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Assessment of the Quality of Life in Patients with Multiple Sclerosis

Ocena jakości życia pacjentów chorych na stwardnienie rozsiane

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Abstract

Introduction. Each progressive incurable disease has an impact on the level and quality of life of those affected, on their family, professional and social roles. Multiple sclerosis is an incurable and progressive disease of the central nervous system. The ambiguous course of the disease, the multiplicity of symptoms and the periodicity of relapses and remissions not only have a negative effect on the body, but also have a significant impact on the subjective assessment of life satisfaction.

Aim. The main aim of the research was to examine the quality of life among patients suffering from multiple sclerosis.

Material and Methods. The study involved 105 patients with multiple sclerosis of the Sandomierz Neurology Center. An original survey questionnaire was used as a research tool.

Results. The analysis of the research results showed that the highest percentage of the respondents suffered from a relapsing-remitting form, mostly young people diagnosed between the ages of 21 and 40. Patients complain of many symptoms related to individual symptoms (movement, sensory, vegetative disorders, visual disturbances). Limitations resulting from physical disability create many problems in the lives of patients. The research shows that their quality of life decreased along with the deterioration of their mobility.

Conclusions. Most patients with multiple sclerosis misjudge the quality of their lives in all its spheres. The lowering of the quality of life is mainly influenced by the health condition, disorders of many organs, advanced disability, psychological disorders, lack of sufficient support from the family, specialist and institutional support. **(JNNN 2021;10(2):58–64)**

Key Words: multiple sclerosis, patients, quality of life

Streszczenie

Wstęp. Każda postępująca nieuleczalna choroba wywiera wpływ na poziom i jakość życia osób nią dotkniętych, na ich role rodzinne, zawodowe i społeczne. Stwardnienie rozsiane jest nieuleczalną i postępującą chorobą ośrodkowego układu nerwowego. Niejednoznaczny przebieg choroby, mnogość objawów oraz okresowość rzutów i remisji nie tylko wpływają negatywnie na organizm, ale również mają istotny wpływ na subiektywną ocenę satysfakcji z życia.

Cel. Głównym celem podjętych badań było zbadanie jakości życia wśród pacjentów chorych na stwardnienie rozsiane.

Materiały i metody. W badaniu wzięło udział 105 pacjentów ze stwardnieniem rozsianym Sandomierskiego Ośrodka Neurologii. W pracy jako narzędzie badawcze zastosowano autorski kwestionariusz ankiety.

Wyniki. Analiza wyników badań wykazała że największy odsetek badanych cierpi na postać rzutowo-remisyjną, w większości są to ludzie młodzi, u których diagnozę postawiono między 21 a 40 r.ż. Chorzy skarżą się na występowanie wielu objawów ze strony poszczególnych objawów (występują zaburzenia ruchowe, czuciowe, wegetatywne, zaburzenia widzenia). Ograniczenia wynikające z niepełnosprawności fizycznej stwarzają w życiu pacjentów wiele problemów. Z badań wynika, że wraz z pogorszeniem się sprawności ruchowej obniżała się ich jakość życia.

Wnioski. Chorzy na stwardnienie rozsiane w większości źle oceniają jakość swojego życia we wszystkich jego sferach. Na obniżenie jakości życia wpływa przede wszystkim stan zdrowia, zaburzenia ze strony wielu narządów, zaawansowana niesprawność, zaburzenia natury psychologicznej, brak dostatecznego wsparcia ze strony rodziny, wsparcia specjalistycznego i instytucjonalnego. **(PNN 2021;10(2):58–64)**

Słowa kluczowe: stwardnienie rozsiane, pacjenci, jakość życia

Introduction

Each progressive, incurable disease has an impact on the level and quality of life of people affected by it, on their family, social and social roles. Multiple sclerosis is an incurable disease of the nervous centers. The ambiguous course of the disease, multilevel multiplicity and periodicity of relapses and remissions not only have a negative effect on the body, but also is intended for subjective assessment of the state of life [1,2].

Multiple sclerosis (Latin sclerosis multiplex — MS) is a chronic and progressive disease of the demyelinating nervous center. The essence of the disease of the brain and spinal cord. The degree of clinical severity and the dynamics of their development vary, and the course is individual [3].

About 2.5 million people worldwide suffer from multiple sclerosis. The first symptoms appeared between 20 and 40 years of age. It happens, however, that the law already in adolescence, and even in childhood, as well as after 50 or 60 years of age. MS affects women more than men. It usually occurs in people living in a temperate and cool climate and in a country with a developed civilization [4,5].

Multiple sclerosis, it can be of various forms, the symptoms of the disease depend on where, from the central nervous system, the disease occurs. There is no pattern of the course of the disease in multiple sclerosis. Each person has a different syndrome that, even in the same person, changes over time in terms of intensity and experience [5,6].

The quality of life, the view, the view of the world should be considered subjectively. Patients with multiple sclerosis have to deal with numerous problems with the help of the motor sphere, as well as mental and social help, which significantly affects their quality of life. Without testing that multiple sclerosis is one of the diseases that negatively affect human existence, failure due to the activity of individual, physical and social activity [7].

The effect of multiple sclerosis is the period of the patient's independence, mental reaction and impaired social functioning. Some people with MS interpret multiple sclerosis as a loss-making disease for all services. They describe it in the context of "the need to say goodbye to everything" and treat it as a disease "leading to the loss of the loan's personality traits" [1].

The main aim of the research was to examine the quality of life among patients suffering from multiple sclerosis.

Material and Methods

The subject of the research was the assessment of the quality of life among patients suffering from multiple sclerosis.

The research was carried out at the Specialist Hospital of the Holy Spirit in Sandomierz, in the Neurology Center. The hospitalized patients were examined with the written consent of the Hospital Management and the Head of the Department, as well as the respondents themselves. The survey was anonymous and voluntary.

105 multiple sclerosis patients who were hospitalized at the Neurology Center were examined. The deadline for the tests is December 2018 and January–February 2019.

To conduct the research in this study, the diagnostic survey method was used. In this work, surveying was used as a research technique. The survey questionnaire consisted of a record and 31 basic questions. He was anonymous.

In the questionnaire, patients were asked about their age, marital status, type of disease, ailments related to the disease, and the bio-psychosocial sphere.

For the purposes of this study, a statistical survey was used. The Pearson chi-square coefficient χ^2 ($p \leq 0.05$) and the correlation coefficient were used for the statistical analysis of the research results, including the verification of the adopted hypotheses.

Results

The study was conducted in a group of 105 people diagnosed with MS. Among the respondents, 66.7% were women, the remaining percentage was men (33.3%). The age of the respondents was defined in five age groups (Table 1). Most of them are young people, most people are aged 31–40 (34.29%). The largest group among the respondents were people with secondary (44.76%) and higher education (33.34%). The smallest group were people with vocational (16.19%) and primary (5.71%) education.

Table 1. Structure of the studied population by age

Sex / Description	Women (N=70)	Men (N=35)	Together	
			N=105	%
From 30 years of age	20	8	28	26.70
31–40	24	12	36	34.29
41–50	20	11	31	29.51
51–60	4	3	7	6.60
60 years and more	2	1	3	2.90
Overall	70	35	105	100

In the surveyed population, 70 (67%) respondents live in the city, the remaining 35 (33%) live in the countryside. When considering the respondents in terms of marital status, it was found that the largest number were married people 71, which constitutes 67.70% of the respondents. The next group were unmarried (16.10%), divorced (7.60%), living in a partner relationship (6.70%), separated (1.90%). The vast majority of the respondents (67.62%) are retired, while 16.19% of the total declare that they work full-time. The remaining respondents continue to learn or study (9.52%), work part-time (4.77%). Unemployment is declared by 1.90% of respondents. The diagnosis was most often made in the age group 21–30 years of age (70.48%), 50 women and 24 men were diagnosed with MS in this MS. In the largest number of 52 (49.52%) respondents the disease has a relapsing-remitting form (37 of which are women and 15 men). The secondary progressive form was diagnosed in 23 (21.90%) subjects. A total of 21 (20%) subjects were treated for primary progressive disease, including 9 (8.58%) subjects who had progressive-relapsing form.

In 36 (34.30%) respondents relapses occur every few years. 24 women and 12 men replied. Less frequently than once a year, relapses occur in 27 (25.72%) respondents. In 25 (23.80%) patients there are no clear relapses, the disease progresses. The relapse occurs once a year. A total of 17 (16.19%) respondents answered this question.

Hypothesis 1: It is Assumed that the Health Status of Multiple Sclerosis Patients Affects their Quality of Life

51.43% of the respondents assessed their quality of life as bad or very bad, 33.33% estimated their quality of life as average, while only 15.24% of the respondents said that their quality of life was good or very good. The subjects were asked to evaluate their current health condition. Only 9.52% of the respondents consider their health to be good, the rest describe their current health as average (49.53%), bad (31.43) and very bad (9.52%).

The conducted study proved the existence of a statistically significant influence of the current health status on the quality of life of patients at the level of p=0.001 (Table 2).

Table 2. The impact of health on the quality of life

How do you assess your current health condition	How would you rate your quality of life?					
	Very good/good (N=16)		Very bad/bad (N=54)		Average (N=35)	
	N	%	N	%	N	%
Very bad	4	25	6	11.2	0	0
Bad	10	63.5	22	40.7	1	2.8
Neither good nor bad	2	12.5	21	38.9	29	82.9
Good	0	0	5	9.2	5	14.3
Independence test			0.001			

Hypothesis 2: Multiple Sclerosis Patients are Assumed to Complain of Health Disorders

The analysis carried out in terms of disorders accompanying the disease showed that MS is the most common cause of chronic fatigue, complained of by 39.04% of respondents. The respondents also often indicated muscle weakness (16.20%), mood disorders (12.40%), paraesthesia, numbness (9.54%). Only 3.80% of the respondents indicated spasticity as a difficulty in everyday functioning. The respondents very often (51.44%) complain about pain and health problems that hinder professional work and everyday functioning. Rarely or very rarely, 12.37% of respondents experience pain.

The conducted study proved the existence of a statistically significant dependence of many disorders on the part of individual systems accompanying the disease p=0.012, the frequency of pain disturbing work p=0.012 and the quality of life of the respondents (Table 3, Table 4).

Table 3. Health disorders and quality of life

What disorders accompanying the disease bothers the most	How would you rate your quality of life?					
	Very good/good (N=13)		Very bad/bad (N=54)		Average (N=38)	
	N	%	N	%	N	%
Spasticity	0	0	0	0	4	10.5
Muscle weakness	6	46.2	11	20.3	0	0
Chronic fatigue	5	38.4	23	42.6	13	34.4
Blurred vision	0	0	3	5.6	3	7.9
Paresthesia	0	0	5	9.2	5	13.1
Imbalance and gait disturbance	0	0	3	5.6	5	13.1
Mood disorder	2	15.4	6	11.1	5	13.1
Bladder disorder	0	0	3	5.6	3	7.9
Independence test			0.012			

Table 4. Pain incidence and quality of life

How often pain interferes with your work	How would you rate your quality of life?					
	Very good/good (N=16)		Very bad/bad (N=54)		Average (N=25)	
	N	%	N	%	N	%
Never	1	6.25	1	1.8	0	0
Very rarely	2	12.5	3	5.7	0	0
Rarely	4	25	4	7.4	0	0
Often	5	31.25	20	37	11	31.4
Very often	4	25	26	48.1	24	68.6
Independence test			0.012			

Hypothesis 3: Multiple Sclerosis is Assumed to be the Cause of Negative Feelings: Depression, Sadness, Anxiety and Stress

The respondents were asked about the frequency of negative feelings such as: depression, sadness, anxiety, depression. The analysis of the conducted research shows that 45 (42.85%) of the respondents very often experience negative feelings.

The results concerning the quality of life assessed through the prism of mental functioning prove the existence of a statistical dependence between the experience of negative psychological feelings, i.e. anxiety, stress, depression, depression, and the quality of life at the level of p=0.001. Respondents expressed the opinion that multiple sclerosis destructively affects their mental state through negative feelings (Table 5).

Hypothesis 4: It is Assumed that the Sick Require Help in Meeting their Life Needs

The respondents were asked whether self-service activities such as daily washing and dressing are difficult. The obtained data show that 37.14% have difficulties with dressing and washing, while 24.78% are unable to dress and wash themselves without the help of another person. I dress and wash as well as before my illness — said 23.80% of the respondents. 37.14% of the respondents move on their own, 22.86% with the use of crutches, and 17.15% with a walking frame. 17.15% of the surveyed people use a wheelchair. I am a lying person — this was what 5.70% answered.

Table 5. The frequency of experiencing negative feelings and the quality of life

Do you often experience negative feelings, i.e. depression, sadness, anxiety, depression?	How would you rate your quality of life?					
	Very good/good (N=16)		Very bad/bad (N=54)		Average (N=35)	
	N	%	N	%	N	%
Very often	9	56.25	25	46.3	11	31.4
Often	0	0	11	20.4	15	42.9
Rarely	2	12.5	15	27.7	7	20
Very rarely	5	31.25	3	5.6	2	5.7
Independence test			0.001			

Table 6. Efficiency in meeting the needs and the quality of life

Efficiency in meeting the needs	How would you rate your quality of life?					
	Very good/good (N=16)		Very bad/bad (N=54)		Average (N=35)	
	N	%	N	%	N	%
I dress and wash as well as before my illness	8	50	14	26	3	8.6
Washing and dressing is difficult for me	1	6.25	18	33.3	20	57
Due to illness, sometimes I cannot dress and wash without the help of another person	2	12.5	16	29.7	8	22.9
I cannot alone, I can hardly wash myself	5	31.25	6	11	4	11.5
Independence test			0.001			

The conducted analysis confirmed that the main problem of patients with multiple sclerosis is overcoming the physical ailments associated with the disease. This is indicated by the strong correlation between the level of physical fitness and the quality of life. The conducted study proved the existence of a statistical dependence in terms of the efficiency in satisfying life needs — p=0.001 and the patient's way of moving (motor activity) — p=0.009, and the quality of life (Table 6, Table 7).

Table 7. Motor skills and the quality of life

How do you move	How would you rate your quality of life?					
	Very good/good (N=16)		Very bad/bad (N=54)		Average (N=35)	
	N	%	N	%	N	%
Independently	9	56.25	24	44.5	6	17
With the help of bullets	0	0	8	14.9	16	46
Using a walking frame	2	12.5	10	18.5	6	17
Wheelchair	4	25	9	16.6	5	14
I am a lying person	1	6.25	3	5.5	2	6
Independence test	0.009					

Hypothesis 5: It is Assumed that Patients with Multiple Sclerosis Require Support

The study showed that the quality of life depends in a statistically significant manner on specialist help (p=0.002) and family support (p=0.042) (Table 8, Table 9).

Table 8. Using family support and the quality of life

Is the family a support for you?	How would you rate your quality of life?					
	Very good/good (N=13)		Very bad/bad (N=54)		Average (N=38)	
	N	%	N	%	N	%
Supports me a lot	7	41	24	44.4	10	29.5
Supports me on average	2	11.5	17	31.5	16	47
Supports me little	6	36	11	20.4	3	9
There is no family support	2	11.5	2	3.7	5	14.5
Independence test	0.042					

Table 9. Use of specialist help and the quality of life

Do you use specialist help?	How would you rate your quality of life?					
	Very good/good (N=16)		Very bad/bad (N=54)		Average (N=35)	
	N	%	N	%	N	%
Physiotherapist	10	62.5	37	68.6	28	80
Guardian/assistant of a disabled person	0	0	0	0	2	5.7
Community nurse	1	6.25	14	26	5	14.3
Psychologist	1	6.25	1	1.8	0	0
Psychiatrist	4	25	1	1.8	0	0
Does not use	0	0	1	1.8	0	0
Independence test	0.002					

Discussion

The quality of life is defined by WHO as: "the sense of an individual as to his/her life position in the cultural aspect and in the aspect of the adopted value system in which he lives, in relation to his achievements, expectations, standards and interests" [8]. The assessment of the quality of life is a measure of the life situation. The incidence of multiple sclerosis in European countries during the year is estimated at approximately 4.3 cases per 100,000 inhabitants [4]. Multiple sclerosis is a disease that affects mainly young people, fully developing their professional career, in the process of gaining material wealth, realizing personal and family plans. It usually begins at a young age, in the period of the most active professional, social and family life.

The symptoms associated with multiple sclerosis are the result of defects in various parts of the central nervous system that are spread over time and place. Apart from sensory disorders, the occurrence of pyramidal and cerebellar syndromes, nystagmus, neurological disorders, fatigue, and visual disturbances, other emotional states may appear — depressive or euphoric, cognitive disorders, and pain syndromes [9].

The analysis of the test results showed:

1. The quality of life of the respondents in the physical dimension:

The highest percentage of the respondents suffered from relapsing-remitting — 52 people, secondary progressive — 23 people, primary progressive — 21 people. Similar data on the frequency of the occurring forms of the disease were obtained in the works of Łabuz-Roszak et al. [8]

The vast majority of these are young people diagnosed between the ages of 21–40. Relapses of the disease occur at different time intervals several times a year, every year, every few years. Similar studies were carried out by Łabuz-Roszak and associates [8].

Patients complain of many symptoms from particular systems. There are movement disorders (limb paresis, ataxia), sensory disorders (persistent paraesthesia, hypoaesthesia, hyperesthesia), cranial nerves (oculomotor paralysis, visual disturbances, trigeminal neuralgia), vegetative disorders, balance and gait disorders, visual disturbances, bladder disorders, spasticity. One of the underestimated, but very troublesome symptoms of the disease is fatigue, which is described in up to 90% of patients. Similar results were obtained by Olek and Dawson who conducted research on the quality of life in multiple sclerosis [10].

Limitations resulting from physical disability create many problems in life, specific to disabled people, e.g. self-service activities: getting dressed, daily body toilet, hygiene maintenance. Patients suffer from motor disorders and therefore require the help of other people. Most of the time, they require frequent hospitalization and systematic medication. This was confirmed by the studies by Talarska and Brzozowska, which in their research on the quality of life of patients with multiple sclerosis showed that the quality of life is not a constant value, it may increase and decrease depending on various factors. One of them was the mobility of patients. The research shows that their quality of life decreased with the deterioration of their mobility [11].

2. The psychological level of the quality of life of the respondents:

Functional disturbances resulting from increasing disability significantly deteriorate the quality of life in patients with multiple sclerosis, but mood disorders also have a significant impact on the patient's well-being. The emergence of the disease usually has long-term consequences, including treatment, coping with the side effects of treatment, reduced quality of life, and often also reduced ability to work and less social contact. The consequences of the disease lead to the loss of meaning in life. People with multiple sclerosis often experience negative feelings such as depression, sadness, anxiety, and depression. It was also reflected in the research by Talarska and Brzozowska [11].

3. The level of the quality of life of the respondents in the social dimension:

The conducted research confirmed the impact of factors such as family support on the quality of life, but did not confirm the institutional support and professional activity of the respondents. Other researchers made a different observation. Bruk I. in his considerations on the importance of social support in chronic diseases describes that the demand for social support increases rapidly in difficult situations and it is easier then to observe its effects. There is a belief in the social consciousness that the kind presence of other people has a beneficial effect on the health and well-being of an individual [12].

Conclusions

Most people suffering from multiple sclerosis are young people who have an average and poor assessment of their quality of life in all areas of life. Physically, mentally and socially. They see through the prism of their disability, their handicap and lack of prospects for further life.

The conducted research allowed to draw the following conclusions:

1. The health condition of patients with multiple sclerosis affects their quality of life.
2. Patients with multiple sclerosis complain of health disorders.
3. Multiple sclerosis causes negative feelings: depression, sadness, anxiety and stress.
4. The sick require help in satisfying their life needs.
5. Patients with multiple sclerosis require the support of a specialist physiotherapist, nurse, psychologist, doctor and family support.

Implications for Nursing Practice

Creating health-supporting environments allows the chronically ill to overcome the difficulties associated with the disease more easily. The functioning of the social support system in the local environment is essential for the perceptible improvement in the quality of life of chronically ill patients. In hospital conditions, support is provided by medical personnel. It is usually instrumental support, consisting in specific instructions on how to proceed the patient during the relapse, and informational support, which is the exchange of information allowing the patient to better understand the situation in which he has found himself, his life situation and problems. Research confirms that patients with multiple sclerosis expect the greatest support from their families, physiotherapists, nurses, caregivers, doctors and psychologists [12]. The role of a nurse in the treatment of patients with multiple sclerosis consists in an active function in the processes of: controlling the patient's health, monitoring the side effects of the applied trap and its effectiveness (improving the neurological and functional condition of the patient), educating and supporting the patient and his family, as well as managing the patient. through the process of multiple sclerosis therapy during and after hospitalization.

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