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Authors' Affiliation:
[1]Medical College of the University of Rzeszów, Faculty of Medicine, Poland
[2]Collegium Medicum of the University of Rzeszów, Department of Surgery, Poland

[*]**Corresponding author:**
Patrycja Patronik, St. Hetmańska 75/85, Rzeszów, 36-078, Poland
e-mail: patronikpatrycja@gmail.com

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Assessment of quality of life in opinion of patients suffering from multiple sclerosis

Patrycja Patronik[1*], Izabella Prządo[1], Łukasz Karaś[1], Sabina Krupa-Nurcek[2]

ABSTRACT

Background: Multiple sclerosis is a disease characterized by multifocal damage to the central nervous system. The incurable and progressive nature of this disease significantly affects the quality of life of patients, covering both physical, mental, and social spheres of life. Aim of the study: Quality of life in the opinion of patients who have multiple sclerosis. Material and methods: A total of 107 individuals participated in an online survey aimed at assessing their quality of life. A diagnostic study design was employed, using the questionnaire as the primary research tool. The analysis focused on aspects such as disease duration, relapse frequency, presence of comorbidities, and the level of support received from family and community. Results: The study allowed us to conclude that the general assessment of the quality of life in the studied group of patients reached a medium level. Factors such as the duration of the disease, the form of multiple sclerosis, and the frequency of relapses had a significant impact on the assessment of the patients' quality of life. Respondents with a longer course of the disease and a higher incidence of relapses declared a lower quality of life. Conclusions: Increasing access to interdisciplinary care for a group of patients with multiple sclerosis is crucial. Respondents emphasize the need for better psychological and physiotherapeutic support. Furthermore, there is a need for additional research to develop methods that enhance the quality of life for patients with multiple sclerosis.

Keywords: quality of life; multiple sclerosis; demyelinating disease; patients.

1. INTRODUCTION

Multiple sclerosis is a chronic disease that affects both the central nervous system and the immune system (Kuhlmann et al., 2017). Exacerbations, remissions, and multifocal damage to the body characterize it. It mainly affects young people, most often diagnosed are people around 20-40 years of age, women suffer from this disease even twice as frequently as men (McGinley et al., 2021; Rzepiński & Maciejek, 2018). Referring to pathogenesis, attention should be focused on the demyelinating process, whose cause remains unknown; however, studies suggest an autoimmune basis of the disease (Haki et al., 2024). People with a genetic predisposition may be more sensitive to negative environmental factors (Nourbaksh

& Mowry, 2019). In addition, patients with multiple sclerosis have an increased risk of chronic comorbidity (Marrie et al., 2023). Potential risk factors include: EBV infection, obesity, smoking, and low vitamin D levels (Ward & Goldman, 2022). Multiple sclerosis presents with various clinical manifestations, the main ones being relapsing-remitting, secondary progressive, and primary progressive.

Relapse is a symptom of a newly formed focus of demyelinating damage, lasts a minimum of 24 hours, but is not associated with fever or infection. Symptoms may become visible for several weeks and then gradually subside, leaving no significant body dysfunctions (Losy et al., 2016). A wide variety and variability characterize the symptoms accompanying the disease, including: extraocular inflammation of the optic nerve, sensory disturbances, paresis, chronic fatigue syndrome, affective and cognitive disorders, and pain (Travers et al., 2022). Quality of life is a complex and multifaceted concept that can be interpreted and defined on many levels within different scientific disciplines (Haraldstad et al., 2019). According to the WHO definition, quality of life refers to a subjective assessment of one's life situation, taking into account the state of physical health, mental condition, level of self-reliance and independence, social relationships, and personal beliefs (World Health Organization, 1997).

The study aimed to assess the quality of life of patients with multiple sclerosis. The study focused particularly on the duration of the disease, the occurrence and frequency of relapses, comorbidities, and their impact on the respondent’s quality of life.

2. REVIEW METHODS

The research conducted the online survey among people with multiple sclerosis. A link to the survey was sent out through social media, forums, and support groups for patients with multiple sclerosis. The study included 107 participants, comprising 73 women and 34 men. The following criteria were established for inclusion in the survey: adults, individuals diagnosed with MS for at least a year, and those who gave informed consent to participate. Exclusion criteria from the survey: minors; patients with a diagnosis other than MS; no informed consent to participate in the study. Surveys that were not completed in full by the respondents were automatically rejected by the computer system.

In our research, we used an original questionnaire consisting of two parts. The first section contained a metric, i.e., questions concerning socio-demographic information (7 closed questions), while the second section included 32 questions, of which closed questions are the dominant part. Table 1 presents the characteristics of the study group.

Table 1. Characteristics of demographic and social characteristics of respondents.

Characteristics of demographic and social characteristics of respondents		
Question	***Number of responses (N)***	***Percent %***
Gender		
Woman	73	68.22
Man	34	31.78
TOTAL	107	100.00%
Age		
Below 20 years	7	6.54
21 - 30 years	17	15.89
31 - 40 years	49	45.79
41-50 years	23	21.50
above 51 years	11	10.28
TOTAL:	107	100.00%
Size of residence		
Village	0	0
A town of up to 20 thousand Residents	5	4.67
The city has 20 thousand to 100 thousand Residents	13	12.14
A city of over 100 thousand.	89	83.19
TOTAL:	107	100.00%

Marital status		
Miss/Bach	48	44.85
Married	26	24.29
Divorced	19	17.77
Widow	8	7.49
Affiliate	6	5.60
TOTAL:	107	100.00%
I currently live with:		
Family	39	36.44
Partner	38	35.51
Guardian	3	2.80
Alone	27	25.25
TOTAL:	107	100.00%
Education		
Basic/Grammar school	3	2.80
Essential professional	6	5.60
Average	27	25.25
Bachelor's, Master's	71	66.35
TOTAL:	107	100.00%
Occupational status		
Working	51	47.66
Student	14	13.08
Unemployed	9	8.41
Pensioner	33	30.85
TOTAL:	107	100.00%

3. RESULTS

The chi-square test revealed highly statistically significant differences in the duration of disease ($\chi^2=98.36$; df=7; $p<0.001$). The most significant percentage of respondents had been struggling with the disease for 3-10 years. The second largest group (24.30%) consisted of people who had the disease for 21-30 years. Among the respondents, 21.50% reported disease duration from 11 to 20 years. A longer duration of 31-40 years was described by 6.54% of respondents, while 4.67% had lived with the disease for 41 years or more. Only 3.74% of people had been struggling with the disease for several months. The percentage of people who have been ill for several months and a year has reached the same value among the respondents, amounting to 1.87%. Table 2 shows the results.

Table 2. Duration of the disease (multiple sclerosis) in respondents.

Duration of the disease	**(N=107)**	**Percent**	**Chi-square test**
41 years and more	5	4,67	$\chi^2=98.36$ df=7 $p<0.001$
31-40 years	7	6,54	
21-30 years	26	24,30	
11-20 years	23	21,50	
3-10 years	38	35,51	
Year	2	1,87	
A few months	4	3,74	
A few weeks	2	1,87	

The majority of the study group (69.16%) declared that they had relapsing-remitting disease. Over 22% of people indicated the secondary progressive form, and 7.48% of people suffered from the primary progressive form. Only one person had a primary progressive form with relapses. The study examined the incidence of relapses in respondents. The vast majority of respondents (33.64%) admitted that relapses occurred every six months. In turn, 29.91% of the respondents reported experiencing relapses at least every month. Longer intervals between relapses were reported by 3.74% as occurring once a year, 4.67% quarterly, and 5.61% less than once a year**.** Difficulties in determining the frequency of relapses occurred in 8.41% of the subjects, and 14.02% did not observe their occurrence. Respondents were asked about the presence of comorbidities and could indicate more than one answer. Cardiovascular diseases affected 59.81% of the respondents, while 29.91% had cerebrovascular diseases. Among the participants, 19.63% struggled with respiratory diseases, and 17.76% had rheumatoid arthritis. The most commonly reported chronic conditions were obesity (17.76%) and diabetes (14.95%). In addition, 10.28% of respondents had osteoporosis, 7.48% struggled with cancer, and 1.87% suffered from epilepsy. The study group did not indicate other variants. The study assessed the impact of the disease on the daily functioning of the respondents. More than half of them (52.34%) admitted that the disease somewhat limits their lives, while 30.84% of patients stated that it significantly limits their normal functioning. In turn, 11.21% reported that their life was relatively normal. The smallest percentage of respondents (5.61%) admitted that the disease had destroyed their lives. The analysis included respondents subjective assessment of the quality of life. The chi-square test revealed significant differences in the evaluation of the quality of life among the respondents (χ^2=12.22; df=4; p≈ 0.016). Nearly 29% of the respondents, rated their quality of life as low, while the fewest respondents (12.15%) described the quality of their lives as very low. Table 3 presents the results.

Table 3. Self-assessment of respondents' quality of life.

Quality of life of respondents	(N=107)	Percent	Chi-square test
Very low	13	12.15	χ^2= 12.22 df= 4 p≈ 0.016
Low	31	28.97	
Rather high	28	26.17	
High	21	19.63	
Very high	14	13.08	

We examined the activities that the respondents had to give up due to the disease. The study group could choose more than one answer. The majority of the respondents (67.29%) had to stop doing sports, nearly half (47.66%) had to give up starting a family, and 44.86% had to give up their intimate life. 31.78% of respondents had to decide to give up driving, and the least number of respondents had to give up driving a car (19.63%). Following this, we assessed the respondents' overall well-being. The results showed that 26.17% of those surveyed felt average, indicating both satisfaction and dissatisfaction. In turn, 20.56% of the respondents were dissatisfied with their lives, and 16.82% felt terrible. Not much less, nearly 15.89% of respondents were somewhat satisfied, 12.15% were unhappy, and only 8.41% expressed satisfaction. None of the respondents was delighted with their lives. Another aspect examined was the mental capacity of the subjects. The chi-square test revealed significant differences in self-assessment of mental fitness (χ^2=22.96; df=4, p<0.001). The results showed that 28.97% rated their mental condition as relatively good. Only 14.02% of the respondents described their mental capacity as good, while only 4.67% described it as very good. Table 4 presents the results.

Table 4. Self-assessment of mental capacity of the respondents.

Mental capacity	(N=107)	Percent	Chi-square test
Very good	5	4.67	χ^2=22.96 df=4 p<0.001
Good	15	14.02	
Rather good	31	28.97	
Bad	29	27.10	
Very bad	27	25.23	

We examined the respondents' level of anxiety about the future. Nearly half of them (43.93%) were occasionally worried about their future. On the other hand, 30.84% of people felt such emotions sometimes, and 19.63% were worried often. The smallest groups were those who had always felt worried about the future (3.74%), and those who had never experienced fear about it (1.87%). Respondents assessed the support they received from their relatives and immediate environment. As many as 38.32% of them rated this support very well, while 19.63% of respondents considered it rather good, and 16.82% assessed it as good. On the other hand, 14.95% of respondents evaluated the support as very bad, and an additional 10.28% rated their relationships with their loved ones and family as bad. Respondents also expressed their opinions on what forms of support could improve their quality of life. The study group could select more than one answer. Nearly all 95.52% of respondents believed that there should be better access to health education provided by doctors. Slightly fewer respondents thought that it was necessary to have a better opportunity to use the help of a psychologist (86.92%) and a social worker (81.31%). The increased possibility of using physiotherapist treatments received 85.98% of responses, while the possibility of using physical activity under the supervision of a professional received 83.18%. More than half of the respondents (68.22%) expressed a need for improved access to health education provided by nursing staff. Furthermore, 40.19% pointed to the need for increased social support, while 14.02% demanded more support from their families.

4. DISCUSSION

This study aimed to assess the quality of life among patients with multiple sclerosis. The conducted research indicates the multidimensionality and ambiguity of the perception of the disease of multiple sclerosis by people suffering from this disease entity. Noun et al., (2023) identified risk factors for multiple sclerosis that may influence clinical outcomes, economic outcomes, and patients' quality of life. Our research assessed the mental capacity of the respondents. The results indicated the complexity of the problem and a very negative assessment of this aspect concerning patients with multiple sclerosis. Both the duration of multiple sclerosis and its form influence patients' quality of life.

Our research results confirm the impact of these factors on patients' perception of their quality of life. The age of the participants in the present study was similar to that of the survey conducted by Sabanagic-Hajric et al., (2022), which aimed to assess the effects of gender, age, and marital status on the quality of life of patients with MS. The aging process of patients with MS is a significant negative factor affecting their perception of physical aspects of quality of life. In contrast, an earlier onset of the disease appears to have a positive effect on how patients with MS perceive their overall health. The results of our study are consistent with findings from international research. It is worth considering the implementation or expansion of support services to enhance the quality of life for patients. It seems crucial to reduce the difficulties resulting from physical limitations in older patients, increase the availability of psychological support for patients, and provide social support for people living alone. The results of our research indicate similar recommendations, i.e., the need for more effective psychological and physiotherapeutic support.

To summarize, the results of our research are mainly consistent with those of the aforementioned authors in various scientific publications. The respondents are primarily satisfied with their quality of life. The disease and the disability associated with it cause significant difficulties that negatively affect the overall health of people who have multiple sclerosis.

5. CONCLUSION

Our findings indicate that the duration of the disease is correlated with the level of life satisfaction, and support from loved ones helps alleviate anxiety about the future. One of the most critical elements is social education and increasing public awareness of the disease, which can contribute to reducing social exclusion and improving their quality of life in the psychological and social dimension. Respondents expect more effective help in the field of psychological and physiotherapeutic therapy. The respondents have the greatest expectations regarding the forms of support concerning improving the quality of life, towards access to health education conducted by doctors.

Author's Contributions
Conceptualization: Patrycja Patronik
Methodology: Patrycja Patronik, Izabella Prządo
Formal analysis: Sabina Krupa-Nurcek
Data curation: Izabella Prządo, Łukasz Karaś

Visualization: Patrycja Patronik, Łukasz Karaś
Investigation: Patrycja Patronik, Izabella Prządo
Writing-original draft: Patrycja Patronik
Writing- review and editing: Izabella Prządo, Patrycja Patronik and Sabina Krupa-Nurcek.
All authors have read and agreed with the final, published version of the manuscript.

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Informed consent
Written & Oral informed consent was obtained from all individual participants included in the study.

Ethical approval
An application was submitted to the Bioethica Committee at the University of Rzeszów (KBE No.09/05/2020) to obtain a positive opinion on the study.

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Conflict of interest
The authors declare that there is no conflict of interest.

Data and materials availability
All data associated with this study will be available based on the reasonable request to corresponding author.

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