

# THE QUALITY OF LIFE IN PATIENTS WITH MULTIPLE SCLEROSIS

## JAKOŚĆ ŻYCIA CHORYCH NA STWARDNIENIE ROZSIANE

EDYTA KĘDRA<sup>1 A,D,E,F</sup>  
JOANNA WILUSZ<sup>1 B,C</sup>

<sup>1</sup> Nursing Institute, Opole Medical School, Opole

**A** – przygotowanie projektu badania | study design, **B** – zbieranie danych | data collection, **C** – analiza statystyczna | statistical analysis, **D** – interpretacja danych | data interpretation, **E** – przygotowanie maszynopisu | manuscript preparation, **F** – opracowanie piśmiennictwa | literature search, **G** – pozyskanie funduszy | funds collection

### SUMMARY

**Background:** Studies assessing the quality of life of patients with multiple sclerosis (MS) seek to determine which quality of life dimensions are the most significantly decreased as a result of the illness. For MS patients the broad term “the quality of life” is not exclusively associated with the degree of physical disability or the progress of the illness. It is also affected by cultural and socio-economic factors.

**Aim of the study:** An assessment of the impact of the chronic disease a multiple sclerosis is which, is a main purpose to the quality of life of persons being dying for it.

**Material and methods:** The study was conducted between 2013 and 2014 on a population of 50 members of the Association of Multiple Sclerosis Patients in Głogów. The study method of choice was a diagnostic survey, including the standardized questionnaire Ferrans and Powers’ Quality of Life Index for Multiple Sclerosis (version III).

**Results:** The highest quality of life satisfaction among MS patients was recorded for the Family subscale and the lowest in the Health/functioning subscale.

**Conclusions:** The general assessment of the quality of life made by the participants rates on an average level (mean 4.34). The result can be considered good and focus may turn on the elements which require additional support.

**KEYWORDS:** quality of life, patient with MS, chronic patient

### STRESZCZENIE

**Wstęp:** W badaniach oceniających jakość życia chorych na stwardnienie rozsiane (MS) poszukuje się odpowiedzi na pytanie, które wymiary jakości życia są najbardziej obniżone na skutek choroby. Szeroko rozumiana jakość życia chorych na MS nie jest jedynie związana ze stopniem ich fizycznej niepełnosprawności i zaawansowania choroby. Wpływ na nią mają również czynniki kulturowe oraz społeczno-ekonomiczne.

**Cel pracy:** Głównym celem pracy jest ocena wpływu choroby przewlekłej, jaką jest stwardnienie rozsiane, na jakość życia osób na nią chorujących.

**Materiał i metody:** Badania przeprowadzono na przełomie 2013 i 2014 r. wśród 50 członków Stowarzyszenia Chorych na Stwardnienie Rozsiane w Głogowie. Wykorzystano metodę sondażu diagnostycznego, a w niej kwestionariusz standaryzowany Indeksu Jakości Życia Ferrans i Powers dla Stwardnienia Rozsianego (wersja III).

**Wyniki:** Najwyższe zadowolenie z jakości życia chorych na MS odnotowano w podskali rodzinnej, a najmniejsze w podskali zdrowie i funkcjonowanie.

**Wnioski:** Ogólna ocena jakości życia dokonana przez badanych chorych mieści się na średnim poziomie (średnia 4,34). Można ją uznać jako dobrą i zwrócić uwagę na te elementy, które wymagają dodatkowego wsparcia.

**SŁOWA KLUCZOWE:** jakość życia, chory na MS, chory przewlekłe

## BACKGROUND

Multiple sclerosis (MS) is one of the most complex neurologic diseases in terms of etiology, course and treatment, and the changeability and diversity associated with its symptomatology. A chronic illness, such as MS, interferes in all areas of a patient's life, becoming the main reason of decreasing quality of life in many aspects. The chronic character of the illness and the fact the recurring afflictions significantly impede on everyday life of a patient should render the assessment of the quality of life as one of the key areas of interest for clinicians. This assessment should also constitute an integral element of nursing care, as being familiar with the areas of life which suffer the worst toll as a result of the illness can help plan long-term support strategy for a patient.

## AIM OF THE STUDY

An assessment of the impact of the chronic disease a multiple sclerosis is which, is a main purpose to the quality of life of persons being dying for it.

## MATERIAL AND METHODS

The assessment of the quality of life was conducted by the co-author of this paper as part of her MA thesis [1] between December 2013 and March 2014 on a population of 50 MS patients, members of the Association

of Multiple Sclerosis Patients in Głogów. The following was the main hypothesis: a chronic illness significantly affects the quality of life of patients with multiple sclerosis.

A diagnostic survey was deemed the most optimal study method. Selecting the questionnaire form allowed the use of the Ferrans and Powers' Quality of Life Index for Multiple Sclerosis (version III) [2]. The respondents answered the questions using a 6-degree satisfaction scale. The results were analysed using the average of the answers, the arithmetic mean and the chi-square test ( $p < 0.05$ ).

## RESULTS

The study population consisted of patients with MS and constituted predominantly of women (44 respondents – 88%), with men constituting only 12% (6 respondents). The largest age group constituted of people over 50 years old (27 respondents – 54%). The size of the groups decreased with age: 41–50 year olds constituted 36% (18 respondents), 31–40 year olds 8% (13 respondents) and 20–30 year olds 2% (1 respondent). 26% (13 respondents) were employed, 10% (5 respondents) were unemployed, 2% (1 respondent) replied – “Other”.

The tables below present the answers to the questions on particular areas of life included in the standardised research tool, the Ferrans and Powers' Quality of Life Index for Multiple Sclerosis (version III), given by the respondents.

**Table 1.** Distribution of the responses in the Health/functioning subscale of the Ferrans and Powers' Quality of Life Index for Multiple Sclerosis (version III) [1]

Specification	Very Dissatisfied	Moderately Dissatisfied	Slightly Dissatisfied	Slightly Satisfied	Moderately Satisfied	Very Satisfied	Answer Average
How important to you is?:							<b>5.46±0.20</b>
Your health?	0	0	0	2	8	40	<b>5.76±1.28</b>
Your health care?	2	1	3	5	9	30	<b>5.16±0.93</b>
The amount of pain that you have?	0	2	2	2	12	32	<b>5.40±1.08</b>
The amount of energy you have for everyday activities?	0	3	0	1	12	32	<b>5.24±1.10</b>
Your ability to take care of yourself without help?	0	0	3	3	4	40	<b>5.62±1.29</b>
The amount of control you have over your life?	0	0	3	1	8	38	<b>5.62±1.21</b>
Your chances of living as long as you would like?	0	0	0	2	13	35	<b>5.66±1.20</b>
Your sex life?	7	3	0	7	1	32	<b>4.76±1.01</b>
Your ability to take care of family responsibilities?	0	1	1	3	15	30	<b>5.44±1.09</b>

Table 1 contd.

How useful you are to others?	0	0	1	5	12	32	<b>5.50±1.07</b>
The amount of worries in your life?	0	0	1	1	11	37	<b>5.68±1.21</b>
The things you do for fun?	0	2	0	5	17	26	<b>5.30±1.02</b>
Your chances for a happy future?	0	0	0	1	14	35	<b>5.68±1.23</b>
How satisfied are you with?:							<b>3.72±0.45</b>
Your health?	6	10	7	11	13	3	<b>3.48±0.34</b>
Your health care?	3	9	12	17	8	1	<b>3.42±0.39</b>
The amount of pain that you have?	9	18	6	11	4	2	<b>2.78±0.22</b>
The amount of energy you have for everyday activities?	4	15	16	10	4	1	<b>2.96±0.29</b>
Your ability to take care of yourself without help?	0	8	9	12	16	5	<b>4.02±0.41</b>
The amount of control you have over your life?	0	3	9	8	23	7	<b>4.44±0.55</b>
Your chances of living as long as you would like?	2	3	10	12	16	7	<b>4.16±0.44</b>
Your sex life?	8	5	2	9	18	8	<b>3.96±0.5</b>
Your ability to take care of family responsibilities?	0	2	8	16	21	3	<b>4.30±0.65</b>
How useful you are to others?	0	5	5	16	17	7	<b>4.32±0.55</b>
The amount of worries in your life?	3	14	18	8	5	2	<b>3.08±0.25</b>
The things you do for fun?	3	3	10	21	12	1	<b>3.78±0.54</b>
Your chances for a happy future?	4	5	7	20	13	1	<b>3.72±0.55</b>

The mean of all answers from the “How important” section in the Health/functioning subscale was  $5.46\pm 0.20$ , which allows to surmise that the assessment is very high and that all assessed aspects of health and functioning are very important for the respondents. The most important area (mean  $5.76\pm 1.28$ ) was “own health”, and “no worries” and “a happy future” (mean  $5.68\pm 1.21$  and  $5.68\pm 1.23$ , respectively). The least important areas were: sex life ( $4.76\pm 1.01$ ) and health care ( $5.16\pm 0.93$ ). The assessment of the degree of satisfaction from the areas included in this subscale was more diversified. The mean of all answers from the “How satisfied” section was  $3.72\pm 0.45$ . It was significantly lower than the assessment of importance. The highest mean was recorded for the amount of control over own

life –  $4.44\pm 0.55$ . Furthermore, quite high means were recorded for “being useful to others” and “the ability to take care of family responsibilities” ( $4.32\pm 0.55$  and  $4.30\pm 0.65$ , respectively). The lowest scores were recorded for “the amount of pain” ( $2.78\pm 0.22$ ) and “the amount of energy for everyday activities” ( $2.96\pm 0.29$ ). It is noteworthy that health (the most important area, according to the respondents) has a quite low degree of satisfaction – only  $3.48\pm 0.34$ . This means that while this area is very important for the respondents, they are not happy with the actual state of it (due to the illness or other factors).

**Table 2.** Distribution of the responses in the Social and economic subscale of the Ferrans and Powers' Quality of Life Index for Multiple Sclerosis (version III) [1]

Specification	Very Dissatisfied	Moderately Dissatisfied	Slightly Dissatisfied	Slightly Satisfied	Moderately Satisfied	Very Satisfied	Answer Average
How important to you is?:							<b>5.21±0.31</b>
Your friends?	1	2	3	3	18	23	<b>5.08±0.95</b>
The emotional support you get from people other than your family?	0	1	4	10	14	21	<b>5.0±0.75</b>
Your neighbourhood?	0	0	2	11	14	23	<b>5.16±0.82</b>
Your home, apartment, or place where you live?	0	0	0	1	12	37	<b>5.72±1.24</b>
Your job (if employed)?*	0	0	0	1	4	9	<b>5.57±1.14</b>
Not having a job (if unemployed, retired, or disabled)?**	3	2	6	5	7	13	<b>4.39±0.56</b>
Your education?	1	0	4	6	13	26	<b>5.16±0.9</b>
How well you can take care of your financial needs?	0	2	1	1	9	37	<b>5.56±1.17</b>
How satisfied are you with?:							<b>4.27±0.62</b>
Your friends?	2	3	4	10	19	12	<b>4.54±0.62</b>
The emotional support you get from people other than your family?	1	3	8	19	13	6	<b>4.16±0.49</b>
Your neighbourhood?	0	4	6	14	14	12	<b>4.48±0.57</b>
Your home, apartment, or place where you live?	0	1	1	7	19	22	<b>5.2±0.93</b>
Your job (if employed)?*	0	0	0	2	5	7	<b>5.36±1.0</b>
Not having a job (if unemployed, retired, or disabled)?**	8	6	9	7	5	1	<b>2.94±0.25</b>
Your education?	4	2	8	15	9	12	<b>4.18±0.48</b>
How well you can take care of your financial needs?	8	6	13	11	9	3	<b>3.32±0.3</b>

\* The question was only answered by professionally active respondents, therefore the values to not total 50.

\*\* The question was only answered by unemployed respondents, therefore the values to not total 50.

The mean of all answers from the “How important” section in the Social and economic subscale was 5.21±0.31. The most important areas were “own house/apartment/place” (5.72±1.24), “taking care of own financial needs” (5.56±1.17) and “job” (for employed respondents – 5.57±1.14). The least important area was “not having a job” (for unemployed respondents)

– 4.39±0.56. The mean assessment of the degree of satisfaction from the areas included in this subscale was 4.27±0.62, lower than the assessment of importance, however the discrepancy is not as high as in the case of the Health/functioning subscale. The highest mean was recorded for “satisfaction with job” (for employed respondents) – 5.36±1.0 and “satisfaction with house/

/apartment" ( $5.20 \pm 0.93$ ). The last area was assessed as the most significant in this subscale. The lowest scores were recorded for "not having a job" (for retired or disabled respondents) –  $2.94 \pm 0.25$  and "taking care of own financial needs" –  $3.32 \pm 0.3$ , which can be seen as a natural result of the former.

The assessments of individual areas were quite evened out, with the highest scores for "own children" ( $5.94 \pm 1.55$ ), "family's health" ( $5.86 \pm 1.44$ ), and "family's happiness" ( $5.82 \pm 1.44$ ). The lowest scores were recorded for "spouse" ( $5.86 \pm 1.44$ ) and "emotional support from family" ( $5.40 \pm 1.07$ ). The mean assessment

**Table 3.** Distribution of the responses in the Psychological/spiritual subscale of the Ferrans and Powers' Quality of Life Index for Multiple Sclerosis (version III) [1]

Specification	Very Dissatisfied	Moderately Dissatisfied	Slightly Dissatisfied	Slightly Satisfied	Moderately Satisfied	Very Satisfied	Answer Average
How important to you is?:							<b>5.61±0.15</b>
Your peace of mind?	0	0	0	4	9	37	<b>5.66±1.16</b>
Your faith in God?	0	2	2	4	16	26	<b>5.24±0.99</b>
You achievement of personal goals?	0	0	1	1	18	30	<b>5.54±1.18</b>
Your happiness in general?	0	0	0	1	9	40	<b>5.78±1.28</b>
Your life in general?	0	0	0	0	8	42	<b>5.84±1.35</b>
Your personal appearance?	0	0	2	6	6	36	<b>5.52±1.13</b>
Yourself in general?	0	0	1	3	6	40	<b>5.70±1.28</b>
How satisfied are you with?:							<b>4.31±0.25</b>
Your peace of mind?	2	7	6	19	13	3	<b>3.86±0.51</b>
Your faith in God?	1	0	5	10	25	9	<b>4.70±0.68</b>
You achievement of personal goals?	1	2	11	20	16	0	<b>3.96±0.63</b>
Your happiness in general?	0	3	1	24	15	7	<b>4.44±0.68</b>
Your life in general?	0	3	12	11	17	7	<b>4.26±0.43</b>
Your personal appearance?	3	1	4	17	19	6	<b>4.32±0.61</b>
Yourself in general?	0	1	3	16	21	9	<b>4.68±0.71</b>

The mean of all answers from the "How important" section in the third subscale, Psychological/spiritual, was  $5.61 \pm 0.15$ . The most important areas were satisfaction with "life in general" ( $5.84 \pm 1.35$ ), "happiness in general" ( $5.78 \pm 1.28$ ) and "yourself in general" ( $5.70 \pm 1.28$ ). The least important area was "faith in God" ( $5.24 \pm 0.99$ ). The mean assessment of the degree of satisfaction from the areas included in this subscale was  $4.31 \pm 0.25$ . The highest satisfaction was recorded for "faith in God" ( $4.70 \pm 0.68$ ) and satisfaction with "yourself in general" ( $4.68 \pm 0.71$ ). It is noteworthy that "faith in God" which was rated the highest on the satisfaction scale was also considered as the least important on this subscale. The respondents were the least satisfied with "peace of mind" ( $3.86 \pm 0.51$ ) and "achievement of personal goals" ( $3.96 \pm 0.63$ ).

The mean of all answers from the "How important" section in the fourth subscale, Family, was  $5.68 \pm 0.24$ .

of the degree of satisfaction from the areas included in this subscale was equally high and amounted to  $5.26 \pm 0.30$ . The highest satisfaction was recorded for "own children" ( $5.82 \pm 1.32$ ) and "family's happiness" ( $5.44 \pm 1.05$ ), the lowest for "emotional support from family" ( $4.72 \pm 0.71$ ).

The structure of Ferrans and Powers' Quality of Life Index for Multiple Sclerosis (version III) is the same for all subscales, i.e. the respondents assess the importance of an area and later the satisfaction from this area. This allowed us to calculate the weighted arithmetic mean for each subscale (with the significance of each area as weight) and compare the satisfaction of the respondents with each of the studied areas. Based on the calculations, the highest level of satisfaction was established for the Family subscale ( $5.26 \pm 0.30$ ) and the lowest for the Health/functioning subscale ( $3.72 \pm 0.45$ ) – the area with the lowest quality of life of

**Table 4.** Distribution of the responses in the Family subscale of the Ferrans and Powers' Quality of Life Index for Multiple Sclerosis (version III) [1]

Specification	Very Dissatisfied	Moderately Dissatisfied	Slightly Dissatisfied	Slightly Satisfied	Moderately Satisfied	Very Satisfied	Answer Average
How important to you is?:							<b>5.68±0.24</b>
Your family's health?	0	0	0	1	5	44	<b>5.86±1.44</b>
Your children?	0	0	0	0	3	47	<b>5.94±1.55</b>
Your family's happiness?	0	1	0	0	5	44	<b>5.82±1.44</b>
Your spouse, lover, or partner?	1	0	2	3	15	29	<b>5.36±1.06</b>
The emotional support you get from your family?	1	1	0	4	13	31	<b>5.40±1.07</b>
How satisfied are you with?:							<b>5.26±0.30</b>
Your family's health?	0	0	2	9	14	25	<b>5.24±0.88</b>
Your children?	0	0	0	0	9	41	<b>5.82±1.32</b>
Your family's happiness?	0	0	0	6	16	28	<b>5.44±1.05</b>
Your spouse, lover, or partner?	1	0	6	0	24	19	<b>5.06±0.10</b>
The emotional support you get from your family?	0	4	1	14	17	14	<b>4.72±0.71</b>

the respondents. The weighted arithmetic mean for the Psychological/spiritual subscale was  $4.31 \pm 0.25$  and for the Social and economic subscale –  $4.27 \pm 0.62$ .

Full verification of the hypothesis of this paper required us to divide it into detailed hypotheses. The first detailed hypothesis assumed that the duration of the illness and age affect the quality of life of patients in particular areas of their everyday functioning.

**Table 5.** The results of the verification of the first detailed hypothesis [1]

Variables	p
Age, Health/functioning subscale	0.79
Age, Social and economic subscale	0.68
Age, Psychological/spiritual subscale	0.79
Age, Family subscale	0.44
Duration of the illness, Health/functioning subscale	0.21
Duration of the illness, Social and economic subscale	<b>0.02</b>
Duration of the illness, Psychological/spiritual subscale	<b>0.05</b>
Duration of the illness, Family subscale	0.24

Based on the calculations we can surmise that for most of the variables, the results of the chi square test are above the predetermined level of significance. The

results are equal to or below the predetermined level of significance for two variables. However, it does not change the fact that the detailed hypothesis is refuted.

The chi square test was used to verify the next two detailed hypotheses: employment, education and place of residence affect the socioeconomic area of the patients' lives and psychologic attitude largely depends on the patient's age and sex. The results for the variables in both hypotheses were higher than the predetermined level of significance, which also pertained to refuting these hypotheses.

**Table 6.** Results of the verification of the second detailed hypothesis [1]

Variables	p
Place of residence, Social and economic subscale	0.60
Education, Social and economic subscale	0.07
Employment, Social and economic subscale	0.43

**Table 7.** Results of the verification of the third detailed hypothesis [1]

Variables	p
Sex, Psychological/spiritual subscale	0.24
Age, Psychological/spiritual subscale	0.79

The next two detailed hypotheses, that socioeconomic situation has significant effect on everyday health and functioning of the patient ( $p = 0.04$ ) and that the family situation affects the patient's psychological/spiritual attitude ( $p = 0.00002$ ), proved correct. In both cases the results for the variables were below the predetermined level of significance ( $p \leq 0.05$ ).

## DISCUSSION

For the patients, the effectiveness of treatment is measured with improved overall state of being, improved ability to handle everyday activities, and, first and foremost, improved quality of life [3–5].

According to a 2004 US study, 3/4 of MS patients were "satisfied" or "very satisfied" with their quality of life. The participants of that study filled out a questionnaire with questions about, inter alia, pain, fatigue, functioning in society, emotional wellbeing, psychological health, and the ability to cope with everyday activities. Asked what they think about their life, 77% of respondents with MS answered that they are "satisfied" or even "delighted". At the same time, these respondents had a worse opinion about their physical condition, vitality, and general health. Based on these results, we can surmise that MS patients have to come to terms with their illness and adapt to the difficulties connected with it. Despite the fact they feel unhappy, they acknowledge their disability more readily, than the consequences of the progressing chronic illness. We can also surmise that MS patients assess their quality of life differently. By coping with severe inconveniences for prolonged periods of time, they begin to expect different things from life. According to the authors, these results should give hope to newly diagnosed patients. An MS diagnosis does not equal a death sentence and does not mean the patient is instantly bound to a wheelchair. The illness can be very destructive, but it is difficult not to notice that many patients continue to have very active lives, in spite of MS [6]. According to the results of the present study, the study group did not assess their quality of life in the particular areas on as high a level as the population of the US study. Satisfaction with the areas on the Health/functioning subscale and with the socioeconomic situation was rated by the respondents as "slightly satisfied". Satisfaction with the areas from the Psychologic/spiritual and Family subscales was rated as "moderately satisfied".

Obara et al. presented the results of their study on the assessment of quality of life, conducted in 2009 in the headquarters of Kielce Association of Multiple Sclerosis Patients [7]. The study was conducted on a population of 30 members of the Association (19 women and 11 men), the study tool used was an own survey. Based on the results of the study, the authors determined that the illness affected the professional and family life of the respondents. Almost half of the women (42%) and 36% of men believed that the illness had negative effect on their relationships with their

friends. From among the respondents, 55% of men and 42% of women admitted they prefer to receive help from their families, and almost 60% of women and over 70% of men stated that family and friends provide invaluable psychological and physical support. However, almost 40% of women and almost 30% of men could not count on support from their family. The progress of the illness affected the professional life of the respondents – 37% of women and 45% of men were professionally active [7]. Furthermore, the results of the present study also show that the illness affected the professional and family life of the respondents. Only 26% of the respondents were professionally active, the remaining participants were disabled, retired, or unemployed. For the unemployed, having a job was "slightly important" and they declared their satisfaction with this fact as "slightly unsatisfied". The respondents were "moderately satisfied" with their friends, while at the same time considering their friends very important. Health and happiness of the family, own children and spouses or partners were deemed "very important" by the respondents, who assessed their satisfaction in these areas as "slightly satisfied". Psychological support from family is helpful when dealing with illness. The respondents were "moderately satisfied" with the support received from their friends and family, and considered it very important.

A study assessing the effect of selected sociodemographic factors was conducted on a population of MS patients in the Clinic of Neurosurgery in Szczecin between 2009 and 2010. The study group consisted of 64 participants (35 women and 29 men). The study showed that sex and place of residence of the participants did not affect their assessment of their quality of life in any of the studied areas; however, good financial situation pertained to better quality of life in physical fitness and general health categories, while advanced age and long duration of the illness constituted significant factors decreasing the quality of life [5].

The results of the present study allowed to draw similar conclusions. The socioeconomic situation had significant effect on the Health/functioning area among the MS patients. The duration of the illness also affected their quality of life – the longer the duration of the illness, the more severe its effect on the Social and economic and Psychologic/spiritual areas.

In another study by Jabłońska et al., published in "Problemy Pielęgniarstwa" (Considerations in Nursing Care) [8], conducted on a population of 31 patients from the Multiple Sclerosis Association in Bydgoszcz show that 42% of the respondents assessed their general quality of life very high and sex was one of the sociodemographic factors which significantly affected this assessment. The analysed clinical results (the form of the disease, age during onset, type of treatment, physical fitness) did not affect the assessment of the quality of life.

The assessment of the quality of life can largely depend on the type of physical therapy. This can be corroborated by the results of a study published in the

Annals of the Pomeranian Medical Academy in Szczecin [9]. Based on the results, it was established that a comprehensive range of physical therapy improved the subjective assessment of quality of life among MS patients, with the highest increase documented for the social functioning sphere. The study population gave their quality of life the highest rating in the psychological sphere.

## CONCLUSIONS

1. The negative effect on the quality of life of patients is the most clearly visible in the Health/functioning subscale, and the least visible in the Family subscale.
2. The duration of the illness variable affects the Social and economic and Psychologic/spiritual subscales.
3. The socioeconomic situation has significant effect of the Health/functioning subscale for MS patients.
4. The MS patients give the highest rating to the Family and Psychologic/spiritual spheres of the quality of life.

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Word count: 4313

• Tables: 7

• Figures: –

• References: 9

### The sources of funding

The review was funded by the authors.

### The conflict of interests

The authors do not report any conflicts of interests.

**Cite this article as:** Kędra E, Wilusz J. The quality of life in patients with multiple sclerosis. *PU-HSP* 2016; 10, 2: 3–10.

### Correspondence address:

Edyta Kędra  
Sikorskiego str. 14/19  
67-200 Głogów  
phone: +48 603 194 182  
e-mail: edyta.kedra@wp.pl

Received: 23.04.2016

Reviewed: 29.05.2016

Accepted: 30.06.2016