Strategies of Coping with Stress and the Quality of Life in Relation to the Adherence to Therapeutic Recommendations in MS — Affected Patients

Strategie radzenia sobie ze stresem i jakość życia a przestrzeganie zaleceń terapeutycznych u chorych na stwardnienie rozsiane

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Abstract

Introduction. Multiple sclerosis (MS) is a chronic, autoimmune disease of the central nervous system, which affects young adults between 20–40 years old. The incidence of MS is increasing worldwide. The symptoms vary and depend on which part of the nervous system is affected. Stress is very common in patients with MS. It can be a risk factor related with relapses of the disease. Coping is defined as the behavioural and cognitive efforts used in an attempt to deal with stressful events. In a long-term treatment, disease modifying therapies are used to reduce the risk of the progression and severity of MS, and reduce the risk of disability. The adherence to therapy has a crucial role in the effectiveness of drugs.
Aim. The aim of the study was to assess the correlation between coping strategies and quality of life in multiple sclerosis patients depending on the degree of adherence.
Material and Methods. The study was conducted in 226 patients suffering from MS.
Results. It was demonstrated that 23.5% of respondents do not follow recommended treatments. Both adherent and non-adherent patients gave the highest grade to their quality of life in its social and psychological aspects. The most often used strategies of coping with stress both in adherent and non-adherent patients were as follows: active coping, planning, positive reframing, acceptance, seeking emotional support and seeking instrumental support. On the other hand, substance use was the least frequently used strategy, irrespective of the adherence level.
Conclusions. The use of the coping-with-stress strategy, associated with an active problem solving and seeking support, plays a positive role in the quality of life of MS patients adhering to therapeutic recommendations. The use of avoidance strategies, i.e. the not taking of actions as well as self-blaming, reduces the quality of life in MS patients, both adherers and non-adherers to recommendations. **(JNNN 2021;10(3):112–119)**
Key Words: adherence, coping with stress, multiple sclerosis

Streszczenie

Wstęp. Stwardnienie rozsiane (SM) to przewlekła, autoimmunologiczna choroba ośrodkowego układu nerwowego, która dotyka młodych dorosłych w wieku 20–40 lat. Częstość występowania SM wciąż rośnie na całym świecie. Objawy są różnorodne i zależą od umiejscowienia zmian demielinizacyjnych w układzie nerwowym. Stres jest bardzo powszechny u pacjentów ze stwardnieniem rozsianym, może być czynnikiem ryzyka związanym z nawrotami choroby. Radzenie sobie jest definiowane jako behawioralne i poznawcze wysiłki podejmowane w celu radzenia sobie ze stresującymi wydarzeniami. W długotrwałym leczeniu stosuje się terapię modyfikującą przebieg choroby w celu zmniejszenia ryzyka progresji i ciężkości SM oraz zmniejszenia ryzyka niepełnosprawności. Przestrzeganie terapii ma kluczowe znaczenie dla skuteczności leków.
Cel. Celem pracy była ocena korelacji pomiędzy strategiami radzenia sobie ze stresem i jakością życia pacjentów ze stwardnieniem rozsianym w zależności od stopnia przestrzegania zaleceń terapeutycznych.

Materiał i metody. Badania zostały przeprowadzone wśród 226 pacjentów chorych na SM.

Wyniki. Wykazano, że 23,5% badanych nie stosuje się do zaleceń terapeutycznych. Zarówno pacjenci przestrzegający zaleceń jak i nieprzestrzegający najwyżej ocenili jakość swojego życia w domenie socjalnej i psychologicznej. Najczęściej stosowanymi strategiami radzenia sobie ze stresem zarówno u pacjentów przestrzegających zaleceń jak i nieprzestrzegających było: aktywne radzenie sobie, planowanie, pozytywne przewartościowanie, akceptacja, poszukiwanie wsparcia emocjonalnego i poszukiwanie wsparcia instrumentalnego. Natomiast najrzadziej stosowaną strategią niezależnie od poziomu przestrzegania zaleceń terapeutycznych było zażywanie substancji psychoaktywnych.

Wnioski. U pacjentów chorych na SM przestrzegających zaleceń terapeutycznych stosowanie strategii radzenia sobie ze stresem związanych z aktywnym rozwiązywaniem problemu oraz poszukiwaniem wsparcia pozytywnie wpływa na ich jakość życia. Stosowanie strategii unikowych tj. zaprzestanie działań, jak i obwinianie się obniża jakość życia chorych na SM zarówno stosujących się do zaleceń, jak i u tych pacjentów, którzy nie przestrzegają zaleceń. **(PNN 2021;10(3):112–119)**

Słowa kluczowe: przestrzeganie zaleceń terapeutycznych, radzenie sobie ze stresem, stwardnienie rozsiane

Introduction

Multiple sclerosis (MS) is a chronic, inflammatory autoimmune disease of the central nervous system. The estimated global incidence accounts for about 2.8 million people worldwide [1]. MS is the most common cause of disability in young adults. The onset of the symptoms is between 20–40 years of age, with a higher prevalence in women. The etiology of the disease is unknown. The symptoms of the disease are variable and related with the localization of the demyelination lesion. The most common symptoms include unilateral retrobulbar neuritis, weakness of limbs, sensory disturbances, brainstem and cerebellar syndromes (dysartria, intranuclear ophthalmoplegia, diplopia, vertigo, hearing impairment, ataxia, gait instability) and bladder dysfunction (urinary urgency, urge incontinence). Other symptoms include cognitive impairment, fatigue and mood disturbances [2].

MS is an unpredictable disease with many stressful events for patients. Stressful factors in life are associated with an increased risk of exacerbation in patients with multiple sclerosis [3]. The problem of stress in MS is knowing about it. The studies about the effects of stress in MS shown that the relationship is complex and dependent on a variety of factors [4–6]. The stress probably has an impact on the disease by changes in the endocrine and immunological system via the hypo-thalamic-pituitary-adrenal axis (HPA) [7]. The chronic character of the disease and related with this level of stress, causes difficulties in personal life and social roles. Generally, patients with MS need activity to reduce a stressful situation [8]. There are many ways of coping with stress. According to the COPE inventory, coping strategies can be divides into two group: problem-focused and emotion-focused methods [9]. In patients with MS the pattern of coping strategies depend on the individual, as well as clinical and psychological factors including gender, educational level, clinical course, mood and mental status, attitude, personality traits, and religious beliefs [10,11].

In the clinical course of the disease we can distinguished two main forms: relapsing-remitting and progressive [12]. The most common form of MS is relapsing-remitting MS (RRMS) affecting 85% of patients. In RRMS typically relapses of symptoms are observed, with periods of remission occurring in between. The primary progressive (PPMS) type of MS occurs in 5–15% of cases and is characterized by the slow progression of symptoms and disability, without relapses. In the classification of both of the forms the progression and activity of the disease are considered [12]. MS is an incurable, long-term disease, which affects the quality of life of patients [13]. The treatment of MS is based on pharmacological treatment, psychological support and rehabilitation. The drugs used for MS include the treatment of relapses, symptomatic treatment and disease-modifying therapy (DMT). The goal of DMT therapy in MS is the reduction of disease activity and reduced risk of disability. The DMT includes injection drugs (interferon, glatiramer acetate), oral therapy (teriflunomide, fingolimod, dimethyl fumarate) and monoclonal antibodies (natalizumab, ocrelizumab, alemtuzumab) [14]. In chronic therapy adherence is very important as it has an influence on the results of the treatment. The term adherence means the extent to which patients take medications as prescribed by their doctor. The rate of adherence is important, especially in the case of a chronic disorder. A low level of adherence to the DMT is associated with poor clinical outcomes, higher rates of relapse, disease progression and higher costs of treatment [15].

The aim of the study was to assess the correlation between coping strategies and quality of life in multiple sclerosis patients depending on their degree of adherence.

Material and Methods

Study Design

A cross-sectional descriptive design with a questionnaire survey was used. The study was conducted among 166 women and 60 men with MS with mean age of 37.3±9.68 years (range 19–64 years). All patients were treated with first-line DMT at four neurological centres in Wroclaw, Poland. Patients who met the inclusion criteria filled out the questionnaires during control visits in neurological centres (when they get their medicine for the next month).

The vast majority of respondents were female (71.53%). The detailed characteristics of the study group are presented in Table 1. Patients were identified as non-adherent (non-ADH) if they missed one or more dose in the 28 days prior to completing the survey [16].

Table 1. Characteristics of the study group

Variable	%
1	2
Gender	
Women	71.53
Men	28.47
Place of residence	
Village	29.48
City up to 100,000 inhabitants	22.07
City from 100,000 to 500,000 inhabitants	10.10
City over 500,000 inhabitants	38.35
Marital status	
Married	59.16
Single	38.74
Widow/Widower	2.1
Education	
Primary	10.49
Secondary	37.60
Higher	51.91
Professional activity	
Blue-collar worker	14.56
White-collar worker	57.49
Annuitant	17.09
Student	7.15
Unemployed	3.71
Socioeconomic status	
Low	15.93
Medium	76.16
High	7.91

Table 1. Continued

1	2
Disease duration	
Up to 1 year	4.20
1–5 years	28.09
6–10 years	39.41
11 years and more	28.30

Qualification Criteria

Inclusion criteria were 1) a confirmed diagnosis of relapsing-remitting MS (RR-MS) based on medical records, 2) taking first-line DMT drugs (Avonex, Rebif, Betaferon, Extavia, Copaxone or Tecfidera), 3) treatment for at least six months prior to participation in the study, 4) age over 18 years, and 5) written informed consent prior to participation in the study. Exclusion criteria were 1) progressive forms of MS, 2) confirmed diagnosis of RR-MS but not taking first-line DMT drugs (Avonex, Rebif, Betaferon, Extavia, Copaxone or Tecfidera), 3) treatment initiated less than six months before participation in the study, 4) severe cognitive impairment (patients unable to follow the test instructions), and 5) lack of written consent to participate in the study.

Research Instruments

Data collection and measurement tools used in this study included two standardized questionnaires: Mini-COPE [17] and the Polish version of BREF WHO Quality of Life Questionnaire [18] and an Authors-Designed Questionnaire (ADQ). A semi-structured and self-administered questionnaire designed by the authors was an original and unstandardized survey for sociodemographic data collection (e.g., age, sex, place of residence, education, marital status, financial status, and duration of illness).

1. Inventory for Measuring Coping with Stress (Mini-COPE)

In order to determine stress-coping strategies, the Polish version of the Mini-COPE was applied [17]. The Mini-COPE consists of 28 statements, which are divided into 14 categories of coping with stress: active coping, planning, positive reframing, acceptance, sense of humour, turning to religion, seeking emotional support, seeking instrumental support, self-distraction, denial, venting, substance use, behavioural disengagement and self-blame.

2. WHO Quality of Life Questionnaire [18]

It was developed in Polish by a team of specialists from Poznań [19]. It covers four areas of life, including physical and mental states, social relationships and the environment. The physical domain, also referred to as somatic, included factors such as: the presence of pain, the level of demand for treatment, the degree of satisfaction with rest and sleep, but also the complacency of daily productivity at work and in private life. The psychological domain takes into account the satisfaction of the patient with the patient's own appearance, the patient's complacency of life and the frequency of feelings such as depression, anxiety, despair, depression and joy. The social domain takes into account relationships with other people and the support of relatives close to the MS patient. The environmental domain includes the sense of security, housing conditions and financial condition of the patient, ability to pursue interests, accessibility to health care and communication. The tool also contains two questions that are analysed individually: the first concerns the self-assessment of the patient's quality of life, and the second individual perceptions of the patient's state of health.

Ethical Considerations

The study was approved by the Bioethics Committee of the Wrocław Medical University in Wrocław, Poland (KB-444/2016). All patients included in the study were informed of its purpose, timeline and requirements. They were also informed of the option to withdraw from participation at any stage. All patients provided signed informed consent at the start of the study. This was a cross-sectional descriptive study thus the STROBE guidelines (Strengthening the Reporting of Observational Studies in Epidemiology) were followed.

Statistical Analysis

Statistical analysis was performed using Statistica 13 (StatSoft, Dell Inc., Tulsa, OK, USA) under the license of Wrocław Medical University, Poland. For the measurable variables, the arithmetic mean (X) and SD were calculated, and for non-measurable variables, the percentages (%) were calculated. All quantitative variables were tested using the Shapiro–Wilk test to determine the type of distribution. The nonparametric Mann–Whitney U test was used to compare the results between groups for continuous variables, and the chi-squared test was used

for categorical data. Correlations of EDSS, Mini-COPE and WHOQoL domains for ADH and non-ADH patients were calculated using the Spearman correlation coefficient. For all comparisons, the level of α=0.05 was assumed, and the obtained P-values were rounded to four decimal places.

Results

It was demonstrated that 23.5% of respondents do not follow the recommended treatments. Regarding sociodemographic variables, there were no statistically significant differences between adherent and non-adherent patients. Both adherent and non-adherent patients gave the highest grade to their quality of life in its social and psychological domains. The most often used strategies of coping with stress both in adherent and non-adherent patients were as follows: active coping, planning, positive reframing, acceptance, seeking emotional support and seeking instrumental support. On the other hand, substance use was the least frequently used strategy, irrespective of the adherence level. The analysis of the research material has not revealed any significant differences between adherent and non-adherent patients in the evaluation of satisfaction from life and a general quality of life (Table 2), as well as the quality of life in respective domains and ways of coping with stress (Table 3).

We have found the existence of a correlation between selected methods of coping with stress and the quality of life domains in patients adhering to the therapeutic recommendations. Patients who actively cope with stress, plan how to cope with stressful situations and use a positive overestimation technique, experience a greater

Table 2. Comparison of quality of life and satisfaction with life for ADH and non-ADH patients

	Variable		ADH		non-ADH		p-value
			N	%	N	%	
WHOQoL	The self-assessment of the quality of life	Very bad	1	1	1	2	0.103
		Bad	5	3	4	8	
		Neither good nor bad	57	33	14	26	
		Good	92	53	23	43	
		Very good	18	10	11	21	
	Individual perceptions of the state of health	Very dissatisfied	7	4	2	4	0.569
		Dissatisfied	46	27	12	23	
		Neither satisfied nor dissatisfied	70	41	19	36	
		Satisfied	39	23	13	25	
		Very satisfied	11	6	7	13	

Table 3. Comparison of results and domains of WHOQoL and Mini-COPE scale for ADH and non-ADH patients

	Variable	ADH (N=173)					non-ADH (N=53)					p-value*
		$\bar{x}$	Me	Min	Max	SD	$\bar{x}$	Me	Min	Max	SD	
WHOQoL	Physical domain	13.2	12.6	6.9	20.0	2.8	13.9	14.3	6.9	20.0	3.3	0.111
	Psychological domain	14.4	14.7	7.3	20.0	2.7	14.4	14.7	6.0	20.0	3.1	0.931
	Social Relationships domain	14.4	14.7	5.3	20.0	3.0	14.7	14.7	6.7	20.0	3.4	0.627
	Environment domain	14.0	14.0	7.4	20.0	2.5	13.9	14.0	6.5	19.0	2.9	0.961
Mini-COPE	Active coping	1.9	2.0	0.0	3.0	0.8	2.0	2.0	0.0	3.0	0.8	0.538
	Planning	1.8	2.0	0.0	3.0	0.8	1.9	2.0	0.0	3.0	0.8	0.369
	Positive reframing	1.8	2.0	0.0	6.0	1.0	1.7	2.0	0.0	3.0	0.8	0.863
	Acceptance	2.0	2.0	0.0	3.0	0.8	1.9	2.0	0.0	3.0	0.8	0.356
	Sense of humour	0.9	1.0	0.0	3.0	0.7	1.0	1.0	0.0	3.0	0.7	0.514
	Turning to religion	0.9	0.5	0.0	3.0	1.0	1.0	0.5	0.0	3.0	1.0	0.680
	Seeking emotional support	1.9	2.0	0.0	3.0	0.9	2.0	2.0	0.0	3.0	0.8	0.381
	Seeking instrumental support	1.6	1.5	0.0	3.0	0.8	1.7	1.5	0.0	3.0	0.8	0.462
	Self-distraction	1.5	1.5	0.0	3.0	0.8	1.6	2.0	0.0	3.0	0.9	0.758
	Denial	0.8	0.5	0.0	3.0	0.8	0.8	0.5	0.0	3.0	0.8	0.851
	Venting	1.3	1.5	0.0	3.0	0.7	1.3	1.5	0.0	3.0	0.7	0.703
	Substance use	0.3	0.0	0.0	3.0	0.7	0.4	0.0	0.0	3.0	0.7	0.496
	Behavioural disengagement	0.7	0.5	0.0	3.0	0.7	0.6	0.5	0.0	2.0	0.6	0.552
	Self-blame	0.9	1.0	0.0	3.0	0.7	0.9	1.0	0.0	2.5	0.7	0.961
	EDSS	1.8	2.0	0.0	8.0	1.6	1.5	1.0	0.0	6.0	1.7	0.153

N — number of people; $\bar{x}$ — mean; Me — median; Min — minimum value; Max — maximum value; SD — standard deviation; *Mann–Whitney U test

Table 4. Correlations of EDSS, coping strategies and WHOQoL domains for ADH patients

	WHOQoL							
Variable	Physical domain		Psychological domain		Social relationships domain		Environment domain	
	r_S	p	r_S	p	r_S	p	r_S	p
EDSS	−0.48	<0.000	−0.24	<0.002	−0.19	0.015	−0.28	<0.000
Active coping	0.14	0.062	0.33	<0.001	0.26	0.001	0.14	0.069
Planning	0.16	0.033	0.35	<0.001	0.31	<0.001	0.18	0.020
Positive reframing	0.22	0.003	0.35	<0.001	0.38	<0.001	0.21	0.006
Acceptance	0.01	0.936	0.21	0.007	0.20	0.010	−0.00	0.977
Sense of humour	0.16	0.033	0.23	0.003	0.24	0.002	0.17	0.022
Turning to religion	−0.08	0.325	0.13	0.080	0.06	0.433	−0.05	0.502
Seeking emotional support	0.10	0.202	0.29	<0.001	0.41	<0.001	0.26	<0.001
Seeking instrumental support	0.06	0.465	0.25	0.001	0.28	<0.001	0.22	0.004
Self-distraction	0.06	0.456	0.17	0.024	0.14	0.057	0.06	0.450
Denial	−0.16	0.038	−0.18	0.019	−0.19	0.013	−0.06	0.419
Venting	−0.10	0.204	−0.12	0.131	−0.08	0.303	−0.01	0.856
Substance use	−0.00	0.969	−0.09	0.220	−0.08	0.270	0.02	0.778
Behavioural disengagement	−0.31	<0.001	−0.40	<0.001	−0.41	<0.001	−0.13	0.085
Self-blame	−0.14	0.062	−0.40	<0.001	−0.32	<0.001	−0.15	0.042

r_S — Spearman correlation coefficient, significant differences (p<0.05) are shown in bold

Table 5. Correlations of EDSS, coping strategies and WHOQoL domains for non-ADH patients

Variable	WHOQoL							
	Physical domain		Psychological domain		Social relationships domain		Environment domain	
	r_S	p	r_S	p	r_S	p	r_S	p
EDSS	−0.57	<0.000	−0.28	0.045	−0.18	0.201	−0.28	0.041
Active coping	−0.03	0.833	0.23	0.098	0.16	0.260	0.33	0.015
Planning	0.12	0.375	0.01	0.921	0.11	0.415	0.16	0.255
Positive reframing	0.19	0.181	0.10	0.488	0.13	0.349	0.14	0.306
Acceptance	0.19	0.182	0.30	0.027	0.15	0.295	0.33	0.015
Sense of humour	0.05	0.735	0.17	0.232	0.19	0.173	0.18	0.200
Turning to religion	0.18	0.205	0.10	0.461	0.09	0.526	0.16	0.262
Seeking emotional support	0.17	0.215	0.32	0.019	0.41	0.003	0.35	0.010
Seeking instrumental support	−0.12	0.394	0.21	0.123	0.25	0.076	0.33	0.015
Self-distraction	0.06	0.670	−0.11	0.434	−0.07	0.599	−0.01	0.968
Denial	−0.07	0.632	−0.04	0.797	−0.02	0.905	0.02	0.881
Venting	−0.03	0.831	−0.20	0.157	−0.19	0.181	−0.13	0.343
Substance use	−0.33	0.017	−0.14	0.321	−0.05	0.706	−0.07	0.632
Behavioural disengagement	−0.39	<0.004	−0.41	0.002	−0.43	0.001	−0.29	0.036
Self-blame	−0.03	0.833	−0.48	<0.001	−0.35	0.011	−0.30	0.031

r_S — Spearman correlation coefficient, significant differences ($p < 0.05$) are shown in bold

quality of life both in psychological and social domains. In contrast, we have found no relationship between active methods of coping with stress and the quality of life in the non-adherers to the therapeutic recommendations (Table 4 and 5).

Moreover, we have found that seeking emotional and instrumental support in stressful situations improves the evaluation of the quality of life within psychological, social and environmental domains in patients adhering to the therapeutic recommendations. Conversely, no relationship between the ways of coping with stress, based on seeking support, and the quality of life has been observed in non-adherers (Table 4 and 5).

The research material analysis has revealed that the use of avoidance strategies, i.e. the stoppage of taking actions as well as self-blaming, reduces the quality of life in MS patients, in both adherers and non-adherers to the recommendations (Table 4 and 5).

Discussion

The goal of disease modifying therapy in multiple sclerosis is to reduce the activity and progression of the disease. The long-term therapy in the case of MS, a chronic disease, is a kind of challenge. Adhering to therapeutic recommendations in MS patients is a key factor to achieve the best possible treatment effects manifested by the diminution of new attacks and the inhibition of disease progression [20]. The adherence is independently associated with several factors such as gender, characteristics of a drug, satisfaction from the treatment [21]. One of the factors connected to a good therapeutic effect and a high level of adherence is the coping strategy [22]. Coping is defined as behavioural and cognitive efforts used in an attempt to deal with stressful events [23].

To the best of our knowledge, both in Poland and in the world, this is the first study evaluating the relationship between coping-with-stress strategies and the quality of life depending on the degree of adherence in MS patients treated with immunomodulatory drugs.

The study material analysis has revealed that the most commonly used strategies of coping with stress in MS patients are active coping, planning, positive reframing, acceptance, seeking emotional support and seeking instrumental support. On the other hand, substance use was the least frequently used strategy, irrespective of the adherence level, which is in line with the findings of Holland et al. [24], Cornero Contentti et al. [25], Kołtuniuk et al. [11], Kotas et al. [10] and Santangelo et al. [26].

Patients with an increased use of problem-focused coping strategies represent a better HRQoL [27,28]. The use of mechanisms based on acceptance and active engagement, such as active coping [11,29], planning [29], emotional and instrumental social support [11,29] and acceptance [29,30], has been associated with a higher

QoL in MS patients. Our study has also confirmed these findings, however only in adherent patients. A study by Garay-Sevilla et al. [31], conducted in type 2 diabetic patients, has demonstrated that patients who look for support, better comply with treatment and adherence to medication. This phenomenon was associated with supporting coping styles.

Strategies such as behavioural disengagement [29,30], denial [11,30], self-controlling [32], escape avoidance [32], distancing [32], venting [11] and substance use [11] were also associated with a lower QoL. Our study has demonstrated that substance use, behavioural disengagement and self-blame strategies were also associated with a lower QoL in both adherent and non-adherent MS patients across various domains. Aldebot et al. [33] reported that that a greater denial in coping is associated with a poorer medication adherence in schizophrenia. A study by Aksoy et al. [34] revealed that patients with bipolar disorders preferring passive coping ways have smaller drug compliance rates. Also, de Brito et al. [35], who thoroughly studied patients with renal grafts taking immunosuppressants, proved that the use of palliative coping pattern (religion/fantasy thoughts and emotion — focused coping) was associated with a non-adherence in those patients. Understanding coping strategies before treatment may allow a personalized support during long-term management of the disease and may improve an adherence to treatment. Patients who exaggerate the consequences of SM are more likely to choose the coping-with-stress strategy oriented to emotions and, as a result, reduce self-management activities. Contrary to that, increasing a problem-solving attitude promotes activities related to the involvement of MS-affected patients in the process of treatment and rehabilitation [36].

Conclusions

The use of coping-with-stress strategy, connected to an active problem solving and seeking support exerts a positive effect on the quality of life in patients adhering to therapeutic recommendations.

Implications for Nursing Practice

A nurse taking care of the patient using disease-modifying therapy should recognize the level of stress and coping strategy used by the patient. A better understanding of the role of coping strategy and other factors contributing to disease-modifying drug non-adherence could improve clinical outcomes and quality of life of patients with MS.

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