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Quality of Life in Patients with Multiple Sclerosis

Jakość życia chorych na stwardnienie rozsiane

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Abstract

Introduction. Multiple sclerosis (MS) is an incurable demyelinating disease of the central nervous system (c.n.s.). The chronic nature of this disease causes deterioration of the physical, mental, emotional and social condition of patients, which significantly reduces their quality of life.

Aim. The aim of the study was to determine the quality of life of patients with multiple sclerosis.

Material and Methods. The study involved 100 patients with multiple sclerosis, associated in support groups operating in the Silesian voivodeship. Among the respondents were 77 women and 23 men. The FAMS questionnaire — version 4 (Functional Assessment of Multiple Sclerosis Quality of Life Instrument) was chosen to measure the quality of life of patients with multiple sclerosis. The obtained research material was subjected to a statistical analysis, using the statistical package STATISTICA v12 for calculations. In order to calculate the variables, the following measures were used: arithmetic mean, standard deviation, coefficient of variation, asymmetry coefficient, kurtosis coefficient, Person linear correlation coefficient, Spearman rank correlation coefficient.

Results. The average results of all subscales of the FAMS questionnaire-version 4 in the examined group reached the value of 111.1 points; that is, a satisfactory level (65% of all respondents), in the absence of bad assessments, and 35% of good grades. The result is at the second level of quality of life, in the numerical range of 58–117 points. The lowest scores were recorded in the “Mobility” subscale (14.39 points), and the highest in “Other ailments” (36.77 points). Strong correlations were found between the FAMS score and individual subscales. As the subscale score increased, the FAMS score increased, and the higher the score, the better the quality of life of MS patients. The higher the respondent’s age, the lower the FAMS results, while the one-way treatment process — either pharmacology or rehabilitation — does not improve the quality of life, only integrated actions increase the quality of life of patients with MS. In the case of a form of the disease — a primary progressive and primary progressive form with exacerbations affect the quality of life of patients with MS.

Conclusions. Most MS patients assessed their quality of life as satisfactory, in the absence of bad and with one-third of good scores. The existence of links between the FAMS results and all subscales indicates that the higher the subscales rated, the higher the FAMS result, i.e. the better quality of life of MS patients. Gender does not determine the quality of life of the respondents, while age, the form of the disease and the type of treatment affect the quality of life. **(JNNN 2019;8(3):95–101)**

Key Words: multiple sclerosis, quality of life, demyelinating disease

Streszczenie

Wstęp. Stwardnienie rozsiane (SM) jest nieuleczalną, demielinizacyjną chorobą ośrodkowego układu nerwowego (o.u.n.). Przewlekły charakter tej choroby powoduje pogorszenie stanu fizycznego, umysłowego, emocjonalnego i społecznego chorych, co znacząco obniża ich jakości życia.

Cel. Celem badań było określenie jakości życia chorych na stwardnienie rozsiane.

Materiał i metody. Badaniem objęto 100 chorych na stwardnienie rozsiane, zrzeszonych w grupach wsparcia działających w województwie śląskim. Wśród respondentów było 77 kobiet i 23 mężczyzn. Do pomiaru jakości życia chorych na stwardnienie rozsiane wybrano kwestionariusz FAMS — wersja 4 (Functional Assessment of Multiple Sclerosis Quality of Life Instrument). Uzyskany materiał badawczy poddano analizie statystycznej, wykorzystując do obliczeń pakiet statystyczny STATISTICA v12.W celu obliczenia zmiennych wykorzystano takie miary jak: średnia arytmetyczna, odchylenie standardowe, współczynnik zmienności, współczynnik asymetrii, współczynnik kurtozy, współczynnik korelacji liniowej Persona, współczynnik korelacji rang Spearmana.

Wyniki. Średnie wyniki wszystkich podskal kwestionariusza FAMS — wersja 4 w badanej grupie osiągnęły wartości 111,1 pkt; czyli poziom zadowalający (65% ogółu badanych), przy braku ocen złych, i 35% ocen dobrych. Wynik mieści się na drugim poziomie jakości życia, w przedziale liczbowym 58–117 pkt. Najniższe oceny odnotowano w podskali „Zdolność poruszania się" (14,39 pkt), a najwyższe w „Innych dolegliwościach" (36,77 pkt). Odnotowano silne korelacje pomiędzy wynikiem FAMS, a poszczególnymi podskalami. Wraz ze wzrostem wyniku podskal, wzrastał wynik FAMS, a im wyższy wynik, tym lepsza jakość życia chorych na SM. Im wyższy wiek respondenta, tym niższe wyniki FAMS, natomiast jednokierunkowy proces leczenia — albo farmokologia, albo rehabilitacja — nie poprawiają jakości życia, dopiero zintegrowane działania podnoszą komfort życia chorych na SM. W przypadku postaci choroby — postać pierwotnie postępująca i pierwotnie postępująca z zaostrzeniami, wywierają wpływ na jakość życia chorych z SM.

Wnioski. Większość badanych chorych na SM oceniła swoją jakość życia jako zadowalającą, przy braku ocen złych i przy jednej/trzeciej ocen dobrych. Istnienie powiązań między wynikami FAMS, a wszystkimi podskalami, pozwala stwierdzić, że im wyżej oceniane podskale, tym wyższy wynik FAMS, czyli lepsza jakość życia chorych na SM. Płeć nie determinuje jakości życia badanych, natomiast wiek, postać choroby i rodzaj leczenia mają wpływ na jakość życia. **(PNN 2019;8(3):95–101)**

Słowa kluczowe: stwardnienie rozsiane, jakość życia, choroba demielinizacyjna

Introduction

Multiple sclerosis is an acquired, chronic, inflammatory disease of the central nervous system, in the course of which, on the basis of the autoimmune reaction against myelin and/or oligodendrocytes, numerous demyelinating foci appear in the brain and spinal cord [1]. It is a disease of early adulthood, affecting people between the ages of 20–40. It affects women 1.5 to 2 times more often than men, due to the effect of female sex hormones on the functioning of the immune system. However, this disease can appear at any age [2]. Poland belongs to the group of high risk of MS occurrence (prevalence rate within 40–80/100.000 of inhabitants). It is estimated that there are approximately 45.000 people with MS in our country, which is more than one person per 1.000 inhabitants. Annually, there are from 1.300 to 2.100 new cases [3]. Both environmental and genetic factors, as well as a complex autoimmune reaction leading to damage of the nervous system play an important role in the immunopathogenesis of MS [4].

Clinical symptoms occurring in MS are associated with damage to parts of the nervous system. Initially, they include sensory disturbances in the limbs, poor visual acuity, increasing movement disturbances and double vision. In the advanced stage of the disease, there are: spastic paresis of the limbs, cerebellar symptoms (ataxia, tremor, dysarthria, nystagmus), bladder dysfunction (urinary incontinence, urinary pressure), dysphagia, cognitive impairment, depression, as well as chronic fatigue syndrome [4].

There are basically four types of clinical course of the disease [2]:

— relapsing — remitting multiple sclerosis — RRMS,
— primary progressive multiple sclerosis — PPMS,
— secondary progressive multiple sclerosis — SPMS,
— progressive — relapsing multiple sclerosis — PRMS.

In the diagnostic process, among the tests, magnetic resonance tomography (MRI) and cerebrospinal fluid examination are the most important, in which the oligoclonal immunoglobulins and/or elevated IgG are found [4].

Three methods are indicated in the treatment of MS: treatment of relapses, therapy with modifying drugs reducing the biological activity of MS, symptomatic treatment. Available therapies prevent relapses and mitigate their effects, however, there is no effective treatment for MS that would stop the disease from progressing. New treatment methods: systemic cryotherapy, the use of stem cells, or the transdermal method consisting in sticking the patch with myelin proteins — may prove extremely beneficial in treating MS in the near future [2,4].

There are many questionnaires and tests examining various aspects of the disease and its consequences. Popular tools used to test the quality of life of MS patients are also available. These include, among others, the questionnaires: FAMS (Functional Assessment of Multiple Sclerosis Quality of Life Instrument), MSQOL-54 (Multiple Sclerosis Quality of Life-54), or SF-36 (Quality of Life-36).

The aim of the study was to determine the quality of life of patients with multiple sclerosis and to determine the relationship between the quality of life and the selected demographic, social and clinical variables.

Material and Methods

The research group consisted of patients with MS (N=100) belonging to support groups operating at the Association of Multiple Sclerosis Patients in Siemianowice Śląskie, as well as patients of the Hospital Outpatient Clinic of the Silesian Medical University in Katowice. The detailed characteristics of the research group are included in the table below (Table 1).

Table 1. Characteristics of the study group (N=100)

Variable	%
1	2
Gender	
Woman	77.0
Man	23.0
Age	
20–29 years	13.0
30–39 years	21.0
40–49 years	28.0
50–59 years	23.0
60–69 years	15.0
Place of residence	
City	76.0
Village	24.0
Marital status	
Single	26.0
Married	64.0
Widow/Widower	7.0
Divorced	3.0
Education	
Primary	–
Vocational	6.0
Secondary	60.0
Higher	34.0
Professional situation	
Professionally inactive people	56.0
Professionally active people	36.0
Unemployed/student	1.0
Time of illness	
14–23 years	26.0
24–33 years	43.0
34–43 years	16.0
44–53 years	15.0
Form of the disease	
Relapsing-remitting	64.0
Secondary progressive	13.0
Primary progressive	18.0
Primary progressive with exacerbations	5.0
Number of metastases	
1	19.0
2	8.0
None	73.0
Type of treatment	
Rehabilitation	28.0
Pharmacology	64.0
Rehabilitation+pharmacology	8.0
Source of income	
Work	43.0
Pension	43.0
Retirement	13.0
Benefit	1.0
Evaluation of the financial situation	
Good	50.0
Sufficient	34.0
Insufficient	12.0
Very good	4.0

As the analysis of the above data shows, the research group was mainly composed of women (N=77) and people aged 40–49, living in the city, being in relationships, professionally inactive, with the duration of the illness of 24–33 years, with the relapsing-remitting form of disease, without metastases, treated pharmacologically, with source of income from work and pension, who assess their financial situation well.

The FAMS questionnaire — version 4 (Functional Assessment of Multiple Sclerosis Quality of Life Instrument), by D. Cella et al. from the University Centre on Outcomes, Research and Education (CORE) from the Evanston Northwestern Healthcare in the United States was selected to measure the quality of life of multiple sclerosis patients. The FAMS questionnaire assesses patients' quality of life in 6 ranges: mobility (0–28 points), symptoms (0–28 points), emotional state (0–28 points), life satisfaction (0–28 points), thinking and fatigue (0–36 points), family and social life (0–28 points).

In terms of mobility, physical condition, work, problems with walking, movement, social activity are assessed, in the sphere of symptoms: muscle, head, joint pains, nausea, general weakness. The emotional state includes: sadness, loss of hope, being overwhelmed with the health condition, and in terms of satisfaction: the problem of fulfilment at work, acceptance of the disease, joy of life, life goals and motivation to act. Questions about thinking and fatigue address the problem of lack of energy, fatigue and rest, concentration, learning new tasks, and good family and social relationships include issues of closeness with family and friends, communication about illness or isolation from personal matters.

The main part of the questionnaire is accompanied by the Other ailments subscale (14 questions), which is used to examine the side effects of treatment, satisfaction with sex life, sleep, satisfaction and urine control, however, its results do not affect the overall score.

The obtained statements were evaluated on a 5-point Likert scale, from 0–4 points. The patient could get from 0–176 points. Based on all subscales, three levels of quality of life were distinguished: 0–57 points — bad 58–117 points — satisfactory, 118–176 points — good.

The obtained research material was subjected to statistical analysis, using the STATISTICA v12 statistical package for calculations. To calculate the variables, the following measures were used: arithmetic mean, standard deviation, variability coefficient, asymmetry coefficient, kurtosis coefficient, Person linear correlation coefficient, Spearman rank correlation coefficient.

Results

The table below (Table 2) presents the characteristics of the structure of FAMS variables together with the results of the general assessment of the quality of life of patients with MS.

The analysis of the results gave rise to the determination of high variability of the analysed variables, coefficient of variation V>20%. The skewness asymmetry coefficient was in the range of <−1, 1>, therefore it can be stated that the variables had moderately asymmetrical distributions. The concentration of individual cases around the mean ranged from <−2, 2>, which shows that the concentration of individual cases was moderate (Table 2).

Based on the collected data, it can be concluded that the respondents rated the overall quality of their lives at 111.01 points (average) with a maximum amount (173 points) and standard deviation 26.92. They rated the mobility (14.39 points) and satisfaction with life (17.19 points) the lowest. Slightly higher — symptoms (18.72 points) and family and social life (18.96 points). The highest score was obtained on the subscale covering other ailments (36.77 points) and the emotional state of the respondents (21.82 points). Thinking and fatigue were assessed at almost 20 points (19.93 points). The obtained results of the general assessment of the quality of life of the respondents — 111.1 points, covers the second level of quality of life, i.e. satisfactory, in the range of 58–117 points. The result is closer to good than bad quality of life (Table 2).

Subsequent analyses concerned the relationship between FAMS results and subscales — for this purpose, the Pearson linear correlation coefficient was used. The analysis of the results contained in the table, in all cases, provided grounds for finding statistically significant positive relationships (where the strength of the relationship was from high r>0.60 to very high r>0.8) between FAMS and the subscales. Therefore, it can be concluded that as the subscale score increased, the FAMS score also improved.

The results in Table 3 show that the strongest correlations occurred between the FAMS results and satisfaction with life (r=0.85), thinking and fatigue (r=0.80). The following remained at a high level, where r>0.60: family and social life (r=0.73), emotional status (r=0.71), other ailments (r=0.71) and mobility (r=0.69). Symptoms (r=0.38) were below the average (r=0.45).

Table 2. Results of the general assessment of the quality of life of patients with MS

	Mean	Min	Max	SD	V. coef.	Skewness	Kurtosis
The ability to move	14.39	2.00	28.00	5.83	40.54	−0.01	−0.21
Symptoms	18.72	5.00	28.00	5.37	28.70	−0.16	−0.48
Emotional state	21.82	5.00	28.00	5.76	26.38	−1.07	0.52
Satisfaction with life	17.19	1.00	28.00	6.31	36.69	−0.33	−0.41
Thinking and fatigue	19.93	1.00	36.00	8.87	44.50	0.07	−0.82
Family and social life	18.96	1.00	28.00	6.00	31.63	−0.65	−0.03
FAMS results — general quality of life	111.01	62.00	173.00	26.92	24.25	0.38	−0.31
Other ailments	36.77	25.00	52.00	6.83	18.58	0.72	−0.3

Table 3. Correlations between FAMS results and variables ($p<0.05$)

FAMS results — overall quality of life	r(X, Y)	r2	t	p
The ability to move	0.69	0.48	9.4	0.000
Symptoms	0.38	0.14	4.1	0.000
Emotional state	0.71	0.50	10.0	0.000
Satisfaction with life	0.85	0.72	15.7	0.000
Thinking and fatigue	0.80	0.63	13.0	0.000
Family and social life	0.73	0.53	10.6	0.000
Other ailments	0.71	0.51	10.1	0.000

The subject of another analysis was the relationship between the age of the respondents and FAMS variables. Table 4 illustrates data in this range ($p<0.05$). Due to the fact that one of the variables was on a rank scale, the Spearman rank correlation coefficient was used. The analyses concerned the relationship between the age range and FAMS variables.

Table 4. Correlation between age of the respondents and the FAMS variables ($p<0.05$)

Age / Variable	r_S	t(N–2)	p
The ability to move	–0.52	–6.1	0.000
Symptoms	–0.18	–1.8	0.080
Emotional state	–0.17	–1.7	0.083
Satisfaction with life	–0.45	–5.1	0.000
Thinking and fatigue	–0.27	–2.8	0.006
Family and social life	–0.31	–3.2	0.002
FAMS results — overall quality of life	–0.45	–5.1	0.000
Other ailments	–0.42	–4.5	0.000

The analysis of the data in table 4 became the basis for finding statistically significant negative correlations $p<0.05$ for almost all variables, except the relations between age and symptoms and emotional state. The results of the analysed variable decrease with the increase of the age.

The study also examined the relationships between the gender of respondents and FAMS results. For this purpose, the t-student test was used for independent tests. Table 5 illustrates the above type of relationship ($p<0.05$).

The data in Table 5 show that significant differences occurred only in the case of symptoms and thinking and fatigue, in which women had lower results than men ($p<0.05$).

Table 5. Correlation between gender of the respondents and the FAMS variables ($p<0.05$)

Gender / Variable	Mean Woman	Mean Man	t	df	p
The ability to move	14.74	13.22	1.10	98	0.274
Symptoms	17.53	22.70	–4.40	98	0.000
Emotional state	21.75	22.04	–0.21	98	0.833
Satisfaction with life	17.05	17.65	–0.40	98	0.691
Thinking and fatigue	18.66	24.17	–2.70	98	0.008
Family and social life	18.92	19.09	–0.12	98	0.909
FAMS results — overall quality of life	108.66	118.87	–1.61	98	0.111
Other ailments	36.13	38.91	–1.73	98	0.087

An important element of the study was to determine the relationship between the form of the disease and the type of treatment, and the results of FAMS (one-way analysis of variance). Table 6 illustrates those relationships in which $p<0.05$.

Table 6. Analysis of the relationship between the form of the disease and type of treatment and FAMS results ($p<0.05$)

	Disease form and FAMS results		Treatment type and FAMS results	
	F	p	F	p
The ability to move	25.45	0.00	33.04	0.000
Symptoms	4.79	0.00	7.74	0.001
Emotional state	1.32	0.27	1.40	0.252
Satisfaction with life	9.74	0.00	8.31	0.000
Thinking and fatigue	1.88	0.14	0.93	0.399
Family and social life	5.34	0.00	2.26	0.110
FAMS results — overall quality of life	7.15	0.00	7.17	0.001
Other ailments	1.50	0.22	1.86	0.160

The analysis of variance gave grounds to conclude that significant differences may occur in the case of variables: ability to move, symptoms, satisfaction with life and FAMS. To identify which groups had significant differences, Tukey's post hoc multiple comparison tests were used for unequal HSD counts (uneven N).

Discussion

Kossakowska [5] stated that "the Polish version of the FAMS questionnaire is a valuable tool for studying the quality of life conditioned by the state of health in multiple sclerosis". By standardizing the FAMS questionnaire (version 4), she conducted a study on a clinical group (N=60) and after analysing the data formulated the following conclusions: disabled patients (above 6 according to the EDSS scale) rated the quality of life the lowest in all spheres, patients with the progressive form of the disease also rated the quality of life lower, in each sphere, compared to patients with relapsing-remitting form, patients with relapsing-remitting form were more satisfied with their daily functioning and emotional support. According to Kossakowska, important determinants in the quality of life of MS patients are mobility and the form of the disease (relapsing-remitting vs. slow-progressive) [5].

In the own study conducted with the help of the FASM questionnaire — version 4, also the impact of demographic (age, gender) and clinical (form of the disease and type of treatment) factors on the quality of life of the patients were analysed. The respondents in their own study assessed their overall quality of life as satisfactory, almost good. The assessment of the quality of life was influenced by both the age and the form of the disease, as well as the type of treatment. There were no significant differences in the results of women and men, hence the conclusion that gender does not have a decisive impact on the quality of life of the respondents. In the case of the form of the disease, the existence of dependences was noted mainly in the primarily progressive and primarily progressive form with exacerbations.

In the study of the quality of life of MS patients by Stachowska et al. [6] using the MSQOL-54 questionnaire and Beck's depression scale, patients rated their quality of life as low. Assessment of depressive disorders according to the Beck's scale showed that 52% of patients did not have depression and 40% had mild depression. There was also age correlation within most of the quality of life scales. Only in the areas of pain, in health difficulties and changes in the state of health such a correlation was not observed. The study showed a strong negative correlation between the quality of life scales and the Beck's depression scale. The lower the values obtained on the life value scales, the higher the Beck's scale values. As stated in the conclusions, the assessment of the quality of life of patients with MS was affected by such factors as: gender, age, professional activity, the form of the disease, the occurrence of depressive and sexual disorders [6].

Own study showed that age affects the quality of life of patients with MS, but the gender does not. In the case of gender, only in two subscales women had lower results than men, they were: symptoms and thinking and fatigue, while in the remaining ones no differences were noted. In terms of age, it has been proven that it has a significant impact on the quality of life, because there were correlations with almost all variables except the relationship with symptoms and emotional state. As the age increases, the results of the variables decrease, which is a signal of a deteriorating quality of life in MS patients.

In another study conducted by Drewniak and Śliwka [7] assessing the quality of life of patients with confirmed MS diagnosis, the SF-36 and MSIS-29 questionnaire were used. Research has confirmed that patients with multiple sclerosis show a reduced level of quality of life. The results of the SM-36 questionnaire correlate with the level of functional efficiency and duration of the disease. This means that the longer the duration of the disease, the lower the functional efficiency that affects the quality of life of the respondents [7].

Łabuz-Roszak et al. [8] also studied the assessment of the quality of life of MS patients depending on the clinical features of the disease, the co-occurrence of the fatigue syndrome and depressive symptoms. The study showed that the quality of life is much worse in patients with MS than in other patients. Similar research results were obtained, among others, by Papuć et al. [9].

In the available literature on the subject we find data indicating that the quality of life of MS patients depends on the age, course of the disease, fitness and treatment. Older people, less physically fit, rated their quality of life much worse that younger people. There was no correlation between the duration of the disease and the quality of life. Also such factors as education, family status or professional activity did not affect the quality of life of patients. However, non-motor symptoms, i.e. fatigue and the presence of depressive symptoms had a significant impact on patients' quality of life [8].

Own study confirmed that the type of treatment affects the quality of life of patients with MS. Most often, reduced quality occurred in patients who were treated pharmacologically or only using rehabilitation. Synergy in treatment, i.e. a combination of pharmacology with rehabilitation brings much better results, also improves the quality of life of terminally ill patients.

The quality of life study conducted with the help of the FAMS questionnaire by Jabłońska et al. [10] among the MS patients found that 42% of respondents rated their overall quality of life as high (136 points). The highest scores were obtained by the following dimensions: family and social life and the emotional state. There was also a relationship between the overall assessment of the quality of life of the respondents and all dimensions of the scale used. As emphasized, gender is the only one of the analysed factors that have a significant impact on the quality of life of respondents, while clinical factors do not affect the quality of life of patients with MS [10].

Own study did not confirm the existence of a relationship between gender and quality of life in MS patients. The respondents rated the following as highest: other ailments (36.77) and emotional state (21.82), while the ability to move (14.39) as the lowest. There was also a correlation between the results of FAMS and all subscales. The strongest relationships were recorded in the subscales: "Satisfaction with life" (0.85), "Thinking and fatigue" (0.80), "Family and social life" (0.71) and "Other ailments" (0.71), and the weakest with "Symptoms" (0.38). The FAMS score increased as the subscale score improved. The higher the score, the better the quality of life of patients with MS.

Conclusions

Most of the patients with MS assessed their quality of life as satisfactory, in the absence of bad and with one-third of good assessments. The existence of links between the FAMS results and all subscales indicates that the higher the subscales rated, the higher the FAMS score, i.e. the better quality of life for MS patients. Age influences the quality of life of patients with MS. As the age increases, FAMS scores decrease, which means that the quality of life of MS patients is deteriorating. Gender does not affect the quality of life of patients with MS, because the results of women did not differ from those of men. The form of the disease determines the quality of life of patients with MS, mainly the primarily progressive and primarily progressive form with exacerbations. The type of treatment used affects the quality of life of patients with MS. Integrated pharmacological and rehabilitation activities provide better quality than just pharmacological treatment or only with the use of rehabilitation.

Implications for Nursing Practice

One of the goals of nursing care for patients with MS, especially during the hospitalization period, is to prepare the patient to function in a community environment — mainly through education about coping with disease symptoms and preventing the deteriorating of the MS symptoms, which significantly improves the quality of life of these patients.

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