated the psychometric properties of the tool, where the WHOQOL-BREF was found to be a more sensitive tool for assessing physical health-related quality of life in depressed patients (18% variance).

Data analysis

SPSS 21.0 software was used for statistical data processing. Statistical processing and evaluation of the empirical data was carried out using descriptive statistics. The creation of raw scores from the domains and their transformation was performed according to the methodology of Dragomirecká and Bartoňová (2006). For statistical processing of the results, we used the t-test statistical method as we wanted to compare two groups of patients: those with a disease duration up to 11 years and those with a disease duration of over 11 years. The F-test was used to determine the normality of the distribution of the set.

Significance of differences in the comparison groups of the set and statistical significance within each item in the domains of the questionnaire was determined at the chosen significance level of alpha = 0.05, where there was the set relationship of: $^* p < 0.05$; $^{**} p < 0.01$; $^{***} p < 0.001$. Using descriptive statistics, we compared the individual relationships of the variables using mean (M), standard deviation (SD), and all findings were compared with the results of the population norm (PN – population norm*) according to Dragomirecká and Bartoňová (2006).

Results

Demographic data

In this paper, we analysed demographic data: age, sex, marital status, duration of the disease. In terms of gender, women were the most highly represented. In total, there were 70 (81.40%) women and only 16 (18.60%) men. In terms of age, we observed the largest representation of people in the range of 31–50 years (49 people – 56.98%).

We found the same representation of people (20.93%) in the age range: 18–30 years and 51–64 years.

We found the same representation (20.93%) for persons in the range: 18–30 years and 51–64 years. Due to the social aspects of the disease, we also investigated marital status. More than half (52.33%) were cohabiting (married).

The duration of the disease is very important in terms of its prognosis and is closely related to the perception of quality of life. The study sample was divided into two main groups: a group of people with disease duration of up to 11 years (52 persons – 60.47%), and a group of persons with disease duration of more than 11 years (34 persons – 39.53%) – Table 1.

Table 1. Demographic characteristics of respondents

Demographic data	*n*	%
Gender		
woman	70	81.40
man	16	18.60
Age		
18–30	18	20.93
31–50	49	56.98
51–64	18	20.93
65 and over	1	1.16
Marital status		
single	28	32.55
married	45	52.33
divorced	13	15.12
Duration of illness		
up to 11 years	52	60.47
over 11 years	34	39.53

The observed groups according to the duration of the disease were different in quantity: the group of people with the length of the disease up to 11 years was larger than the group of people with the length of the disease over 11 years.

Based on the analysis of our findings, statistical significance was confirmed in agility and mobility ($p = 0.002^{**}$). Items such as pain ($p = 0.07$) and dependence on medical care ($p = 0.09$) were not confirmed. Other items such as presence of energy, fatigue ($p = 0.74$), and work performance ($p = 0.74$) were not confirmed at all. In the observed population norm by Dragomirecká and Bartoňová (2006), items such as pain and discomfort (PN = 4.03), dependence on medical care (PN = 4.16), and mobility (PN = 4.27) were rated more positively. In the group with a disease duration of up to 11 years, the mobility item achieved a lower mean (M = 3.48) compared to the population norm (PN = 4.27), but for the group with a disease duration of over 11 years, the mean in achieving mobility was quite low (M = 2.80) – Table 2.

Statistical significance was confirmed in the concentration domain ($p = 0.045^*$) – see Table 3. An interesting finding was the perception of negative emotions ($p = 0.068$ In the dimension of mental health, our findings in selected items were close to the results of the observed population norm of Dragomirecká and Bartoňová (2006).This was most evident for the item: positive emotions, where the mean of those with a disease duration of up to 11 years was lower (M = 3.45), increased for those with a disease duration over 11 years (M = 3.53), and was clearly highest in the population norm (PN = 3.83). There

Table 2. Physical activities quality of life

Domain	Up to 11 years		Over 11 years		p	PN
	M	SD	M	SD		
Q3 Pain and unpleasant feelings	2.54	1.05	2.93	1.14	0.070	4.03
Q10 Energy and fatigue	2.74	0.49	2.67	0.89	0.745	3.62
Q16 Sleep and rest	3.07	0.48	2.88	1.16	0.482	3.61
Q4 Dependence on medical care	2.25	1.03	2.58	1.02	0.095	4.16
Q15 Mobility	3.48	1.15	2.80	0.99	0.002**	4.27
Q17 Daily activities	3.08	0.85	2.82	0.95	0.218	3.76
Q18 Work performance	2.80	1.03	2.72	0.93	0.766	3.76

Note: * $p < 0.05$; ** $p < 0.01$; *** $p < 0.001$, M, SD, PN – population norm * (Dragomirecká and Bartoňová, 2006).

are interesting results in the area of negative emotions, where those with a disease duration of up to 11 years have a lower mean (M = 3.02) than the population norm (PN = 3.47) – see Table 3.

Table 3. Psychological activities quality of life

Domain	Up to 11 years		Over 11 years		p	PN
	M	SD	M	SD		
Q5 Positive emotions	3.45	1.13	3.53	1.14	0.649	3.83
Q7 Concentration	2.89	0.89	3.14	0.73	0.045*	3.55
Q11 Body image	3.13	1.28	3.00	0.92	0.629	3.90
Q19 Self-evaluation	3.22	0.90	3.05	0.88	0.459	3.57
Q26 Negative emotions	3.02	0.97	2.60	1.04	0.068	3.47
Q6 Meaning of life	3.34	0.62	3.30	1.27	0.586	3.86

Note: * $p < 0.05$; ** $p < 0.01$; *** $p < 0.001$, M, SD, PN – population norm * (Dragomirecká and Bartoňová, 2006).

From the results of perception of illness in the social domain, it is evident that persons with the illness for over 11 years perceive personal relationships (M = 3.35) and social support (M = 3.53) to be less challenging than persons with the illness for under 11 years, where the perception of social support was higher (M = 3.66) – see Table 4.

Table 4. Social activities quality of life

Domain	Up to 11 years		Over 11 years		p	PN
	M	SD	M	SD		
Q20 Personal relationships	3.45	0.86	3.35	0.94	0.724	3.75
Q21 Sex life	3.00	0.99	2.70	1.09	0.217	3.64
Q22 Social support	3.66	0.47	3.53	1.04	0.598	3.85

Note: * $p < 0.05$; ** $p < 0.01$; *** $p < 0.001$, M, SD, PN – population norm * (Dragomirecká and Bartoňová, 2006).

Interesting findings were obtained in the item: environment, where the evaluation of the group with the duration of the disease up to 11 years (M = 3.35) and the evaluation of the group with the duration of the disease over 11 years (M = 3.27) was higher than in the monitored population norm by Dragomirecká and Bartoňová (2006) (PN = 2.85). Different results were recorded in the item: financial situation in the group with illness duration up to 11 years (M = 2.39), also in the group with illness duration over 11 years (M = 2.55) compared to the observed population norm (PN = 2.87).

Differences in the length of the illness are evident in the item: access to health services, where the group with the duration of the illness up to 11 years (M = 2.96) achieved lower results compared to the group with the duration of the illness over 11 years (M = 3.35) and the observed population standard (PN = 3.70).

Statistical significance was confirmed for the item: availability of health services ($p = 0.027$**). The findings point to the fact that people who suffer from the disease for a longer period accept the availability of health services (Table 5).

A statistically significant relationship was only confirmed in the domain of satisfaction with health ($p = 0.049$*). When comparing individual quality of life, domains and population norms, we can see clear differences. In the physical health do-

Table 5. Evaluation of the environmental area

Domain	Up to 11 years		Over 11 years		p	PN
	M	SD	M	SD		
Q8 Safety and security	3.03	0.69	3.10	0.91	0.521	3.24
Q9 Environment	3.35	1.25	3.27	1.18	0.771	2.85
Q12 Financial situation	2.39	1.11	2.55	1.04	0.372	2.87
Q13 Access to information	3.56	0.43	3.35	0.94	0.459	3.87
Q14 Free time activities	2.85	0.94	2.75	1.12	0.585	3.33
Q23 Environment	3.11	0.38	3.10	0.87	0.587	3.54
Q24 Availability of health services	2.96	0.83	3.35	0.81	0.027**	3.70
Q25 Transport	3.08	0.89	3.30	0.66	0.246	3.19

Note: * $p < 0.05$; ** $p < 0.01$; *** $p < 0.001$, M, SD, PN – population norm * (Dragomirecká and Bartoňová, 2006).

main, the mean in the under 11 group is M = 13.18 compared to the population norm (PN = 15.55). It is a similar case for social (M = 13.75) and population norms (PN = 14.98). The smallest difference was found in the environment domain (M = 13.98; PN = 13.30) – Table 6.

Table 6. Differences in the domains of the monitored groups

Domain	Up to 11 years		Over 11 years		p	PN
	M	SD	M	SD		
Domain 1 Physical health	13.18	2.90	13.06	2.95	0.721	15.55
Domain 2 Psychological health	13.22	3.12	14.62	3.11	0.534	14.78
Domain 3 Social health	13.75	2.22	13.84	2.31	0.302	14.98
Domain 4 Environment	13.98	2.84	13.90	2.91	0.825	13.30
Q1 Quality of life	3.45	0.83	3.32	0.79	0.132	3.82
Q2 Satisfaction with health	2.77	1.06	2.97	0.86	0.049*	3.68

Note: * $p < 0.05$; ** $p < 0.01$; *** $p < 0.001$, M, SD, PN – population norm * (Dragomirecká and Bartoňová, 2006).

Discussion

Currently, MS is displaying a significant upward trend. In Europe, the incidence and prevalence of sclerosis multiplex has seen a sharp increase, particularly between 1985 and 2011. The greatest increase in the prevalence of sclerosis multiplex has been reported in the Nordic countries and in the northern regions of the British Isles (Kingwell et al., 2013). In terms of gender, women are more commonly affected, accounting for 70% of the total number of patients with sclerosis multiplex. In our study, the demographic data also confirmed a higher prevalence of the disease in women (81.40% women). In terms of age distribution, the disease causes disability in young adults between the ages of 20 and 40 years – which is 31.7 years on average (Havrdová et al., 2013). The findings regarding the age of SM patients also correlate with our results, as the age range of 31–50 years (56.98%) was the most represented in our sample. We found the same representation (20.93) for persons in the range of 18–30 years and 51–64 years, confirming that SM predominantly affects young people. The prognosis of the disease is different in terms of age and associated diseases. We investigated marital status because of the social aspects of the disease. More than half (52.33%) were cohabiting (married). A good family background and social support is the basis for the effectiveness of treatment of the disease.

The duration of the disease is very important in terms of its prognosis and is closely related to the perception of quality of life. The study sample was divided into two main groups – those with disease duration of up to 11 years (60.47%) and those with disease duration of more than 11 years (39.53%). In a pilot study by Majerníková (2022), investigating the psychometric validation of the MSQoL-54 questionnaire on a sample of 104 respondents, the average duration of MS was 7.8 ± 6.9 years. Up to 81% of respondents used immunomodulating treatment, which significantly affects the perception of health in relation to the quality of life in the long term.

The individual perceives the disease and its impact in various areas of life, while prioritizing satisfaction in relation to health. In MS, the perception of quality of life almost always changes proportionally with the prolongation of the duration of the disease. Many studies confirm that the quality of life decreases proportionally quickly with the increasing value of the EDSS (Expanded Disability Status Scale) diagnostic criteria. For the MS disease, a comprehensive assessment of all its symptoms using standardized tools is important in order to ensure the effectiveness of therapeutic interventions. Currently, we know specific tools for measuring the quality of life of patients with MS. In addition to the MSQOL-54 (Multiple Sclerosis Quality of Life), MusiQOL (Multiple Sclerosis International Quality of Life) tools, they are FAMS (Functional Assessment of Multiple Sclerosis), MSQLI (Multiple Sclerosis Quality of Life Inventory), MSIS-29 (Multiple Sclerosis Impact Scale), MOVIES (Functional Index for Life with Multiple Sclerosis) and others (Majerníková, 2022).

Impaired mobility was described as the most important symptom of MS. A reduction in the ability to move independently represents the greatest correlation with a reduction in quality of life. 64–85% of patients with MS demonstrate gait disturbances. Studies confirm that the ability to move independently has the greatest impact on the quality of life of people with both early and advanced MS, regardless of gender (Heesen et al., 2008). In our research, statistical significance was also confirmed in the mobility domain ($p = 0.002^*$), which is the most feared phenomenon of the disease. When comparing the groups, we can see that mobility is severely limited: mobility is is relatively lower in the MS group up to 11 years (M = 3.48) and greatly reduced in the MS group over 11 years (M = 2.80) compared to the population norm (PN = 4.27).

Sensory disturbances in brainstem damage appear on the contralateral half of the body but can also appear on the face. Sensory disturbances may manifest as hypesthesia, absence of sensitivity to touch, heat, pressure, or paraesthesia (burning, itching, pinching, tingling, freezing). Central motoneuron involvement is clinically represented by muscle weakness, hyperreflexia, and increased muscle tone with manifestations of spasticity (Kantorová, 2018). The primary progressive form represents a steadily increasing neurological deficit from the onset of the disease, with varying long periods of compensation. A prognosis of this type is not very favourable (Jankovičová and Kurča, 2016).

Items such as pain ($p = 0.070$) and dependence on medical care ($p = 0.095$) were not confirmed in our study. The prevalence of pain syndromes in the MS population varies in the range of: 66.5% (Gürkan and Gürkan, 2018). In a study by Drulovic et al. (2015) that involved 650 patients, 57.4% were taking pain medication throughout the MS course: nonsteroid anti-inflammatory drugs – 48.2%, tricyclic antidepressants – 10.8%, antiepileptic medications – 4.9%, and spasmolytics – 9.5%. Univariate linear regression analyses (dependent variable: presence of pain) showed that older age ($p < 0.001$), primary-progressive course of MS ($p = 0.034$), higher EDSS score ($p = 0.008$), higher scores of HDRS (Hamilton Depression Rating Scale) ($p < 0.001$), and MSSS (The Multiple Sclerosis Severity Score) ($p < 0.001$) were the significant predictors of pain in our MS patients. Multivariate linear regression analysis revealed only age (standardized ß coefficient = –0.178, $p < 0.001$) and anxiety, measured by MSSS (standardized ß coefficient = –0.198, $p = 0.005$) as independent predictors of pain. The pain is stimulated by demyelination of the nucleus trigeminus and its sensory pathways. The pain sensations, although of short duration, are of a very intense nature, as they occur in periods recurring several times during the day. Pain-inducing factors include opening the mouth, chewing food, or increasing or decreasing the temperature in the facial area (Kantorová, 2018; Kantorová et al., 2012). Pain and discomfort were not confirmed in our set ($p = 0.070$). However, pain was perceived differently in the up to 11 years group (M = 2.54) than in the over 11 years group (M = 2.93).

Currently, the importance of aerobic training is highlighted as part of rehabilitation programs for patients with MS, as well as a preventive program for the risk of reduced mobility and the occurrence or increase in pain intensity. Aerobic endurance is characteristic of prolonged physical activity of low and moderate intensity, therefore dynamic and endurance physical activities are suitable for aerobic training. Training positively affects the cardiovascular system and reduces the risk of atherosclerosis, diabetes, obesity, and osteoporosis. In patients with MS, it has a positive effect on fatigue, improves mental fitness, sleep, and overall quality of life.

In study on the sample 89 patients that started treatment early (median EDSS = 3.0; interquartile range = 2.0–3.6), they achieved mean fatigue subscale [standard deviation, SD ± 42.6 (8.0)], 43 persons received aerobic training and 46 had received the control intervention.

A significant post-intervention between-group mean difference (MD) on the fatigue subscale ($p = 0.014$) points was found in favour of aerobic training. However, this was not sustained during follow-up (Heine et al., 2017). The need for mobility in patients with MS was also confirmed ($p = 0.002^{**}$). Creating rehabilitation programs for MS patients in collaboration with physiotherapists appears to be the solution. An effective model is a multidisciplinary approach in caring for a patient with MS (nurse, physiotherapist, psychologist, social worker).

Fatigue is one of the most common symptoms of the disease and is often the result of impaired mobility and persistent pain. It occurs in up to 80% of patients, and about a third of them perceive fatigue as the worst part of the disease as it significantly limits their daily activities and social functioning (Donáth, 2017). In our sample, both groups showed similar perceptions of fatigue (the up to 11 group, M = 2.74, and the over 11 group, M = 2.67). This indicated that for both groups, fatigue was of substantial importance in their quality of life. During the course of the disease (even at its outset), cognitive impairment may occur. This most commonly presents itself as impaired concentration, as confirmed by our research ($p = 0.045^*$), and short-term memory deficits (Grossmann et al., 2017).

Cognitive impairment is very common in patients with MS. It is estimated that up to 40–70% of patients suffer from cognitive impairments, with memory functions and information processing speed being the most affected; executive functions and visuospatial functions are also affected (Patti, 2009). Chronic insomnia has been confirmed in approximately 40% of patients (Vitková, 2016). In practice, a new screening questionnaire that assesses the quality of nocturnal sleep, the Pittsburgh Sleep Quality Index (PSQI) (Hudáková et al., 2016), is being used. In our study, we found impaired concentration in MS patients ($p = 0.045^*$).

Changes in mood, personality, and cognitive function are symptoms of MS that limit the individual in the psychological domain. Research confirms the high incidence of psychological problems in MS patients. The aetiopathogenesis of these difficulties is closely related to lesions and degenerative changes in specific areas of the brain responsible for emotions. Approximately two-thirds of patients report transient mood changes, increased irritability, and anxiety (Kantorová, 2018). Similarly, we found that negative emotions were higher in patients with a disease duration of up to 11 years (M = 3.02) compared to the group with a disease duration over 11 years (M = 2.60).

In many patients, cognitive impairment is progressive. The results of a 10-year longitudinal study in Italy, which included patients up to 1.5 years after diagnosis, confirmed that 26% of patients with MS had cognitive dysfunction at disease onset, 49% after four years of disease, and 56% after ten years of disease duration.

Cognitive dysfunction significantly reduces the quality of life of patients, causes unemployment in people of working age, affects social participation, leads to deficits in the implementation of daily activities, affects the survival of personal relationships, and adherence to treatment (Amato et al., 2006; Elshebawy et al., 2021).

Klímová (2020) points out the essential importance of immunomodulatory therapy for patients with MS, where cognitive deficits cannot be effectively influenced. Positive results were observed in patients treated with interferon-beta, but also with amantadine sulphate, which was administered in MS patients with the intention of alleviating the symptoms of fatigue. Its beneficial impact on cognitive function was discovered much later.

About half of MS patients (40–50%) develop depression during the disease. Many studies have confirmed that the presence of depressive symptoms negatively affects not only the psychological but also the physical health of the patient (Kantorová et al., 2014). Depression is a very common cause of insomnia, exacerbates fatigue, and is also closely related to cognitive function, especially when it comes to information processing speed, concentration, memory, or executive function. The most used questionnaires assessing the presence and intensity of depressive symptoms include the BDI (Beck Depression Inventory) or the HADS (Hospital Anxiety and Depression Scale) (Vítková, 2016).

In our study, the incidence of negative emotions in patients with MS was not confirmed ($p = 0.068$). Štourac et al. (2011) investigated the impact of glatiramer acetate treatment on various aspects of life in 766 patients with MS. The results confirmed that treatment with glatiramer acetate improved family relationships, reduced fatigue, and increased energy ($p < 0.01$). In addition to these aspects, they also found treatment-dependent, statistically significant improvements in factors such as flexibility, social isolation, work ability, motivation, mental concentration and need for rest ($p < 0.001$). In our study, statistical significance was also confirmed in the item concentration in patients with MS ($p = 0.045$).

Our paper confirmed a substantial need for social support in the under 11 group (M = 3.66). In the context of prevention of social isolation, we recommend cooperating with self-help groups to provide the patient and family with specific information about the possibilities of group membership, convalescent stays, educational meetings, etc. Gait disorders are also the most common cause of reduced work productivity or loss of employment. In a study by Heesen et al. (2008), a clear correlation between mobility and employment ($p < 0.0001$) was determined. There was also a strong correlation between mobility and the amount of annual income ($p < 0.0001$) in the entire study group. A Canadian study involving 602 patients with MS confirmed an unemployment rate of up to 78%. The top three causes of job loss were gait disturbance (41%), fatigue (39%), and memory and vision impairment (12%). In addition to mobility, a statistically significant correlation with job loss has also been found for cognitive impairment ($p = 0.001$) (O'Donnell et al., 2017). Our study also confirmed statistical significance in the areas of mobility ($p = 0.002^{**}$) and concentration ($p = 0.045^{*}$), which are closely related to fatigue and memory disorders.

An interesting pilot study was conducted by Eliášová et al. (2015), which aimed to compare the quality of life of patients with sclerosis multiplex in the Presov region in terms of the use of self-help group support. In their paper, they used the same WHOQOL-BREF tool to compare the two groups. The first group of respondents consisted of MS patients who did not attend a self-help group (NSHG). The second study sample consisted of patients with MS, registered as members of the MS club in Presov, attending a self-help group (SHG). Social functioning is an important component of quality of life. Satisfaction with the social situation was expressed predominantly by respondents attending the club ($p < 0.000^{***}$). Significant differences in opinions were observed in the areas of satisfaction with personal relationships ($p < 0.001$) and satisfaction with economic situation ($p < 0.01$) in favour of SHG patients. Social support was also absent in our patients with a disease duration of up to 11 years (M = 3.66) and a disease duration over 11 years (M = 3.53).

In our research sample, statistical significance was confirmed in the domain of availability of health services ($p < 0.027^{**}$).

This finding correlates both with the standard of living of the current population and with the proportion of people with MS in the age-related decline in the use of health services.

Conclusion

On average, respondents rated overall quality of life (and especially individual WHOQOL-BREFF domains) more negatively than the population norm. Both groups of MS patients (up to 11 years and over 11 years of disease duration) had, on average, poorer scores in physical health, emotional experience, and social relationships compared to the population norm. The opposite relationship was found in the environment domain, where both our sample groups scored higher than the population norm (PN = 13.30). As part of nursing care, we recommend checklists for patients and their relatives, which will contain recommendations for coping with the daily activities of patients with MS and be part of the treatment and regime measures.

Progress in improving the quality of life of patients is possible by increasing the multidisciplinary cooperation of nurses, physiotherapists, psychologists and social workers with the aim of achieving comprehensive care for these persons.

We recommend the validation of standard tools for patients with MS for effective monitoring of their needs and problems. Special programs for patients with MS, such as educational, rehabilitation, social and others, which are completely absent, prove to be interesting.

Ethical statement

The study was approved by the Ethics Committee of the Hospital of St. Jakob in Bardejov. It was carried out according to the Data Protection Regulations (GDPR) and the Helsinki Declaration (2013). The questionnaire survey was anonymous and voluntary. Study participants were informed about the objectives and relevance of the study and the processing of personal data.

Conflict of interest

The authors have no conflict of interest to declare.

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Kvalita života u pacientov so sclerosis multiplex

Súhrn
Cieľ: Skleróza multiplex sa vyznačuje rôznorodým klinickým priebehom a vysokou invaliditou ochorenia. Cieľom štúdie bolo identifikovať a analyzovať kvalitu života pacientov so sclerosis multiplex.
Metódy: Autori zozbierali údaje pomocou nástroja WHOQOL-BREF. Výskumnú vzorku tvorilo 81,40 % žien a 18,60 % mužov. Z hľadiska veku bolo najväčšie zastúpenie u osôb vo veku 31–50 rokov (56,98 %). Výskumná vzorka bola rozdelená do dvoch skupín: osoby s dĺžkou ochorenia do 11 rokov (60,47 %) a osoby s dĺžkou trvania ochorenia nad 11 rokov (39,53 %).
Výsledky: Zistenia výskumu v každej doméne sme porovnali so štandardnou populáciou. Štatistická významnosť bola potvrdená vo fyzickej doméne v oblasti mobility (p = 0,002**). Bolesť a diskomfort boli v oboch skupinách vnímané pozitívnejšie (M = 2,54 a M = 2,93) ako v populačnom štandarde (PN = 4,03). Potvrdili sme štatistickú významnosť prežívania v oblasti koncentrácie (p = 0,045*). Dostupnosť zdravotníckych služieb sa ukázala ako dôležitá (p = 0,027**) v environmentálnej oblasti. Pri porovnaní oboch skupín z hľadiska trvania ochorenia sa potvrdila štatistická významnosť v doméne spokojnosti so zdravím (p = 0,049*).
Záver: Znížená schopnosť samostatného pohybu predstavuje najväčšiu koreláciu so zníženou kvalitou života. Pre pacientov so sklerózou multiplex je vhodné vytvoriť check listy a rehabilitačné programy na zlepšenie kvality ich života.

Kľúčové slová: kvalita života; populačný štandard; skleróza multiplex; spokojnosť so zdravím; trvanie choroby

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