THE INFLUENCE OF SELECTED SOCIODEMOGRAPHIC FACTORS ON THE QUALITY OF LIFE OF PATIENTS WITH MULTIPLE SCLEROSIS

WPŁYW WYBRANYCH CZYNNIKÓW SOCJODEMOGRAFICZNYCH NA JAKOŚĆ ŻYCIA CHORYCH NA STWARDNIENIE ROZSIANE

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ABSTRACT

Introduction. Multiple sclerosis (MS) is a chronic demyelinising disease with numerous clinical signs, such as: balance and coordination disorders, visual disturbances, muscle weakness, paresis, feeling of chronic fatigue, mood disorders, genitourinary dysfunction, spasticity and paresthesias.
Aim. Analysis of the influence of sociodemographic factors on the quality of life of patients with multiple sclerosis.
Material and methods. The research covered 105 patients and was conducted at St. Luke´s Regional Hospital and in the Multiple Sclerosis Association in Tarnow in 2015. The criterion for inclusion was medical diagnosis of multiple sclerosis and the voluntary consent of the patient to participate in the research. The study used: the EQ-5D (Health related quality of life questionnaire), the EQ-VAS (EuroQol-visual analogue scale), the EDSS (Kurtzke Expanded Disability Status Scale) and the authors' original questionnaire.
Results. High self-esteem regarding their own health condition and higher quality of life in all dimensions were shown more often by people with full functional efficiency (p <0.0001). The research analysis showed that 65.7% of the people reported no problems in terms of self-care. Younger people significantly more frequently had no problems with mobility (p = 0.0006), self-care (p = 0.0328). Also, anxiety or depression were less frequent among them (p = 0.0022). People with higher education were less likely to feel pain / discomfort (60.9%).
Conclusions. Self-assessment of the quality of life of the respondents depends significantly on age, marital status, education and the source of livelihood.

KEYWORDS: multiple sclerosis, quality of life.

STRESZCZENIE

Wstęp. Stwardnienie rozsiane (*sclerosis multiplex* – SM) jest przewlekłą chorobą demielinizacyjną o licznych objawach klinicznych, takich jak: zaburzenia koordynacji i równowagi, zaburzenia widzenia, niedowłady, nasilone zmęczenie, zaburzenia nastroju, spastyczność czy parestezje.
Cel. Analiza wpływu czynników socjodemograficznych na jakość życia chorych na stwardnienie rozsiane.
Materiał i metody. Badanie przeprowadzono wśród 105 pacjentów Szpitala Wojewódzkiego im. św. Łukasza oraz członków Stowarzyszenia Stwardnienia Rozsianego w Tarnowie w 2015 roku. Kryterium włączenia było rozpoznanie SM oraz dobrowolna zgoda chorego na udział w badaniu. W badaniu posłużono się Skalą EQ-5D (Health related quality of life questionnaire), Skalą EQ-VAS (EuroQol-visual analogue scales), Rozszerzoną Skalą Niewydolności Ruchowej Kurtzkego (EDSS) oraz kwestionariuszem ankiety własnego autorstwa.
Wyniki. Wysoką samoocenę własnego stanu zdrowia oraz wyższą jakość życia we wszystkich wymiarach miały częściej osoby w pełni wydolne funkcjonalnie (p < 0,0001). Analiza badań wykazała, że 65,7% osób nie zgłaszało problemów w zakresie samoopieki. Osoby młodsze istotnie częściej nie miały problemów z mobilnością (p = 0,0006), samoopieką (p = 0,0328). Rzadziej występował u nich również niepokój czy przygnębienie (p = 0,0022). Osoby z wykształceniem wyższym rzadziej odczuwały ból/dyskomfort (60,9%).
Wnioski. Samoocena jakości życia badanych zależy istotnie od wieku badanych, stanu cywilnego, wykształcenia oraz źródła utrzymania.

SŁOWA KLUCZOWE: stwardnienie rozsiane, jakość życia.

Introduction

Multiple sclerosis (MS) is a chronic demyelinising disease with numerous clinical signs, such as: balance and coordination disorder, visual disturbances, muscle weakness, paresis, the feeling of chronic fatigue, mood disorders, genitourinary dysfunction, spasticity and

paresthesias which negatively affect the quality of patients' life. The intensification of the symptoms of the disease, motor disability in particular, causes limitations in social contacts, decreases professional activity, and in consequence, influences the lowering of the quality of such patients' life. MS affects not only the patient, but also his/her family, friends and the environment in which he or she lives [1, 2, 3].

What is characteristic for MS is the progressive character of the disease, which brings about gradual degradation of physical fitness with critical thinking ability usually fully maintained. It is a serious problem worldwide, and in the countries with high morbidity rate, including Poland, it is one of the most frequent reasons of disability of young people between 20 and 40 years old. The disease affects women twice as often as men. In Poland it is assumed that around 40 thousand people suffer from multiple sclerosis [1, 4, 5].

The aim of the paper is to assess the impact of sociodemographic factors on the quality of life of patients with multiple sclerosis.

Material and methods

The study was conducted from March to May 2015 among patients of the neurology ward and the neurological centre of St. Luke's Regional Hospital, and among members of the Multiple Sclerosis Association in Tarnow. The criterion for inclusion was the clinical diagnosis of multiple sclerosis and the patient's voluntary consent to participate in the research. The study used the diagnostic pool method, a questionnaire technique. Moreover, the following were used: the EQ-5D (Health related quality of life questionnaire) for self-rating of the quality of patients' life, the EQ-VAS (EuroQol-visual analogue scale) for the overall assessment of the respondents' health state, and the EDSS (Kurtzke Expanded Disability Status Scale) to assess the clinical condition of the participants. Also the authors' original questionnaire was applied. The differences among variables were verified with the use of the chi-square independence test, the Mann-Whitney U test and the Kruskal-Wallis test. The significance level p<0.05 was adopted. The calculations were made with the IBM programme SPSS Statistics 20.

The group of the respondents consisted of 105 people (41% were men, 59% were women). The most numerous group were people aged 31–40 (33.3%). The participants aged 41 to 50 and above 50 constituted two groups of 25.7%. There were 14.3% of patients aged 20 to 30, and individuals below 20 years old made up only 1% of the respondents. For 50.5% of the respondents the place of residence was the country, and the remaining patients (49.5%) indicated the city. There were

63.8% of married people, whereas single people made up 16.3% of the studied group. Divorced people made up 12.4% of the respondents, and widows/widowers were 7.6% of the respondents. The majority of the study participants had secondary education (47.6%), then vocational education (29.5%), higher education (21.9%) and primary education (1%). Among the respondents, 73.3% had children, 46.7% of the overall number were employed, 53.3% were not. In 42.9% patients MS was diagnosed when they were 21-30. Less than one-fourth of the respondents (24.8%) had the disease diagnosed when they were 31-40, in 12.4% it was diagnosed when they were below 20, in 12.4% – when they were 41-50, and for 7.6% the diagnosis took place when they were above 50 years old. Among the respondents, people suffering from MS for up to 10 years prevailed (from 6 to 10 years – 33.3%; from 1 to 5 years – 28.6%). One-fifth of the survey participants (20%) were ill for 11 to 15 years, whereas 8.6% of the respondents – for more than 20 years.

Results

The quantification of motor disability conducted in accordance with the Kurtzke Expanded Disability Status Scale proved that 23.8% of patients had symptoms of minimal disability (they obtained 2 points in the EDSS). No disability, with minimal neurological signs present was indicated by 15.2% of the respondents (1.5 points), whereas 14.3% of the patients showed moderate disability (**Figure 1**).
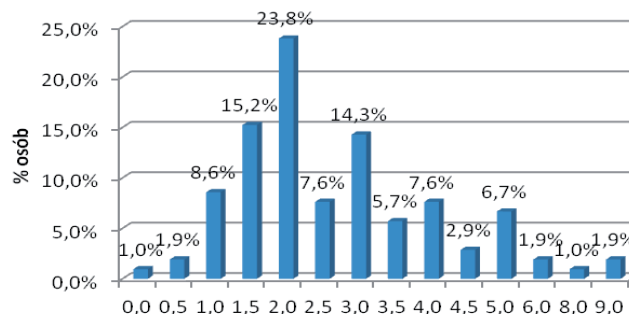

Figure 1. Results of the Kurtzke EDSS
Source: author's own analysis

45.7% of patients needed assistance with some everyday activities, 7.6% of the respondents were totally unable to care for themselves. Almost everybody (94.3%) could count on the support from the family and friends. The influence of the family support was appreciated by 81.9% of the respondents. The expectations of the study participants towards family and friends concerned the need for mental support (70.5%), more understanding (48.6%), assistance in everyday activi-

ties (43.8%), as well as attention and care (21.0%). To a lesser extent they expected financial support (8.6%).

In the case of 58.1% of responding patients, the disease did not change their contacts with other people. According to 20% of the respondents, as a result of the disease, the contacts worsened significantly. The participation in meetings with friends a few times a week was declared by 25.7% of the respondents. Occasional contacts with friends were indicated by 32.4% of patients, whereas 12.4% of the respondents did not take part in such meetings. More than one-fifth of the participants (21.9%) reported the feeling of loneliness. Frequent contacts with other people suffering from MS were only declared by 18.1% of the respondents, occasional – by 43.8% of people. The respondents who did not keep such contacts constituted 38.1% of the total number.

In the opinion of 80% of patients, help from state institutions in our country is insufficient for people suffering from MS and the disabled. Less than a half of the respondents (47.6%) claimed that it is absolutely insufficient, 7.6% did not use this kind of help in the past. On the other hand, 12.4% considered such help sufficient. Taking advantage of the MS treatment programme refunded by the National Health Fund was declared by 74.3% of the respondents. Other patients (25.7%) did not use the programme.

The respondents assessed their own health differently. 19% of the patients assessed it high, 64.8% thought it was moderate, and 16.2% of the respondents regarded it low. The research analysis proved that 65.7% of patients did not report any problems with self-care. 36.2% of the study participants did not have any problems with pain/discomfort, and 34.3% with mobility. 28.6% of the respondents did not signal anxiety and depression. On the other hand, as many as 66.7% patients declared that they felt anxious and depressed, had problems with mobility (61.9%), felt pain/discomfort (61%) and had difficulties with undertaking activities (52.4%) and self-care (29.5%). An extreme problem, according to respondents, was undertaking everyday activities (5.7%), self-care (4.8%), anxiety and depression (4.8%), mobility (3.8%), and, to the least extent, pain/discomfort (2.9%) (**Figure 2**).

An analysis of the collected data enabled to find out that younger people significantly more frequently had no problems with mobility (p=0.0006), self-care (p=0.0328). Anxiety or depression did not occur in their case (p=0.0022), either. Lower quality of life in those dimensions was experienced more often by people above 40. The age of the patients did not influence everyday activities undertaken by them and the feeling of pain/discomfort.
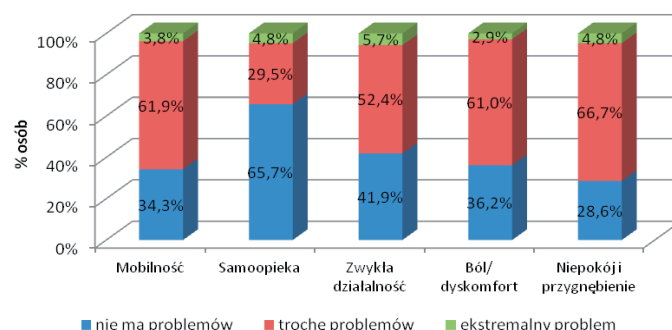

Figure 2. Life quality of the surveyed patients (the EQ-5D scale)

Source: author's own analysis

Mobilność – Mobility
Ekstremalny problem – Extreme problem
Zwykła działalność – Everyday activities
Ból/dyskomfort – Pain/Discomfort
Niepokój i przygnębienie – Anxiety and depression
Nie ma problemów – No problem
Trochę problemów – Some problems
Samoopieka – Self-care

The study results indicated that women (62.9%) more often than men (58.1%) had problems with undertaking everyday activities. They experienced pain and discomfort more often (69.4%) than men (51.2%). Anxiety and depression were also experienced more often by women (74.2%) than by men (41.9%) (**Table 1**).

Table 1. Sex of the surveyed patients and their life quality

Category of life quality		Sex				p
		Female		Male		
		N	%	N	%	
Mobility	no problems	16	25.8	20	46.5	0.0840
	some problems	43	69.4	22	51.2	
	extreme problems	3	4.8	1	2.3	
Self-care	no problems	39	62.9	30	69.8	0.5615
	some problem	19	30.6	12	27.9	
	extreme problems	4	6.5	1	2.3	
Routine activity	no problems	19	30.6	25	58.1	**0.0190**
	some problems	39	62.9	16	37.2	
	extreme problems	4	6.5	2	4.7	
Pain/discomfort	no problems	16	25.8	22	51.2	**0.0154**
	some problems	43	69.4	21	48.8	
	extreme problems	3	4.8	0	0.0	
Anxiety and depression	no problems	12	19.4	18	41.9	**0.0352**
	some problems	46	74.2	24	55.8	
	extreme problems	4	6.5	1	2.3	

Source: author's own analysis

The research showed that anxiety and depression at the extreme level were experienced more often by country dwellers (9.4%). City dwellers (36.5%) did not report this problem (p < 0.0253). It was also found that single people significantly more often experienced no problems with mobility, self-care, pain/discomfort or anxiety or depression. The problems occurred more often in the remaining respondents – **Table 2**.

Table 2. The quality of life and the marital status of the respondents

Category of life quality		Marital status								p
		Single		Married		Widow/ Widower		Divorced		
		N	%	N	%	N	%	N	%	
Mobility	no problems	11	64.7	23	34.3	1	12.5	1	7.7	
	some problems	6	35.3	43	64.2	6	75.0	10	76.9	**0.0045**
	extreme problems	0	0.0	1	1.5	1	12.5	2	15.4	
Self-care	no problems	15	88.2	47	70.1	3	37.5	4	30.8	
	some problems	2	11.8	18	26.9	4	50.0	7	53.8	**0.0140**
	extreme problems	0	0.0	2	3.0	1	12.5	2	15.4	
Routine activity	no problems	10	58.8	31	46.3	1	12.5	2	15.4	
	some problems	7	41.2	33	49.3	6	75.0	9	69.2	0.0812
	extreme problems	0	0.0	3	4.5	1	12.5	2	15.4	
Pain/Discomfort	no problems	10	58.8	24	35.8	1	12.5	3	23.1	
	some problems	7	41.2	42	62.7	7	87.5	8	61.5	**0.0235**
	extreme problems	0	0.0	1	1.5	0	0.0	2	15.4	
Anxiety and depression	no problems	11	64.7	16	23.9	0	0.0	3	23.1	
	some problems	6	35.3	49	73.1	7	87.5	8	61.5	**0.0033**
	extreme problems	0	0.0	2	3.0	1	12.5	2	15.4	

Source: author's own analysis

In effect of the research it was found out that people with higher education more often felt no pain/discomfort (60.9%). The problem occurred significantly more frequently in other respondents (p < 0.0375). No other statistically significant differences between the respondents' quality of life and education were found out.

The self-rating of health state (the VAS) significantly differentiated the quality of life of the study participants (p<0.0001). The people who assessed their health better had also a better quality of life in individual dimensions. With the drop of health self-assessment, also the quality of respondents' life decreased.

People with full functionality had more often higher self-assessment of their own health and higher quality of life in all dimensions (p<0.0001). The analysis of own research proved that the patients in whom the disease had the relapsing-remitting form did not have any problems with mobility, self-care, everyday activities, pain/discomfort. In the patients with the following forms of MS: primary progressive, secondary progressive and progressive relapsing, problems connected with the quality of life occurred more often – **Table 3**.

Table 3. The quality of life and the form of MS

Category of life quality		Form of SM								p
		Relapsing-remitting form		Primary progressive form		Secondary progressive form		Progressive relapsing form		
		N	%	N	%	N	%	N	%	
Mobility	no problems	31	49.2	4	20.0	0	0.0	1	7.7	
	some problems	30	47.6	16	80.0	7	77.8	12	92.3	**0.0002**
	extreme problems	2	3.2	0	0.0	2	22.2	0	0.0	
Self-care	no problems	47	74.6	13	65.0	1	11.1	8	61.5	
	some problems	14	22.2	6	30.0	6	66.7	5	38.5	**0.0083**
	extreme problems	2	3.2	1	5.0	2	22.2	0	0.0	
Routine activity	no problems	36	57.1	6	30.0	0	0.0	2	15.4	
	some problems	25	39.7	13	65.0	6	66.7	11	84.6	**0.0001**
	extreme problems	2	3.2	1	5.0	3	33.3	0	0.0	
Pain/discomfort	no problems	30	47.6	6	30.0	0	0.0	2	15.4	
	some problems	32	50.8	14	70.0	7	77.8	11	84.6	**0.0007**
	extreme problems	1	1.6	0	0.0	2	22.2	0	0.0	
Anxiety and depression	no problems	22	34.9	3	15.0	1	11.1	4	30.8	
	some problems	38	60.3	17	85.0	6	66.7	9	69.2	0.0643
	extreme problems	3	4.8	0	0.0	2	22.2	0	0.0	

Source: author's own analysis

Patients taking advantage of the MS treatment programme refunded by the National Health Fund more often had high and moderate self-assessment of their health. The quality respondents' life in terms of mobility (p = 0.0003), self-care and everyday activities (p < 0.0001), pain/discomfort (p = 0.0021), as well as anxiety and depression (p = 0.0002) was lower in patients who did not take advantage of the MS treatment refunded by the National Health Fund.

The authors' own research proved that respondents who had MS diagnosed in older age more often experienced a few problems with mobility, everyday activities, pain/discomfort, depression and anxiety. Respondents who had MS diagnosed in younger age more often had no problems with the mentioned spheres of life or more often the intensification of the their problems was considerable – **Table 4**.

Table 4. The quality of life and the age at which MS was diagnosed

Category of life quality		Age at which MS was diagnosed		p
		Average	SD	
Mobility	no problems	27.06	8.53	**0.0003**
	some problems	35.23	10.38	
	extreme problems	27.50	12.34	
Self-care	no problems	30.80	9.67	0.1520
	some problems	35.52	11.71	
	extreme problems	29.60	11.67	
Routine activity	no problems	28.32	8.58	**0.0039**
	some problems	35.45	11.00	
	extreme problems	29.67	10.44	
Pain/ discomfort	no problems	27.37	8.66	**0.0012**
	some problems	35.09	10.46	
	extreme problems	29.33	14.43	
Anxiety and depression	no problems	29.03	11.58	**0.0074**
	some problems	33.99	9.89	
	extreme problems	24.80	4.76	
Total		32.13	10.53	

Source: author's own analysis

What results from the research is that people who rated their physical activity higher had fewer problems with mobility, self-care, everyday activities ($p < 0.0001$) and experienced less pain/discomfort ($p = 0.0004$). Problems of life quality in these areas occurred more often in people who were less physically active.

Discussion

Quality of life is a term which is very differently defined, therefore, in medicine the term Health Related Quality of Life (HRQoL) has been introduced. The problem of the quality of life is the area of interest of numerous scientists all over the world. The intractability of multiple sclerosis and a broad scope of symptoms concerning the majority of the spheres of life definitely lower the quality of those patients' functioning.

The analysis of the conducted research proved that the quality of life of patients with MS depends on many factors, such as age, the course of the disease, fitness and the applied treatment. Younger people with the relapsing-remitting form of the disease, with a lower score in the EDSS, treated immunomodulatorily, included in the programme refunded by the National Health Fund, assessed their quality of life better than older people with the progressing form of the disease, with lower functionality, with a higher score in the EDSS, and not included in the treatment. The relationship between the age, the course of the disease, fitness, the applied treatment and the assessment of the quality of life is also emphasised by the findings of the research conducted by Łabuz-Roszak and associates [6]. In the research carried out by Jabłońska and associates the relationship was not confirmed [7].

As the own research findings proved, most often patients expect mental support (70.5%), and a great majority of them (94.3%) confirm that they can count on the support from their families and friends. It helps them to survive difficult moments connected with the disease, and, in addition, it performs a therapeutic function because it gives an opportunity to express their own thoughts and describe difficulties which the disease carries. The findings are also confirmed by other authors. In her research, Kossakowska proved that patients with MS search for support among their relatives and friends, and the strategy is correlated with the sex of patients. Women expected support, asked for help, were able to talk about their problems or met in support groups more often [8].

Own research showed that men with moderate self-assessment of their own health more often claimed that support of the family considerably improved their quality of life with the disease. Such a relationship was not found in the group of women. A lot of the surveyed people (45.7%) declared a need for assistance with some everyday activities. It depended significantly on the marital status of the respondents (p=0.0095), the source of income (p=0.0007), possessing children

(p = 0.0432). The patients who were more mobile in terms of basic everyday activities assessed the quality of their life better. Similarly, Humańska and associates in their research proved that patients who were fitter assessed the quality of their life higher in the somatic, psychological, social and environmental area [10].

What arises from the conducted research is that the self-assessment of the quality of life (the EQ-5D scale), significantly influenced the overall quality of life. In the mobility dimension, some problems were experienced by 61.9% of patients, extreme problems were reported by 3.8% of the respondents. In the self-care aspect, problems were declared by 65.7% of the respondents, in the dimension of everyday activities problems were reported by 52.4%. Pain and discomfort were experienced by 61.0%. The respondents assessed their emotional state as low. More than a half said that they were sadder and more depressed (66.7%). Few respondents (4.8%) reported that they felt very intensified anxiety and depression. In the dimension of each sphere of life of the respondents, more than a half had problems which determined the overall assessment of the quality of life. The research also showed that in the group of women, self-assessment of their own health was more often moderate, and among men it was more often high. Men significantly more often indicated the lack of problems connected with everyday activities, pain/discomfort, and they experienced anxiety and depression more seldom.

Self-assessment of health (EQ-VAS scale) significantly differentiated the respondents' quality of life. People who assessed their health higher had also a better quality of life in individual dimensions. With the drop in the self-assessment of health, the respondents' quality of life also decreased. This is also confirmed by other authors, for example Jabłońska and associates proved that patients who had a positive mood, assessed their quality of life higher [7].

The analysis of own research indicated that nearly half of the patients noticed the worsening of their health in comparison with the period a year before. Similar results concerning a change in the assessment of health state was presented by Kowalik in her work [11]. The authors' own research did not prove that the duration of the disease significantly differentiates self-assessment of patients' own health. Low self-assessment of own health was declared by 16.2% of people, moderate by 64.8% and high by 19.0% of the surveyed patients. Similarly as in the case of other authors [6, 11], no relationship between the duration of the disease and the quality of life of the patients was proved.

To sum up, however, it should be emphasised that the subjective assessment of the quality of life is not a constant value and may undergo a change depending on numerous factors. The worsening of the mobility of the patient, as well as a worse emotional state can be such a factor. Therefore, it should be remembered that regardless of the level of the disease progression, patients are very sensitive and their self-esteem depends on themselves and the people in the nearest environment.

Conclusions

1. Self-assessment of the respondents' quality of life depends significantly on the age of patients, their marital state, education and the source of income.
2. The quality of respondents' life decreases with the drop of the self-assessment of the health state.
3. Younger and single people less frequently experienced problems with mobility, self-care and everyday activities. People above 40 years old had lower quality of life in those dimensions.

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