

Quality of life and social support in patients with multiple sclerosis

Jakość życia a wsparcie społeczne chorych na stwardnienie rozsiane

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Abstract

Background and purpose: The aim of the study was to evaluate quality of life (QoL) in multiple sclerosis (MS) patients and to assess the relationship between QoL and social support taking into account key clinical factors and other socio-demographic variables.

Material and methods: Two hundred and ten MS patients (150 women and 60 men) aged between 21 and 59 years were evaluated; the MS group was compared with 108 healthy controls. QoL (MSQOL-54), disease severity (Expanded Disability Status State, EDSS), social support (Social Provisions Scale, SPS), mood (Beck Depression Inventory, BDI) and basic clinical and demographic data were assessed.

Results: Disease severity was mild (EDSS < 4) in 85% of patients, and depressive symptoms (BDI > 13) were present in 41% of patients. Mean physical health composite of MSQOL-54 was 53.6 ± 20.7 and mean mental health composite was 60.0 ± 19.8 . MS patients scored significantly lower than healthy subjects. Mean SPS was 78.2 ± 10.9 (range, 6–96) which indicated high social support. In bivariate analysis, social support correlated significantly with the majority of MSQOL domains; in multivariate analysis, however, this relationship was not significant. Emotional well-being was the main predictor of QoL, in both physical and mental domains.

Conclusions: MS influences QoL but to a greater extent in the physical than the psychological domain. The role of social

Streszczenie

Wstęp i cel pracy: Celem pracy była ocena jakości życia (JŻ) chorych na stwardnienie rozsiane (SR) oraz analiza zależności pomiędzy JŻ i wsparciem społecznym z uwzględnieniem kluczowych czynników klinicznych i innych zmiennych społeczno-demograficznych.

Materiał i metody: Zbadano 210 chorych na SR (150 kobiet i 60 mężczyzn) w wieku od 21 do 59 lat. Zastosowano kwestionariusze oceny JŻ (MSQOL-54), nasilenia objawów choroby (*Expanded Disability Status Scale* – EDSS), wsparcia społecznego (*Skalę wsparcia społecznego* – SWS) i nastroju (*Inwentarz depresji Becka* – BDI); przeanalizowano dane demograficzne i kliniczne. Jakość życia chorych porównano z wynikami uzyskanymi u 108 osób zdrowych z grupy kontrolnej.

Wyniki: U 85% chorych stwierdzono niewielkie nasilenie objawów SR (EDSS < 4), a u 41% występowały zaburzenia depresyjne (BDI > 13). Średnia punktów w MSQOL-54 wynosiła w dziedzinie fizycznej $53,6 \pm 20,7$, a w dziedzinie psychicznej $60,0 \pm 19,8$. Oceny JŻ chorych były istotnie niższe niż osób zdrowych. Średnia SWS (zakres: 6–96) wynosiła $78,16 \pm 10,9$, co odpowiada wysokiej ocenie wsparcia. W analizach dwuzmiennych wsparcie korelowało istotnie z większością dziedzin MSQOL-54, w analizach wielowymiarowych zależność ta była jednak statystycznie nieistotna. Głównym czynnikiem predykcyjnym JŻ, zarówno w dziedzinie fizycznej, jak i psychicznej, był stan emocjonalny.

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support in QoL is generally positive but its protective function may be weakened when interacting with other factors. Depression is the main predictor of QoL when adjusted for other factors. Thus, treatment of mood disturbances might significantly improve QoL in MS patients.

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

Wnioski: Jakość życia chorych na SR jest obniżona, przy czym w większym stopniu w dziedzinie fizycznej niż psychicznej. Znaczenie wsparcia dla JŻ jest generalnie pozytywne, lecz w interakcji z innymi czynnikami jego protekcyjna rola może być osłabiona. Objawy depresyjne stanowią główny czynnik prognostyczny JŻ po uwzględnieniu innych zmiennych, co wskazuje, że leczenie zaburzeń nastroju może w istotny sposób poprawić JŻ chorych na SR.

Słowa kluczowe: stwardnienie rozsiane, jakość życia, wsparcie społeczne.

Introduction

Multiple sclerosis (MS) is one of the most common disorders of the central nervous system, affecting the population of young adults. The prevalence of MS in European countries in the last three decades is estimated to be approximately 30-200 per 100 000, and the mean prevalence in Europe is 83 per 100 000 [1]. MS prevalence in Poland varies from 43 to 91 per 100 000, according to different authors [2].

Multiple sclerosis is characterized by a vague, unpredictable course and a wide spectrum of clinical signs, resulting in various syndromes of functional disorders and various degrees of impaired social functioning. The burden of the disease is important both for the individual and for the community. The disability-adjusted life years (DALY) index for MS, according to the World Health Organization (WHO), was 307 000 years in 2002 [2,3]. The overall view of MS consequences seen from the individual perspective is reflected by the studies focused on the quality of life (QoL). They show a clearly negative influence of MS on professional activity, financial status, family life, social contacts and the level of satisfaction with life.

After 15 years of disease, almost 70% of patients are unemployed, about 40% experience a major decline of financial status and are unable to manage the household independently, 25% of patients partially or completely abandon contacts with family and friends, and almost 50% change their leisure activities [4-8].

The studies with standardized tools designed to assess the QoL also confirm the negative influence of MS on the QoL. They report significantly worse QoL in MS patients than in comparable control groups or available normative values [9,10].

The burden related to MS urges scientists to search for any factors that might be modified or used in treatment and rehabilitation in order to decrease the negative influence of the disease. There are several groups of factors that decrease health-related QoL (HRQoL); they are divided into strong, moderate, and weak ones, according to the strength of their influence. The strong factors include mood disorders, cognitive impairment, lack of autonomy, pain, and lack of social support [7]. The importance of depression, cognitive decline, pain and lack of autonomy, especially in regard to the sense of self-efficacy, has repeatedly been confirmed in relevant studies [11-17].

The role of social support, on the other hand, although frequently studied, has only rarely been the subject of detailed analyses. A search of the available literature revealed only a few studies on that topic [13,18-20]. All of them suggested a positive influence of social support on the QoL, but their research issues and related choice of variables, study groups and methods of QoL assessment illuminated this complex issue only partially. Some of those studies limited the assessment of the QoL to selected areas (social functioning, mental domain) [18,19]; others did not include depression as a potential predictor [18-20]; yet another evaluated subjects who were very active physically [13].

While the QoL and social support in MS patients have been studied separately in the Polish population [21-25], no single study dealing specifically with the discussed problem has been published in Poland as yet.

This study was designed to evaluate QoL in MS patients and to assess the relationship between QoL and social support, taking into account key clinical factors and sociodemographic variables.

Table 1. Sociodemographic and clinical characteristics of the study sample*

Sociodemographic characteristics	
Gender	
Female	150 (71)
Male	60 (29)
Age [years]; mean (SD), median, IQR, range	37.4 (10.2); 36, 15.8, 21-59
Age strata	
20-29	54 (26)
30-39	73 (35)
40-49	46 (22)
50-59	37 (17)
Marital status	
Single (never married)	41 (20)
Married	126 (60)
Cohabiting	23 (11)
Divorced	15 (7)
Widowed	5 (2)
Place of living	
City	149 (71)
Country	61 (29)
Living conditions	
Alone	11 (5)
With family	195 (93)
With other persons	4 (2)
Education	
Primary	11 (5)
Vocational	35 (17)
Secondary	84 (40)
Higher	80 (38)
Employment status	
Employed/student	104 (50)
Disability pension or retired	93 (44)
Unemployed	13 (6)
Clinical characteristics	
Duration of illness [years]; mean (SD), median, IQR, range	6.9 (6.0); 6.3, 6.8, ≤ 1-29
EDSS score; mean (SD), median, IQR, range	2.6 (1.7); 2.0, 2.9, 0-8
BDI score; mean (SD), median, IQR, range	12.3 (9.9); 10, 12, 0-49

*data are presented as n (%), unless otherwise stated
SD – standard deviation, IQR – interquartile range, EDSS – Expanded Disability Status Scale, BDI – Beck Depression Inventory

Material and methods

Study participants

The study included 210 patients with MS hospitalized in the neurological ward between October 1, 2007 and February 1, 2008, as well as between October 1, 2008 and March 1, 2009. The major inclusion criterion was MS diagnosed according to McDonald's criteria. Exclusion criteria comprised other illnesses affecting functioning or abuse of alcohol or psychoactive drugs. The study group consisted of 150 women and 60 men, aged between 21 and 59 years (mean, 37.4; SD, 10.2). Most of them (71%) lived in urban areas. Most of them were married (60%), lived with the family (93%), and were moderately (40%) or highly educated (38%). Half of patients were employed; most subjects assessed their financial status as good (Table 1).

The comparative group consisted of 108 healthy subjects (74 women and 34 men), aged between 20 and 56 years (mean, 37.3 years; SD 9.2). Patients and controls did not differ significantly regarding sex, age, education or marital status. Control subjects more often were employed (98% vs. 50%, $p < 0.001$). The study was approved by the Research Ethical Committee at the Poznań University of Medical Sciences. All enrolled patients gave informed consent.

Measures

The following standardized research tools were used: (1) MSQOL-54 by Vickrey *et al.* [11], adapted for Polish by Jaracz *et al.* [26]. According to the scale content, the QoL concept indicates subjectively assessed health status in terms of abilities, limitations of functioning and symptoms, as well as the subjective assessment regarding the feelings and experiences associated with the disease.

MSQOL-54 contains a 36-item generic module derived from the SF-36 questionnaire, and an 18-item module related to the specific clinical condition. MSQOL comprises 52 items grouped into 12 domains: 1 – physical function, 2 – health perceptions, 3 – energy, 4 – role limitations – physical, 5 – pain, 6 – sexual function, 7 – social function, 8 – health distress, 9 – overall quality of life, 10 – emotional well-being, 11 – role limitations – emotional, and 12 – cognitive function. Domains 1, 2, 4, and 10 are identical to those in SF-36;

domains 3, 5, and 7 were modified by adding one question, and others are new domains, specific for MS.

The physical health composite consists of the first 8 domains, and domains 8-12 are combined into the mental health composite. MSQOL-54 also contains two additional questions related to the change in health and satisfaction with sexual function. Each subscale and each composite score ranges from 0 to 100, with a higher score indicating better QoL. Composite scores are derived from weighted sums of subscale scores. Cronbach's alpha reliability coefficient for the physical health composite of MSQOL-54 is 0.94, and for the mental health composite 0.91.

Some parts of the MSQOL questionnaire, namely domains 1-5, 7, and 10, were used to assess the QoL of the healthy subjects of the comparative group.

(2) Social Provisions Scale (SPS) by Cutrona and Russell (used with permission) [27]. The Polish translation was prepared by two independent translators using backward translation. Cronbach's alpha reliability coefficient for the Polish version of SPS is 0.89. SPS is based on the theoretical model of provision described by Weiss (1974), who combined major issues presented earlier and most influential concepts of provision (by Caplan, Cobb, Cohen, and Lazarus, among others). The SPS questionnaire contains 24 items grouped into 6 subscales: (1) *guidance*, meaning awareness of the existence of other persons from whom advice or information could be obtained; (2) *reassurance of worth*, understood as the relationship with persons who recognize the patient's competence; (3) *social integration*, meaning the sense of belonging to a group of friends sharing similar beliefs, interests, and leisure time activities; (4) *attachment*, i.e. emotional closeness; (5) *nurturance*, understood as providing assistance to others; (6) *reliable alliance* – assurance that some persons can be counted on. The total score of SPS ranges from 6 to 96 points (1-16 for individual subscales), a higher score denoting a higher level of support. SPS has already been used in earlier studies in MS patients [13].

(3) Beck Depression Inventory (BDI) to evaluate the patient's mood. This instrument enables the assessment of the most commonly observed depressive symptoms scored on a 4-grade scale of self-assessed symptom severity (0-3). The total score ranges from 0 to 63. In line with other authors, the cut-off value of at least 13 points was established as suggestive of the presence of depressive symptoms. BDI is the most commonly used scale to assess the mood of MS patients.

(4) Expanded Disability Status Scale (EDSS) to assess the severity of the disease through the evaluation

of seven functions most commonly affected by MS. A higher score indicates more severe clinical status. According to other authors, the EDSS score was used to discern three categories of clinical status: 0-4 pts – lack of symptoms or mild severity of symptoms (full mobility, patient can walk 500 m unaided and without rest); 4.5-6.5 pts – moderate severity of symptoms (motor disability interferes with activities of daily living); and 7-9.5 pts – severe symptoms (patient confined to a wheelchair).

Statistical analysis

Comparisons between groups were performed with Mann-Whitney U-test. A correlation-regression model was used to perform analyses within the patient group.

The first stage consisted of the correlation analysis between the physical health and mental health composites and the potential predictors of QoL: sociodemographic and clinical variables, and also social support. Pearson correlation coefficient was used to assess the relationships between continuous variables, and η coefficient was used to assess the relationships between continuous and nominal variables. For the purpose of that analysis, categorical variables were transformed into dummy variables ('0' or '1'): sex (men – 0, women – 1); education (secondary or higher – 0, primary/vocational – 1); marital status (married or cohabiting – 0, others – 1); living conditions (with other person – 0, alone – 1); employment status (employed – 0, unemployed – 1), disease form (relapsing-remitting – 0, others – 1). The second stage consisted of linear regression analysis with the entering method. It included the assessment of model assumptions, with residuals analysis. QoL was the dependent variable, and the variables that proved to be significant in correlation analyses were independent variables. *P*-value of < 0.05 was considered significant. Statistical analyses were performed using SPSS v.12 and Graph-Pad Prism v. 5 for Windows.

Results

Quality of life

Mean MSQOL score for the mental health domain was 60.0 (SD 20.7), and for the physical health domain, 53.6 (SD 19.8). The highest scores within the mental health domain were noted for overall quality of life (mean 69.7, SD 20.2), and the lowest ones for role limitations – emotional (mean 51.1, SD 44.7). The highest

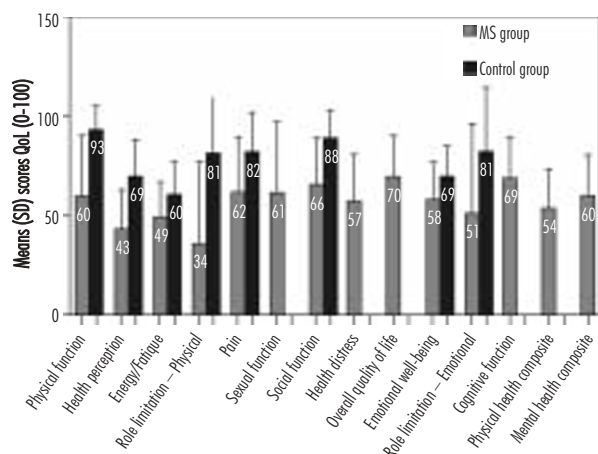


Fig. 1. Quality of life in MS patients: Physical and Mental Composite scales

scores within the physical health domain were noted for social function (mean 65.6, SD 23.1), and the lowest ones for role limitations – physical (mean 35.9, SD 40.9). The QoL in patients was worse than in controls in all compared domains of MSQOL-54 ($p < 0.01$) (Fig. 1).

Clinical variables and social support as potential predictors of QoL

The majority of patients (119, 57%) had relapsing-remitting MS. Secondary progressive MS was found in 77 (37%) patients, and primary progressive MS in 14 (7%) patients. Mean duration of the disease in the whole study group was 6.9 years (SD 6.0). The time since diagnosis was < 1 year in 15%, 1-5 years in 38%, 5-10 years in 28%, 10-20 years in 16%, and 20-29 years in 3% of patients. At the time of the study, 75% of patients experienced symptoms and signs related to relapse of the disease. Symptoms and signs were mild

Table 2. Social support according to Social Provisions Scale (SPS)

SPS subscales	Mean	SD	Median	IQR	Range
Guidance	13.7	2.3	14.0	4	6-16
Reassurance of worth	12.2	2.2	13.0	3	5-16
Social integration	12.6	2.2	12.0	2.3	5-16
Attachment	13.3	2.4	14.0	4	6-16
Nurturance	12.6	2.3	13.0	3	6-16
Reliable alliance	13.6	2.3	13.0	4	6-16
Total score	78.0	10.9	79.0	16	36-96

SD – standard deviation, IQR – interquartile range

(EDSS ≤ 4) in 179 (85%) patients, moderate (EDSS 4.5-6.5) in 28 (13%) patients, and severe (EDSS ≥ 7) in 3 (2%) patients. Mean EDSS score in the whole group was 2.6 (SD 1.7).

The mood according to the BDI score was normal in 124 patients (59%). BDI score suggested presence of depressive symptoms in 86 (41%) patients. Mean BDI score was 12.3 (SD 19.9) (Table 1).

The mean total SPS score was 78.0 (SD 10.9). The majority of patients (136, 65%) had an SPS score above the third quartile, which suggested a high level of perceived support. Mean scores of the six subscales were similar and ranged between 12.2 and 13.7 pts (Table 2).

Correlation analysis between physical health and mental health composites of MSQOL-54 and potential predictors of QoL

A significant inverse correlation was noted between the physical health composite or mental health composite

Table 3. Correlation analysis between quality of life (MSQOL – 54 composite scores) and sociodemographic factors, clinical variables and social support

Variable	MSQOL – 54	
	Physical health composite	Mental health composite
Age	-0.45**	-0.32**
Employment ^a	-0.30**	-0.32**
Education ^a	-0.30**	-0.19**
Disease form ^a	-0.41**	-0.35**
Duration of illness ^a	-0.38**	-0.27**
Symptom severity (EDSS score)	-0.45**	-0.27**
Depression (BDI score)	-0.59**	-0.69**
Social support (SPS)		
1. Guidance	0.23**	0.31**
2. Reassurance of worth	0.20**	0.25**
3. Social integration	0.16*	0.21**
4. Attachment	0.21**	0.34**
5. Nurturance	0.19**	0.23**
6. Reliable alliance	0.17**	0.24**
Total score	0.27**	0.33**

* $p < 0.05$, ** $p < 0.01$

^athe eta coefficient has been used, for the remaining variables Pearson's coefficient was applied. EDSS – Expanded Disability Status Scale, BDI – Beck Depression Inventory, SPS – Social Provisions Scale

and age, employment status, education, disease form, disease duration, EDSS score and the severity of depression (BDI score) (Table 3). Social support scores positively correlated with QoL, both in terms of the total score and for each subscale. The correlation coefficient values ranged from 0.16 to 0.33 (Table 3). Additional analyses among specific SPS subscales and mental health and physical health domains in MSQOL-54 mostly confirmed the correlations seen previously for the total scores of QoL. Correlation coefficient values were 0.2-0.4 and were significant for 33 out of 48 physical health domains and for 27 out of 30 mental health domains.

Regression analysis

Multiple regression analysis with the physical health composite as the dependent variable showed the independent effect of: (1) age (QoL worse with more advanced age), (2) employment status (QoL worse in the unemployed), (3) disease form (QoL better with relapsing-remitting MS), and (4) depression (QoL worse with more severe depressive symptoms). All those variables explained 60% of variability of the analysed variable, and depressive symptoms were the most potent predictor of QoL (see Table 4 for standardized β coefficients).

Analogous analysis with the mental health composite as the dependent variable revealed independent effects of the severity of depressive symptoms and disease form. Those variables together explained 56% of variability of QoL. Again, social support was not significant (Table 4).

Additional regression analyses were performed after the exclusion of depression. Independent predictors of MSQOL – mental health composite included social support ($\beta = 0.27, t < 0.001$), disease form ($\beta = -0.27, t < 0.001$) and employment status ($\beta = 0.18, t = 0.007$). Independent predictors of MSQOL – physical health composite included: age ($\beta = -0.27, t < 0.0001$), employment status ($\beta = -0.26, t < 0.0001$), disease form ($\beta = -0.19, t = 0.001$), and EDSS score ($\beta = -0.27, t = 0.002$).

Discussion

HRQoL includes several domains that are subject to change to various degrees due to the disease. This study showed that the QoL in MS patients was significantly worse than in controls. The negative influence of the disease was greater in physical domains than in psychosocial domains. The unfavourable consequences of MS were seen predominantly in limitations of functioning and activities due to the problem with physical health and in the decreased self-estimation of health status. A similarly divergent profile of QoL in MS patients was reported by other authors, who suggested better adaptation to the disease in the mental than the physical domain [11,21,28,29].

Assessment of the relationship between QoL and social support was one of the major goals of this study. According to the theoretical assumptions, support is a protective factor for QoL and plays the role of a moderator, involved in the complex mechanism of stress and coping in the case of disease [30]. Consequently, a positive relationship between studied factors was expected.

Table 4. Significant predictors of quality of life

	B	β	t	P
Predictors of physical health composite^a				
Age	-0.39	-0.20	-4.1	< 0.001
Employment	-0.68	-0.19	-3.8	< 0.001
Form of illness	-5.81	-0.15	-3.0	0.003
Disability (EDSS score)	-1.86	-0.16	-3.2	0.002
Depression (BDI score)	-0.94	-0.46	-9.9	< 0.001
Predictors of mental health composite^b				
Depression (BDI score)	-1.43	-0.67	-14.1	< 0.001
Form of illness	-9.19	-0.22	-4.64	< 0.001

^a $F_{(5,202)} = 62.9; p < 0.001; \text{adjusted } R^2 = 0.60, \text{ } ^bF_{(5,205)} = 129.9; p < 0.001; \text{adjusted } R^2 = 0.56, \text{ EDSS – Expanded Disability Status Scale, BDI – Beck Depression Inventory}$

However, the expected relationship was revealed in simple analyses only (correlation analysis), but it became non-significant in the presence of other variables. It may be suggested that the major factor playing the role of suppressor was emotional status, which was the most potent predictor of QoL. This is also supported by the additional regression and correlation analyses. They showed that the association between support and depression was stronger ($r = 0.42$) than with the QoL (see Table 3).

Our data suggest that the role of support in QoL of MS patients is not unconditional and one-dimensional. This view is supported by some reports of other authors [25,31-34]. Pakenham *et al.* [32] studied 122 MS patients and showed that the major predictors of adaptation to the disease included level of ability and coping directed towards problem solving, while support was of small importance. Messmer Uccelli *et al.* [33] also stated that the attendance of MS patients at support groups did not improve their QoL, and it exerted a negative effect in patients with good mental functioning. Szepietowska and Przybyło [25] established that social support was not associated with the sense of self-alienation. Mohr *et al.* [34], on the other hand, observed that the improvement of social support in MS patients during antidepressive treatment was associated with an improvement in emotional status. It may be concluded, therefore, that the positive influence of provision of social support requires additional conditions, e.g. stable emotional status, or should be adjusted to the needs, as suggested by the literature [34]. This thesis requires further studies, possibly complemented by qualitative analyses.

As previously noted, the emotional status was the predominant predictor of QoL, in both the physical and mental domain. This result confirms several previous reports, both Polish and foreign ones, according to which mood disorders, especially depressive ones, are among the most important factors that decrease patients' QoL [16,24,35,36].

Those data and the scale of the problem (lifetime prevalence of depression reaching 36-54%) substantiate the early detection and treatment of depressive disorders in the course of MS.

The disease form was the second independent determinant of both studied areas of QoL. This is also confirmed by other authors, who reported that primary progressive MS exerted a much greater negative impact than secondary progressive MS, which in turn affected QoL more negatively than the remitting-relapsing form [36].

Other factors explaining QoL in the physical domain included neurological status, age and employ-

ment status. The importance of symptoms severity is confirmed by the majority of researchers, although it explains no more than 30% of QoL variability [20,36].

The results related to employment status confirm the importance of professional work in the life of an individual. It may also be partially associated with the notion that the unemployed patients were in significantly worse neurological status than those who were employed. The negative relationship between QoL and age might be partially explained by the correlation of that factor with the duration of the disease ($r = 0.48$), although most studies show that the predictive value of age for QoL in MS patients is limited, similarly to other sociodemographic variables [37].

Several limitations of the study should be acknowledged. The study group included mostly patients with mild disability and with short duration of the disease. Thus, the generalization of the results for the whole MS population should be made cautiously. Similar limitations are due to the fact that the vast majority of patients were studied during a relapse, and it might translate into worsening of the emotional status and increased depressive symptoms. Nevertheless, this study provided valuable data related to the QoL in MS patients, and highlighted that the problem of support in this chronic neurological disorder is probably more complex than previously thought. It is therefore worthy of note and of further study.

Conclusions

1. MS influences QoL in both the physical and psychological domain.
2. Emotional status is the major predictor of QoL in these patients.
3. Social support has a positive impact on QoL in general, but its effect might be weakened in patients with severe depressive symptoms.
4. Early detection and treatment of mood disturbances might significantly improve QoL in MS patients.

Disclosure

Authors report no conflict of interest.

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