Psychiatr. Pol. 2017; 51(5): 923–935

PL ISSN 0033-2674 (PRINT), ISSN 2391-5854 (ONLINE)

www.psychiatriapolska.pl

DOI: https://doi.org/10.12740/PP/64709

Quality of life and social support in patients with multiple sclerosis

Katarzyna Rosiak, Paweł Zagożdżon

Department of Hygiene and Epidemiology, Medical University of Gdansk

Summary

Aim. Quality of life and need for social support in persons diagnosed with multiple sclerosis (MS) are to a large extent determined by the degree of their disability. The aim of the study was to analyze an association between specific forms of MS, subjectively perceived quality of life and social support.

Method. The study included subjects with established diagnosis of MS, treated at rehabilitation centers, hospitals and in a home setting, as well as the members of patient organizations. After being informed about objectives of the study, type of included tasks and way to complete them, each participant was handed out a set of questionnaires: Berlin Social Support Scales (Łuszczyńska, Kowalska, Schwarzer, Schulz), Quality of Life Questionnaire (WHO-QOLBREF), as well as a survey developed specifically for the purposes of this project. The results were subjected to statistical analysis with STATA 12 package.

Results. The study included a total of 110 persons (67 women and 43 men). Quality of life overall, as well in physical, psychological, social relationships and environmental health domains, turned out to be particularly important in patients with primary-progressive MS. Irrespective of MS type, social support overall did not play a significant role on univariate analysis. However, subgroup analysis according to sex demonstrated that men with MS received social support four times less often than women.

Conclusions. Quality of life in individuals with primary-progressive MS is significantly lower than in patients presenting with other types of this disease. Men with MS are more likely to present with worse scores for social support overall. They are less likely both to acknowledge the need for support and to realize the availability of support they actually need.

Key words: multiple sclerosis, social support, quality of life

Introduction

Although multiple sclerosis (MS) is widespread worldwide, due to yet unknown reasons, its incidence is geographic latitude-specific. No etiological factor for MS has been identified thus far. MS is a chronic progressive disease of the central nervous

system and the most common neurological cause of disability in the young people. Its symptoms include leg paresis, optic neuritis, ataxia, spasticity, and speech disorders [1]. Due to such spectrum of symptoms, MS may negatively affect the cognitive sphere. MS is twice as prevalent in women as in men, and since no efficient treatment has been found thus far, represents a lifelong disease [2]. The outcome of the disease is unpredictable and varies from subject to subject. However, information on the type of MS present in a given patient may be helpful in establishing prognosis and implementing appropriate treatment.

As both the diagnosis and the disease itself have many devastating consequences, social support plays an important role in life of every MS patient.

The issue of support is within the scope of interest of authors representing various scientific disciplines – psychologists, sociologists, psychiatrists, and pedagogues. Support is defined as resources received due to interactions with other people [3]. Typically, three types of resources are being identified in the context of support. The first of them is emotional support (i.e., attention, understanding of patients' emotions and most of all, promoting their self-esteem). Equally important is informative support, i.e., an advice helping patients to understand their medical problems, etiology and management thereof – this is the second type of resources. The third type, practical support, provides patients with physical and financial help and help necessary for specific activities [4]. This enables them to develop an optimal way to achieve their life objectives that have been modified due to the disease. The developed solutions should enable them to succeed, show them new possibilities to achieve intrinsic balance and give them motivation to satisfy their individual needs [5].

Researchers showed that social support may promote health through attenuating negative psychological consequences of stress.

The possibility of achieving support influences cognitive assessment of a stressor and ability to cope with the latter. Furthermore, close relationships with others may stimulate positive emotions and confidence that the support will be available in future as well [3]. In this study, we analyzed social support as perceived available support, need for support, support seeking, actually received support and protective buffering support.

An important aspect of many patients' life is its quality, which can vary considerably due to obvious reasons. Quality of life is always assessed subjectively and to a large extent depends on mental status, personality traits, system of values, etc. Definitions of the quality of life vary depending on the specialty of their authors. Most often, however, quality of life is defined as a degree of one's satisfaction with his/her life and wellbeing. The term health-related quality of life was introduced by Schipper [as cited in: 6]. This author demonstrated that health status exerts a considerable effect on human life and functioning, i.e., on the quality of life. The definition and measures of quality of life are still a matter of discussion. In medical sciences, this term corresponds to the definition of health that has been approved by the World Health Organization (WHO), according to which "health is a state of complete physical, mental and social

wellbeing and not merely the absence of disease or infirmity". In 1994, the World Health Organization Quality of Life (WHOQOL) Group has been created within the WHO structures. This body defined quality of life as "individuals' perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns. It is a broad ranging concept affected in a complex way by the person's physical health, social relationships and their relationship to salient features of their environment" [7].

The quality of life in MS patients was first examined in 1950 [8]. Research on this matter is important not only for the evaluation purposes, but also for the identification of factors that may improve or worsen quality of life. Quality of life is a multifaceted construct comprised of at least three broad domains: physical, psychological and social one [9]. In this study, we additionally considered an environmental health domain of the quality of life.

The aim of the study was to analyze an association between specific forms of MS, subjectively perceived quality of life and social support.

Method

The study included subjects treated at the Rehabilitation Centers for MS patients in Borne Sulinowo and Dabek, outpatients from the Provincial Specialist Hospital in Gdansk, members of the Polish Multiple Sclerosis Society and individuals remaining in their home setting. The study was conducted between March 2014 and December 2014. The inclusion criteria of the study were: diagnosis of MS confirmed on the basis of McDonald's criteria and at least a 2-year history of the disease. After being informed about objectives of the study, type of included tasks and way to complete them, each participant was handed out a set of questionnaires: Berlin Social Support Scales (Łuszczyńska, Kowalska, Schwarzer, Schulz), Quality of Life Questionnaire (WHOQOL-BREF) as well as a survey developed specifically for the purposes of this project.

The Berlin Social Support Scales (A. Łuszczyńska, M. Kowalska, R. Schwarzer, U. Schulz) is a measure of received social support. It includes 38 statements, each scored on a scale from 1 to 4, where 1 means that a given statement is completely false, and 4 that it is completely true. The questionnaire comprises five independent subscales to measure perceived available support, need for support, support seeking, actually received support, and protective buffering support.

The Quality of Life Questionnaire (WHOQOL-BREF) is composed of 26 questions regarding life, health and other domains, e.g.: "How would you rate your quality of life?", "How much do you enjoy life?", "How safe do you feel in your daily life?", "How satisfied are you with your sleep?", etc. The answer to each question can be: "Not at all", "A little", "A moderate amount", "Very much" or "Extremely". The questionnaire is designed to determine quality of life of the respondents in psychological, physical, environmental and social domain.

Authors' original survey used in this study included 33 questions. It was used to collect information about various characteristics of patients, such as age, sex, origin, current place of residence, education, socioeconomic status, occupation, family medical history, group of blood, past diseases, frequency of infections. Moreover, the survey contained questions about the diagnosis, clinical course and symptoms of MS.

Most patients have completed the questionnaires by themselves, and only few (8 participants) required assistance of another person. All participants were ascertained about an anonymous and voluntary character of the study and signed respective informed consent forms. The protocol of the study was approved by the Local Bioethics Committee at the Medical University of Gdansk. All collected data were archived on specially prepared forms and then recorded in an electronic database.

Characteristics of the patients were stratified according to four types of MS they have been diagnosed with: relapsing-remitting, secondary-progressive, primary-progressive, and progressive-relapsing one. The analyzed characteristics included sex, age, family history of MS in the first – and second-degree relatives, history of childhood diseases, blood group, etc. Also relationships between quality of life (QoL) and the type of MS, and between the type of MS and social support broken down into: perceived available support, need for support, support seeking, actually received support and protective buffering support) were analyzed.

As some participants did not respond to all the study questions, the cumulative number of answers for various parts of the survey varied.

The results were subjected to statistical analysis with STATA 12 package. Statistical characteristics of continuous variables were presented as means and their standard deviations (SD), and characteristics of qualitative variables as percentages. If their distribution was normal, statistical characteristics of continuous variables were compared using the Student's t-test (for two groups) or one-way analysis of variance (for more than two groups). If the distribution was not normal, statistical characteristics of patients with various MS types were compared using the Kruskal-Wallis test. Distributions of categorical variables were compared using χ^2 test. The results were considered significant at p < 0.05. The results regarding quality of life and social support were analyzed depending on the MS type after stratifying patients into two groups according to the obtained result on a respective scale: below the 50^{th} percentile or equal to the median or higher. Then, univariate and multivariate logistic regression analyses were conducted to determine odds ratios (OR) and their 95% confidence intervals for the decreased scores (below the 50^{th} percentile) in patients with various MS types.

Results

The study included a total of 110 persons, among them 67 women and 43 men. Mean age of the study subjects was 50.97 years; the youngest participant was 18 years old, and the oldest one was 67 years old. Mean duration of the disease was: 10.61 years for relapsing-remitting MS, 19.32 years for secondary-progressive MS, 13.05 years for

primary-progressive MS, and 13.86 years for progressive-relapsing MS. Nearly a half of the respondents – 56 (51.38%) had secondary education; 38 persons (34.86%) had higher, 13 (11.93%) – vocational and 2 (1.83%) – primary education. Two subjects did not answer the question about their educational level. The study group included 68 (61.81%) married persons, 9 (8.33%) widowers/widows, 21 (19.44%) singles and 10 (9.26%) divorcees; 2 (1.16%) participants did not disclose their marital status. The patients represented all types of MS: 36 patients had relapsing-remitting type (32.72%), 28 – secondary-progressive type (25.45%), 33 – primary-progressive type (30%), and 8 – progressive-relapsing one (7.27%). In 5 (4.54%) cases the type of MS remained unknown. The following treatments have been administered in 41 (37.3%) of the study subjects: interferon beta 1b (19 participants), interferon beta 1a (5 participants), glatiramer acetate (10 participants), mitoxantrone (1 participant), natalizumab (4 participants), and teriflunomide (2 participants).

Initial manifestations of MS in the study participants (Table 1) usually included visual impairment, balancing disorders, tingling and numbness. The least frequently reported symptoms were mood disorders and limb tremors. Primary ailments reported at the time of the study included problems with maintaining balance and motor coordination, fatigability, bladder and bowel dysfunction.

ruste 1. Initial symptoms and disorders present earlierly in 1125 patients					
Symptoms	Initial symptoms [%]	Current disorders [%]			
Balancing disorders	41.28	88.07			
Visual impairment	40.91	47.71			
Tingling, numbness	37.27	-			
Excessive fatigability	34.55	77.98			
Spasticity	13.64	61.47			
Tremors	8.18	-			
Mood disorders	8.18	-			
I do not remember	6.38	-			
Paresthesia	-	62.39			
Bladder and bowel dysfunction	-	69.72			
Sexual disorders	-	36.7			
Heat intolerance	-	46.79			
Disorders of speech	-	33.94			

Table 1. Initial symptoms and disorders present currently in MS patients

Patients with various types of MS differed significantly in terms of the incidence of strep throat, pharyngitis and raised body temperature in their childhood. Virtually none (aside from 2 persons, i.e., 6.06%) of the study subjects had a history of childhood tuberculosis. The most common diseases of the childhood reported by the study participants were chickenpox and mumps, the latter in more than a half of the subjects.

The vast majority of patients declared lack of allergies. Furthermore, our analysis showed that upon being diagnosed with MS, 22% of individuals quitted their bad habits, specifically alcohol drinking and tobacco smoking.

Table 2. Characteristics of patients with MS, stratified according to the clinical type of this disease

Specification	Relapsing- remitting MS	2. Secondary- progressive MS	3. Primary- progressive MS	4. Progressive- relapsing MS	p-value
Mean (age±SD)	43.30±11.19	55.08±10.32	55.82±8.52	45.13±7.64	<0.001
Men (N,%)	16 (15.24)	6(5.71)	13(12.38)	5(4.76)	0.11
Duration of disease (age±SD)	10.61±5.57	19.32±11.59	13.05±8.07	13.86±8	0.002
History of a strep throat (<i>N</i> ;%)	7(19.44)	6(22.22)	15(45.45)	5(62.50)	0.01
Tonsillitis (N;%)	5(13.89)	5(18.52)	8(24.24)	1(12.50)	0.74
Pharyngitis (N;%)	10(27.78)	5(18.52)	12(36.36)	6(75.00)	0.02
Low-grade fever (N;%)	15(41.67)	2(7.41)	9(27.27)	3((37.50)	0.01
Frequent episodes of common cold (N;%)	14(38.89)	5(18.52)	13(39.39)	5(62.50)	0.09
Chickenpox (N;%)	32(88.89)	16(59.26)	20(60.61)	8(100.00)	<0.001
Rubella (N;%)	20(55.56)	8(29.63)	10(30.30)	2(25.00)	0.08
Tuberculosis (N;%)	0(0.00)	0(0.00)	2(6.06)	0(0.00)	0.31
Mumps (N;%)	23(63.89)	14(51.85)	17(51.52)	6(75.00)	0.51
Measles (N;%)	11(30.56)	11(40.74)	13(39.39)	4(50.00)	0.67

Very few patients (7/110), i.e. 6.4% declared presence of MS in their closest relatives, such as mother, grandfather, daughter. We did not find a significant relationship between blood group and specific MS type (p = 0.65). Mean age of the patients was: 43.30 years, SD = 11.19 for relapsing-remitting MS; 55.08 years, SD = 10.32 for secondary-progressive MS; 55.82 years, SD = 8.52 for primary-progressive MS; and 45.13 years, SD = 7.64 for progressive-relapsing MS. The intergroup differences in patients' age turned out to be significant on statistical analysis.

Analyzing the quality of life and role of social support in MS, the following results were obtained depending on the type of MS (Table 3).

 $\label{thm:confidence} \begin{tabular}{ll} Table 3. Odds \ ratios (OR) \ and \ their 95\% \ confidence \ intervals (95\% \ CI) \ for \ deteriorated \\ quality \ of \ life \ and \ social \ support \ in \ patients \ with \ various \ types \ of \ MS \end{tabular}$

		pport in patient				
Variable	Type of MS	Model 1 ^a OR (95% CI)	р		Model 2 ^b OR (95% CI)	р
					1	
Quality of life – general	RR	1			3.77 (0.61–23.2)	0.15
	SP	1.69 (0.45–6.25)	0.43	Age	8.11 (1.43–45.0)	0.02
health	PP	4.03 (1.24–13.0)	0.02	Sex	4.27 (0.46–39.1)	0.2
	PR	3.72 (0.67–20.7)	0.13		1.01 (0.96–1.07)	0.49
		,			1.88 (0.62–5.76)	0.27
					1	
	RR	1			0.67 (0.18–2.54)	0.56
Quality of life – physical	SP	0.66 (0.22–2.0)	0.47	Age	4.28 (1.21–15.01)	0.02
health	PP	3.5 (1.3–9.43)	0.01	Sex	2.85 (0.51–16.08)	0.23
	PR	3.33 (0.68–16.3)	0.14		0.99 (0.95–1.04)	0.83
					0.99 (0.37–2.61)	0.98
					1	
	RR	1			1.58 (0.36–6.81)	0.54
Quality of life – psychological	SP	1.16 (0.36–3.72)	0.79	Age	3.95 (1.0–15.61)	0.05
health	PP	3.29 (1.16–9.33)	0.02	Sex	2.87 (0.46–17.7)	0.26
	PR	3.5 (0.71–17.2)	0.12		1.0 (0.95–1.05)	0.95
					1.92 (0.7–5.25)	0.2
					1	
	RR	1			1.06 (0.25–4.48)	0.94
Quality of life – social health	SP	0.87 (0.28–2.67)	0.8	Age	2.89 (0.75–11.07)	0.12
	PP	2.76 (1.02–7.5)	0.05	Sex	1.43 (0.23–9.06)	0.70
	PR	1.56 (0.31–7.78)	0.56		1.01 (0.96–1.06)	0.64
					5.0 (1.78–14.0)	<0.001
Quality of life – environmental health					1	
	RR	1			2.29 (0.60–8.72)	0.22
	SP	1.44 (0.5–4.18)	0.5	Age	7.39 (1.91–28.58)	<0.001
	PP	4 (1.46–10.98)	0.01	Sex	4.33 (0.73–25.66)	0.11
	PR	4.33 (0.87– 21.60)	0.07		0.97 (0.92–1.02)	0.23
		,			1.02 (0.38–2.69)	0.97

		1				
Overall social support	_				1	_
	RR	1			0.89 (0.23–3.48)	0.87
	SP	0.74 (0.26–2.1)	0.58	Age	3.12 (0.85–11.48)	0.09
	PP	2.42 (0.92–6.36)	0.07	Sex	0.51 (0.07–3.52)	0.5
	PR	0.52 (0.09–2.97)	0.46		1.00 (0.96–1.06)	0.72
					4.25 (1.55–11.69)	<0.001
					1	
	RR	1			0.91 (0.25–3.31)	0.88
Perceived available support	SP	0.59 (0.21–1.66)	0.32	Age	1.98 (0.55–7.1)	0.29
rerceived available support	PP	1.18 (0.46–3.03)	0.74	Sex	0.65 (0.11–3.88)	0.63
	PR	1.25 (0.27–5.79)	0.78		0.98 (0.93–1.03)	0.40
					4.05 (1.55–10.6)	<0.001
					1	
	RR	1			1.98 (0.52–7.47)	0.31
Nood for ourport	SP	1.02 (0.37–2.79)	0.97	Age	4.29 (1.13–16.31)	0.03
Need for support	PP	2.13 (0.81–5.58)	0.12	Sex	0.24 (0.23–2.5)	0.23
	PR	0.22 (0.02–2.02)	0.18		0.97 (0.92–1.02)	0.24
					3.44 (1.27–9.34)	0.01
Support seeking	RR SP PP PR	1 0.8 (0.27–2.34) 4.0 (1.47–10.89) 0.28 (0.03–2.59)	0.68 0.01 0.27	Age Sex	1 1.87 (0.49–7.15) 8.29 (2.09–32.97) 0.39 (0.04–4.02) 0.96 (0.91–1.01)	0.36 <0.001 0.43 0.13
					1.49 (0.55–4.07)	0.43
Actually received support	RR SP PP PR	1 0.72 (0.18–2.86) 0.55 (0.16–1.93) 1.20 (0.12– 12.27)	0.64 0.35 0.88	Age Sex	1 1.03 (0.16–6.68) 0.45 (0.08–2.39) 1.11 (0.09–14.08) 0.97 (0.91–1.04) 0.31 (0.09–1.09)	0.98 0.35 0.93 0.47 0.07
Protective buffering support					1	
	RR	1			0.97 (0.29–3.33)	0.98
	SP	0.78 (0.28–2.15)	0.63	Age	1.11 (0.33–3.74)	0.86
	PP	0.91 (0.35–2.38)	0.85	Sex	0.21 (0.02–2.1)	0.19
	PR	0.2 (0.02–1.8)	0.15		0.97 (0.93–1.02)	0.28
					1.24 (0.49–3.18)	0.65

 $^{^{}a}$ raw data; b adjusted for age and sex; RR – relapsing-remitting MS; SP – secondary-progressive MS; PP – primary-progressive MS; PR – progressive-relapsing MS

Quality of life in general health domain turned out to be particularly important in patients with primary-progressive MS (p = 0.02). We showed that individuals with this type of MS were four times more likely to present with deteriorated quality of life than subjects with the relapsing-remitting type (OR = 4.03). Strong significant relationship between the quality of life in general health domain and primary-progressive MS was observed also when the results were adjusted for patients' sex and age; in the adjusted model, odds for worse general health in primary-progressive MS were twice as high as in the case of raw data (OR = 8,.11).

Moreover, primary-progressive MS was associated with worse quality of life in physical health domain, also when the results were adjusted for patients' age and sex (OR = 3.5 and OR = 4.28). Psychological health domain also turned out to be statistically significantly in patients with primary-progressive MS (p = 0.02). Patients with this type of MS were three times more likely to present with deteriorated quality of life in this domain than reference group, also when the results were adjusted for age and sex (OR = 3.29 vs. OR = 3.95). This means that in both the first and the second case people suffering from primary – progressive MS were three times more likely to present with deteriorated quality of life in psychological domain, compared to people affected by relapsing-remitting MS, and gender and age do not play a significant role here.

Compared to women, men were five times more likely to present with lower scores for the quality of life in social functioning domain (OR = 5.0); this value was highly significant (p < 0.001). Quality of life in environmental health domain turned out to be significant for patients with primary-progressive (p = 0.01) and progressive-relapsing MS (p = 0.07). The risk for deteriorated quality of life in persons with either MS type were four times higher than in the reference group. When the results were adjusted for age and sex, OR for progressive-relapsing MS remained unchanged but respective p-value increased to p = 0.11; in turn, the adjusted odds ratio for primary-progressive MS was more than seven-fold greater (OR = 7.39) than for the relapsing-remitting type.

The results presented in Table 3 suggest that irrespective of the MS type, overall social support did not play a significant role in univariate analysis. However, after adjustment for patient's sex as a potential confounder, men turned out to be four times more likely to score worse on this scale than women (OR = 4.25). The result was statitically significant (p < 0.001). Furthermore, men, irrespective of their MS type, were four times more likely to score lower on the perceived available support subscale (p = 0.00, OR = 4.05), and three times more likely to score worse on the need for support subscale.

Our findings imply that support seeking is particularly important in the case of primary-progressive MS. The relationship was highly significant both for the raw data and after adjustment for age and sex (p=0.01 and p<0.001); upon the adjustment for patients' age and sex, OR value for this relationship increased from 4.0 to 8.29. We did not find significant relationships between MS type and the scores for actually received support and protective buffering support.

Discussion

MS is a disease that raises growing interest of physicians, scientists and researchers. This condition may cause many serious problems for both patients and their close relatives. The outcome of MS is always unpredictable and its etiology remains unknown. The symptoms of MS can be heterogeneous: paresthesia, visual impairment, muscle weakness, depression, speech disorders, cognitive problems, balancing disorders, chronic fatigue, limited mobility and even disability in more severe cases. Therefore, quality of life in MS patients is considerably worse than in healthy persons. This phenomenon was already documented in 2011, in a study of patients treated at the Neurology Outpatient Clinic in Zabrze [10], and confirmed by other reports [11, 12]. However, some studies produced contradictory results [13], implying that MS patients may obtain high scores in subjective quality of life.

Our present study showed that compared to patients with relapsing-remitting MS, individuals with primary-progressive type of the disease are characterized with worse quality of life. They score substantially lower on the physical health, psychological health and social health scales as well as in the environmental health domain. Similar findings have been also presented by other authors [14]. Perhaps this should be linked to stage of the disease, its duration and/or specific characteristics of its various types. Moreover, previous research showed that that patients' quality of life may deteriorate due to disease-related decrease in physical fitness. Some researchers emphasized an association between quality of life and physical fitness of patients [15]. To attenuate a negative impact of the disease on patients' life, appropriate joint activities need to be undertaken to support patients in retaining their dignity and good quality of life [16]. Unfortunately, decreased mobility was also shown to result in lesser amount of social support offered to patients. As a result, they feel useless, resigned, helpless, and present with lower self-esteem [17, 18]. Under such circumstances, also their quality of life deteriorates.

As mentioned previously, quality of life is with no doubt linked to social support defined as resources provided due to interactions with other people [3]. Social support plays an important role in maintaining human health, protects against diseases and supports the healing process [19]. Need for social support increases especially in the face of difficult life situations – in such situations support and care shown by others causes a reduction of tension associated with stress and makes it easier to find a solution. As it turns out, availability and accuracy are particularly important for intervention in the form of support [20]. This relationship was confirmed by a study conducted in Lublin in 2013. Patients with MS were shown to function considerably better in physical and mental spheres whenever they received various forms of social support [5].

The same study showed unequivocally that accurate information from medical personnel about the illness as well as the ability to cope with the limited physical resources, are the most important among various forms of support (material, informative, emotional, instrumental support).

Another aspect which should be considered in the discussion about the support is its perception and the ability to accept it, which is very often gender-specific. Our study showed that, compared to women, men achieve markedly worse results in this matter. Men are less likely to perceive available support and score lower on the need for support scale. This can be interpreted in terms of a gender stereotype. In line with this stereotype, men less often establish relationships based on close emotional bond and feel uncomfortable asking for help. In turn, women are more eager to create various social relations and emotionally open.

However, it should be remembered that one's response to social support is not necessarily positive. Most people require a sense of independence and control over their own lives. Consequently, excessive support may negatively affect their self-esteem, stimulate a feeling of being dependent from their environment as well as to raise concerns about sharing their problems with others and lack of understanding thereof. Furthermore, it may prevent them from accepting a support, since they often perceive it as agreeing for a lower position within a community. However, this is mostly a problem with accepting him/herself as a person in need, rather than an ingratitude of any kind.

This study was not free from a few limitations. One of them stems from the fact that not all the participants provided answers to all the questions and therefore the surveys were not necessarily complete. Despite anonymous character of the survey, we encountered problems with obtaining some sensitive or private information. Moreover, completing the survey required referral to the past which also might affect the accuracy of the results. Unfortunately, information provided by the patients could not be verified against their medical documentation since the latter was not available. Furthermore, the survey was time consuming; due to resultant fatigue, some respondents might be reluctant to search for accurate answers for some questions included in the last part of the survey.

It should be emphasized that holistic approach constitutes the only way to effectively work with MS patients and providing them with an efficient support. This requires cooperation between specialists in various disciplines. Management of MS should not be limited solely to administration of medications slowing down progression of the disease. Instead, patients should be ascertained that people from their environment (medical personnel from both primary and MS-dedicated healthcare centers, friends, family, etc.) can provide them with a complex care, addressing all aspects of their lives.

Conclusions

- 1. Quality of life in individuals with primary-progressive MS is significantly lower than in patients presenting with other types of this condition.
- 2. Age did not exerts significant effects on subjective assessment of social support and quality of life in MS.
- Sex influences perception of social support in some domains. Men with MS are more likely to present with worse scores for overall social support, perceived available support and need for support than women with this condition.

References

- 1. Balla S. *Stwardnienie rozsiane jest nas czterdzieści tysięcy*. Warsaw: MEDYK Publishing House; 2004.
- 2. Odrobińska I. SM i... najważniejsze fakty, z. 1. Warsaw; 2006.
- Sheridan CL, Radmacher SA. Psychologia zdrowia. Warsaw: Institute of Health Psychology; 1998.
- 4. Wojciszke B. Psychologia społeczna. Warsaw: Scholar Publishing House; 2012.
- Lorencowicz R, Jasik J, Komar E, Przychodzka E. Wpływ wsparcia społecznego dla jakości codziennego funkcjonowania osoby chorej na stwardnienie rozsiane. Pielęgniarstwo Neurologiczne i Neurochirurgiczne 2013; 2(5): 205–215.
- Majkowicz M. Jakość życia w chorobie nowotworowej. In: Walden-Gałuszko de K. ed. Psychonkologia. PPA Editorial/Publishing Committee. Krakow: Library of Polish Psychiatry; 2000. 141–146.
- 7. Kukielczak A. *Rozwój zainteresowania w naukach medycznych badaniami nad jakością życia*. Przegląd Epidemiologiczny 2012; 66: 539-545.
- 8. Brownscombe I, Laupacis A, Rice GPA, Ebers GC, Noseworthy JH. *Development of a disease specific quality-of-life measure for multiple sclerosis*. Neurol. 1990; 40(Suppl. 1): 142.
- 9. Opara J, Jaracz K, Brola W. Quality of life in multiple sclerosis. Journal of Medicine and Life 2010; 3(4): 352–358.
- Łabuz-Roszak B, Kubicka-Bączyk K, Pierzchała K, Horyniecki M, Machowska-Majchrzak A, Augustyńska-Mutryn D et al. Quality of life in multiple sclerosis – association with clinical features, fatigue and depressive syndrome. Psychiatr. Pol. 2013; XLVII(3): 433–442.
- 11. Rothwell PM, McDowell Z, Wong CK, Dorman PJ. Doctors and patients don't agree: Cross sectional study of patients' and doctors' perceptions and assessments of disability in multiple sclerosis. BMJ 1997; 314: 1580–1588.
- 12. Benito-Leon J, Morales JM, Rivera-Navarros J, Mitchell AJ. *A review about the impact of multiple sclerosis on health-related quality of life*. Disabil. Rehabil. 2003; 25:1291–1303.
- 13. Jabłońska R, Gajewska P, Ślusarz R, Królikowska A. *Ocena jakości życia chorych ze stwardnieniem rozsianym*. Problemy Pielęgniarstwa 2012; 20(4): 442–453.
- 14. Beiske AG, Naess H, Aarseth JH, Andersen O, Elovaara I, Farkkila M et al. *Health-related quality of life in secondaryprogressive multiple sclerosis*. Mult. Scler. 2007; 13: 386–392.
- 15. Hwang JE, Cvitanovich DC, Doroski EK, Vajarakitipongse JG. *Correlations between quality of life and adaptation factors among people with multiple sclerosis*. Am. J. Occup. Ther. 2011; 65(6): 661–669.
- Talarska D, Brzozowska E. Jakość życia pacjentów ze stwardnieniem rozsianym. Neurol. Neurochir. Pol. 2003; 3: 570.
- 17. Grochans E, Wieder-Huszla S, Jurczak A, Stanisławska M, Augustyniak K, Januzik K. Ocena wsparcia społecznego pacjentów ze stwardnieniem rozsianym. Problemy Higieny i Epidemiologii 2008; 89(3); 419–422.
- 18. Costa DC, Sa MJ, Calheiros JM. *The effect of social support on the quality of life of patients with multiple sclerosis*. Arq. Neuro-psiquiat. 2012; 70(2): 108–113.

- 19. Piecha M, Konińska M. Wsparcie społeczne i psychiczne wśród pielęgniarek. Annales Academiae Medicae Silesiensis 2002 Suppl. 34.
- 20. Sęk H. Rola wsparcia społecznego w sytuacji kryzysu. In: Kubacka-Jasiecka D, Lipowska-Teusch A ed. Oblicza kryzysu psychologicznego i pracy interwencyjnej. Krakow: ALL; 1997: 143–158.

Address: Katarzyna Rosiak Medical University of Gdansk, Department of Hygiene and Epidemiology 80-211 Gdańsk, Dębinki Street 7, building 15, 2nd floor