

# The relationship between psychopathology, psychosocial adjustment, social support and quality of life in multiple sclerosis

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## ABSTRACT

**Objectives:** Multiple Sclerosis (MS) is a chronic disease which affects physical, psychological and social functioning of patients. In this study we aim to indicate psychiatric comorbidity, some psychosocial factors and their associations with quality of life in patients with MS.

**Methods:** A total of 227 patients underwent psychiatric examination and the following scales were applied: Socio-demographic data form, Hospital Anxiety and Depression Scale (HADS), Multiple Sclerosis Quality of Life-54 (MSQOL-54), Psychosocial Adjustment to Illness Scale-Self report (PAIS-SR) and Multidimensional Scale of Perceived Social Support (MSPSS).

**Results:** Among 227 patients with MS, 67.8% (n = 154) had psychiatric diagnosis; 24.2% (n = 55) had depression, 19.8% (n = 45) had adjustment disorder, 14.9% (n = 34) had anxiety disorder, 7.1% (n=16) had dysthymic disorder and 1.8% (n = 4) had bipolar disorder. Patients with a psychiatric diagnosis had lower scores in role limitations due to emotional problems, emotional well-being, health perceptions, social function, cognitive function, health distress and mental health composite of MSQOL-54. PAIS-SR and MSPSS scores were significantly lower in MS patients with a psychiatric diagnosis. PAIS-SR scores were negatively correlated with role limitations-emotional, emotional well-being, social function, sexual function, satisfaction with sexual function, physical health composite and mental health composite scores of MSQOL-54. MSPSS total score was positively correlated with emotional well-being score of MSQOL-54.

**Conclusions:** In MS patients, there is a high prevalence of psychopathology and it is associated with quality of life, perceived social support and psychosocial adjustment of the patients. Quality of life is reduced especially in emotional and mental aspects in patients with a psychiatric diagnosis. Diagnosis and treatment of psychopathology in MS patients seems crucial to decrease disease burden.

**Keywords:** Multiple sclerosis, psychopathology, psychosocial adjustment, social support, quality of life

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**M**ultiple sclerosis (MS) is a chronic inflammatory disease of the central nervous system which causes motor and sensory impairment by progressive demyelination. It is the most common cause of neurologic disability in young and middle-aged adults. MS is twice as common in females as in males [1].

The relationship of psychological and psychiatric disorders with MS is complex. They might be related to psychosocial factors or they might be symptoms resulting from the neuropathological process. They aggravate physical symptoms like fatigue leading to disability, suffering and disruption of family, work and social life adding to the burden of the chronic inflammatory disease [2]. The rate of depression and other psychiatric disorders is greater in MS than in other chronic medical or neurological diseases [3, 4]. Treating depression actually results in improvements on a number of aspects of social support and there is evidence that depression itself may actually cause reduced social support [5, 6]. The lifetime prevalence of any anxiety disorder observed in MS was about 35.7%. Female gender, comorbidity of depression, and restricted social support were considered as risk factors, but the diagnosis of anxiety disorders had been overlooked and not been treated in most subjects [7].

The literature about bipolar disorder in patients with MS is scarce. Like depression, mania may occur as part of the physical disorder or secondary to drug treatments. There is a doubled rate of bipolar disorder in MS compared with the general population [8].

Psychosocial adjustment to MS can be understood as the ability to foster a positive outlook on life, continuing to grow and develop in spite of MS [9]. Among the key elements of successful adjustment to a chronic illness are the successful performance of adaptive tasks (eg, adjustment to disability, maintained emotional balance, healthy relationships), the absence of psychological disorders, the presence of low negative affect and high positive affect, adequate functional (eg, work) status, and the satisfaction and wellbeing in various life domains [10].

Social support is defined as the degree to which an individual's needs for socialization, assistance, cognitive guidance, social reinforcement, and emotional sustenance are met through interaction with the social network [11]. Recent research showed that social support acts as primary protective factor for

mortality, morbidity and disability in chronic patients by facilitating healthy behaviors and compliance to treatments [12]. In general, the research suggests that social support is related to better psychosocial adaptation to MS [13].

Chronic illnesses have a major impact on all aspects of an individuals' life, affecting physical, psychological and social functioning [14]. Chronic symptoms, long-lasting treatment, incomplete recovery after relapses, the accumulation of new deficits, and the progressive nature of the condition interfere with daily activities of individuals and have negative impact on their wellbeing. Studies show that QoL measurements are constantly lower in patients with MS. Estimation of health related QoL (HRQoL) is necessary when analyzing the effectiveness of treatment modalities and in follow up of patients with chronic diseases such as MS. Main factors related with HRQoL are physical factors (sensitive/motor deficits, fatigue, pain, and sexual/bladder dysfunction), psychological factors (depression, anxiety, cognitive disturbances, and coping strategies) and social factors (family/social relationships and work activity) [15].

In the current study, we aim to investigate the features of psychosocial adjustment to disease, perceived social support, and their relations with health related quality of life in patients with MS. We also aim the relation of these variables with comorbid psychopathology.

## **METHODS**

This study was conducted at Psychiatry and Neurology Departments of Uludag University Medical Faculty Hospital in Turkey. Two hundred and fifty five patients who applied to Neurology department and were diagnosed as MS were recruited. The exclusion criteria for the patients were as follows: psychotic, demented or mentally retarded patients, alcohol or substance abusers, patients who were on psychiatric treatment during last 3 months, patients who had an active MS episode, patients who were on steroid treatment, patients who had an invasive procedure during last 3 months, patients with another chronic disease other than MS and illiterate patients. After applying the exclusion criteria, 227 patients were included in the study. Physical and neurological

examinations were done by a neurologist and routine blood tests were applied to all subjects. Patients underwent a psychiatric examination comprised of a semi-structured clinical interview of the DSM-IV-TR [16]. The Ethical Committee of the institution approved the study. All subjects gave written informed consent to participate in this study. The assessments were performed using the scales below: Socio-demographic data form, Hospital Anxiety and Depression Scale (HAD), Multiple Sclerosis Quality of Life-54 (MSQOL-54), Psychosocial Adjustment of Illness Scale – Self Report (PAIS-SR) and Multidimensional Scale of Perceived Social Support (MSPSS).

## Measures

### *Socio-demographic data form:*

A form prepared by the researchers in order to obtain socio-demographic data and to assess clinical features related with MS.

### *Hospital Anxiety and Depression Scale (HADS):*

The Hospital Anxiety and Depression Scale (HADS) is a 14-item scale that provides a brief state measure of anxiety and depression. Turkish version of HADS is valid and reliable in medically ill patients [17].

### *Quality of Life Scale (QOL) Short Form 36 (SF-36):*

The form was developed by Ware and Sherbourne [18]. Turkish validity study was done by Koçyiğit et al. [19]. It is composed of 36 items that measure eight dimensions: physical functioning, social functioning, limitations of role functioning based on physical problems, limitations of role functioning based on emotional problems, mental health, energy/vitality, body pain and general health perceptions. Higher scores point to increased quality of life [19].

### *Psychosocial Adjustment to Illness Scale-Self Report (PAIS-SR):*

Developed by Derogatis and Lopez in 1983, this is a multidimensional scale to examine the psychosocial adjustment to the disorder [20,21]. Lower scores from the PAIS-SR scale indicate good psychosocial adjustment to the disorder. PAIS-SR scores below 35 are considered as “good psychosocial

adjustment”, scores from 35 to 51 as “fair psychosocial adjustment” and scores above 51 as “poor psychosocial adjustment”. Turkish adjustment of PAIS-SR and its validity and reliability studies in Turkey were performed by Adaylar [20].

### *Multiple Sclerosis Quality of Life-54 (MSQOL-54):*

Quality-of-Life was measured by the disease-specific instrument MSQOL-54 (Turkish version). This questionnaire includes one of the most widely used QOL measures, the SF-36, as a generic core and an additional 18 items that are specific to MS. Scoring was performed using the Likert method, and higher values indicated better functioning and well-being. The Turkish adaptation was developed by Tulek in 2006. The MSQOL-54 consists of two sections as physical health composite (MSQOL-54P) and mental health composite (MSQOL-54M). It also has two section scores, 13 category scores and two independent items [22].

## Statistical Analysis

All statistical analyses were performed with SPSS ver. 22.0. Shapiro Wilk test was used as normality test. Continuous variables were compared using Student's t-test for normally distributed data and Mann-Whitney U test when the data were not normally distributed. Categorical variables were compared using Pearson's chi-squared test, Fisher's exact test and Fisher-Freeman-Halton test. Correlations between variables were tested using Spearman correlation coefficients. A  $p$  value  $< 0.05$  was considered as significant.

## RESULTS

Demographic findings including age, gender, marital status, education level, smoking status and exercise status and data about presence of a psychiatric diagnosis are given in Table 1. Among 227 patients, 32.2% ( $n = 73$ ) had no psychiatric diagnosis, 24.2% ( $n = 55$ ) had depression, 19.8% ( $n = 45$ ) had adjustment disorder, 14.9% ( $n = 34$ ) had anxiety disorder, 7.1% ( $n = 16$ ) had dysthymic disorder and 1.8% ( $n = 4$ ) had bipolar disorder.

The clinical characteristics of the patients are given in Table 2. There were no statistically significant difference between patients with or without a

**Table 1.** Demographic features of multiple sclerosis (MS) patients

Demographic features	MS patients (n = 227)
Age (years)	37.0 ± 9.9
<b>Gender</b>	
Male	64 (28.2%)
Female	163 (71.8%)
<b>Marital Status</b>	
Married	41 (18.1%)
Single	149 (65.6%)
Divorced or widowed	37 (16.3%)
<b>Education Level</b>	
Primary school	113 (49.8%)
High school	73 (32.2%)
University	41 (18.1%)
<b>Smoking Status</b>	
Smoking	49 (21.6%)
Nonsmoking	178 (78.4%)
<b>Exercise Status</b>	
Exercising	68 (30%)
Not exercising	159 (70%)
<b>Psychiatric Diagnosis</b>	
Depressive disorder	55 (24.2%)
Adjustment disorder	45 (19.8%)
Anxiety disorder	34 (14.9%)
Dysthymic disorder	16 (7.1%)
Bipolar disorder	4 (1.8%)
<b>No psychiatric diagnosis</b>	73 (32.2%)

Data are mean ± standard deviation or number (%). MS = multiple sclerosis

**Table 2.** Clinical characteristics of multiple sclerosis (MS) patients

Clinical Characteristics	MS Patients (n = 227)
<b>Type of MS</b>	
Clinically Isolated Syndrome	33 (14.5%)
Relapsing-remitting MS	158 (69.6%)
Primary progressive MS	20 (8.8%)
Progressive-relapsing MS	9 (4.0%)
Secondary progressive MS	7 (3.1%)
<b>Duration of disease (years)</b>	6.8 ± 3.5
<b>Number of attacks</b>	3.5 ± 1.8
<b>Number of hospitalizations</b>	3.1 ± 1.6
<b>Medication</b>	
Interferon beta	151 (66.5%)
Glatiramer acetate	36 (15.9%)
Natalizumab	29 (12.8%)
Other (Fingolimod, Mitoxantrone, Cyclophosphamide)	11 (4.8%)

Data are mean ± standard deviation or number (%). MS = multiple sclerosis

psychiatric diagnosis in terms of demographic variables, MS type, duration of MS, number of attacks and hospitalizations and medication type.

Table 3 shows mean scores of PAIS-SR, HADS, MSPSS and MSQOL-54 in two groups of MS patients with and without a psychiatric diagnosis. Depression ( $p < 0.001$ ) and anxiety ( $p < 0.001$ ) scores of patients with a psychiatric diagnosis are significantly higher than those without a psychiatric diagnosis. PAIS-SR scores of patients without a psychiatric diagnosis were significantly lower than those with a psychiatric diagnosis ( $p < 0.001$ ). Regarding MSPSS; total score, family, friends and significant other score were significantly higher ( $p < 0.05$ ) in patients without a psychiatric diagnosis. Emotional role limitations ( $p < 0.001$ ), emotional well-being ( $p < 0.001$ ), health perceptions ( $p < 0.05$ ), social function ( $p < 0.001$ ), cognitive function ( $p < 0.05$ ), health distress ( $p < 0.05$ ) and mental health composite ( $p < 0.001$ ) domains of MSQOL-54 differed significantly between groups. Patients without a psychiatric diagnosis had higher scores in these domains.

Correlation of age, duration of disease, number of attacks and hospitalizations were evaluated with the scores of applied scales. There was a positive correlation between the number of attacks and HADS anxiety score ( $r = .138, p = 0.037$ ) as the only correlation, and there was not any other significant correlation.

When the scale scores were evaluated, there were significant positive and negative correlations among each other. PAIS-SR scores were positively correlated with HADS depression ( $r = .307, p < 0.001$ ) and anxiety ( $r = .161, p = 0.015$ ) scores. PAIS-SR scores were negatively correlated with role limitations-emotional ( $r = -.192, p = 0.004$ ), emotional well-being ( $r = -.156, p = 0.019$ ), social function ( $r = -.225, p = 0.001$ ), sexual function ( $r = -.163, p = 0.014$ ), satisfaction with sexual function ( $r = -.179, p = 0.007$ ), physical health composite ( $r = -.144, p = 0.030$ ) and mental health composite ( $r = -.193, p = 0.004$ ) scores of MSQOL-54.

Multidimensional Scale of Perceived Social Support (MSPSS) total score was negatively correlated with HADS depression ( $r = -.243, p < 0.001$ ) and anxiety ( $r = -.146, p = 0.028$ ) scores. MSPSS total score was also positively correlated with emotional well-being ( $r = .134, p = 0.044$ ) score of

**Table 3.** Scale scores and p values of patients with and without psychiatric diagnosis

Scales	Patients with psychiatric diagnosis (n = 154)	Patients without psychiatric diagnosis (n = 73)	p value
<b>PAIS-SR</b>	62.2 ± 15.4	52.7 ± 16.9	< <b>0.001</b>
<b>HADS</b>			
Depression score	9.6 ± 4.0	4.6 ± 2.5	< <b>0.001</b>
Anxiety score	10.2 ± 3.4	6.1 ± 2.6	< <b>0.001</b>
<b>MSPSS</b>			
Total	58.7 ± 15.5	65.1 ± 13.8	<b>0.002</b>
Family	20.6 ± 6.5	22.9 ± 5.8	<b>0.016</b>
Friend	18.8 ± 6.7	20.8 ± 5.9	<b>0.029</b>
Significant other	19.9 ± 7.0	21.4 ± 5.4	<b>0.022</b>
<b>MSQOL-54</b>			
Physical function	55.7 ± 21.1	59.5 ± 22.6	0.256
Role limitations-physical	41.0 ± 22.1	45.9 ± 19.9	0.106
Role limitations-emotional	46.1 ± 20.9	63.8 ± 20.1	< <b>0.001</b>
Bodily pain	64.3 ± 18.7	66.5 ± 24.5	0.376
Emotional well-being	55.4 ± 15.6	70.3 ± 18.4	< <b>0.001</b>
Energy	51.3 ± 19.1	52.8 ± 18.8	0.639
Health perceptions	47.6 ± 18.9	54.5 ± 17.2	<b>0.006</b>
Social function	58.6 ± 18.8	75.4 ± 20.8	< <b>0.001</b>
Cognitive function	70.6 ± 19.1	76.4 ± 20.7	<b>0.017</b>
Health distress	59.8 ± 17.6	65.8 ± 20.8	<b>0.026</b>
Sexual function	61.6 ± 19.3	65.9 ± 23.1	0.162
Change in Health	52.9 ± 20.5	55.2 ± 19.9	0.455
Satisfaction with sexual function	55.6 ± 18.7	60.9 ± 22.3	0.124
Overall quality of Life	54.8 ± 17.6	59.1 ± 16.7	<b>0.066</b>
Physical health composite	52.7 ± 16.2	56.1 ± 16.5	0.172
Mental health composite	50.8 ± 16.0	65.6 ± 15.7	< <b>0.001</b>

HADS = Hospital Anxiety and Depression Scale, MSQOL-54 = Multiple Sclerosis Quality of Life-54, MSPSS = Multidimensional Scale of Perceived Social Support, PAIS-SR = Psychosocial Adjustment to the Illness Scale-Self-Report

MSQOL-54.MSPSS family score was negatively correlated with HADS depression ( $r = -.197, p = 0.003$ ) score.MSPSS friend score was negatively correlated with HADS depression ( $r = -.176, p = 0.008$ ) and anxiety ( $r = -.149, p = 0.025$ ) scores. MSPSS significant other score was negatively correlated with HADS depression ( $r = -.141, p = 0.033$ ) and positively correlated with health perceptions ( $r = .157, p = 0.018$ ) and cognitive function ( $r = .141, p = 0.034$ ) scores of MSQOL-54.

## DISCUSSION

In the present study, we found that among 227 patients with MS, 32.2% (n = 73) had no psychiatric

diagnosis, 24.2% (n = 55) had depression, 19.8% (n = 45) had adjustment disorder, 14.9% (n = 34) had anxiety disorder, 7.1% (n = 16) had dysthymic disorder and 1.8% (n = 4) had bipolar disorder. Our study revealed a high prevalence of psychopathology in patients with MS in comparison to what is expected in the general population. A significant prevalence of psychological and psychiatric symptoms in patients with MS, compared to general population and individuals with similar degrees of disability, has been reported in the literature [23]. Among the psychiatric disorders, depression is the most frequently related [24] as our study also reveals. Depression is thought to be more common in MS than in other chronic illnesses and neurologic disorders. Limited data on anxiety disorders in MS patients reveal that anxiety is

common enough to necessitate consideration in the clinical area [25]. Although, prevalence of bipolar disorder (1.8%) is only slightly higher than general population (1%) in our study, there are studies suggesting a higher prevalence of about 13% in MS [26]. General conception is that bipolar disorder and MS coexistence is not common but well proven [27]. To our knowledge there is no study investigating the prevalence of dysthymia in MS.

There are some studies which found associations between depression and severity and duration of disease, age and gender; but those findings could not be replicated in most of the other studies [3, 6, 25, 28]. Clinically, depression and anxiety seem to be associated with disease activity but not with duration or severity. No definite evidence supports the association between interferon beta and depression. Instead, the control of psychiatric symptoms seems to improve the adherence to long-term disease-modifying drugs [23]. In our study, we found no significant difference between psychiatric situation of patients with demographic and clinical characteristics of MS, in line with literature data.

A diagnosis of MS which usually comes in people's most productive years, has great psychosocial impact [29]. MS adds new demands and challenges to both the individual and the family. People with MS experience loss of roles, relationship changes and financial difficulties. These aspects of the disease have a direct effect on psychosocial wellbeing [30]. The high prevalence (14.9%) of adjustment disorders found in our study reflects the psychosocial burden of the disease. In the present study, PAIS-SR scores were significantly higher in MS patients with psychopathology indicating poorer psychosocial adjustment. Poorer psychosocial adjustment is found to be correlated with higher depression and anxiety scores. Literature data supports negative impact of psychopathology on psychosocial adjustment in physical illness [31, 32]. Poorer psychosocial adjustment to chronic illness has also negative impact on quality of life parameters [33]. In a recent study, psychosocial adjustment was found to be a statistically significant predictor of QoL in patients and caregivers in Parkinson's Disease. Psychosocial adjustment process helps patients to fit their social activities and expectations with their new situation and therefore

facilitate the reconstruction of their self-identity and their sense of control in the new situation that seems to affect their QoL [34]. Similarly, in the present study, PAIS-SR scores were found to be negatively correlated with role limitations-emotional, emotional well-being, social function, sexual function, satisfaction with sexual function, physical and mental health composite domain scores of MSQOL-54.

Social support is defined as a type of positive interaction and helpful behavior provided to a person in need of support [35]. A review of the literature revealed that social support was related to positive outcomes on individual's health and well-being and increased individual's adaptive capacity to deal with stress and illness [36]. Social support was found to be an important factor that helped people with MS cope with their diagnosis and symptoms [37]. Numerous studies indicate that social support is an important determinant of HRQoL and depression and anxiety in different chronic diseases [38, 39]. Increased social support positively affects outcomes through a number of mechanisms, including decreased levels of depressive affect, increased quality of life, increased access to health care, increased patient compliance with therapies, and direct physiologic effects on the immune system. Low levels of social support could be viewed as a risk factor for depression and anxiety and a target for early intervention by clinicians [40]. In line with this literature data, perceived total, family, friends and significant other social support was significantly lower in patients with psychopathology compared with patients without psychopathology in our study. Furthermore, MSPSS total score was negatively correlated with HADS depression and anxiety scores. Whether lower perceived social support increases the risk of psychopathology or the presence of psychopathology affects the perception of social support is controversial. Having a psychopathology itself could prevent socialization.

Schwartz and Frohner [41] indicated that social support in MS patients had a significant contribution to quality of life. HRQoL correlates strongly with measures of social stigma and perception of social desirability to which close personal relationships are perhaps the biggest influence [42]. In the present study; MSPSS total score was positively correlated with emotional well-being score of MSQOL-54

indicating relation of social support with emotional well-being. MSPSS significant other score was positively correlated with health perceptions and cognitive function scores of MSQOL-54 indicating the importance of close relationships in mental domains of QoL.

Health-related quality of life (HRQoL) has been more intensively studied in multiple sclerosis (MS) than in any other neurological disorder. Many psychosocial factors such as coping, mood, self efficacy, and perceived support influence the quality of life of patients with MS more than biological variables such as weakness or extent of MRI lesions [43]. Depression is one of the strongest predictors of HRQoL in MS [44]. Depression impairs motivation retarding physical progress, can distort an individual's view of the world and his/her health and reciprocally low quality of life can lead to depression [44]. Anxiety is also a known risk factor for poor HRQoL in many disorders but has rarely been studied in patients with MS. health anxiety involving fears of disease progression is most troubling for many patients with a physical disease [45]. In MS, anxiety has been linked with low HRQoL in some, but not all studies [46, 47]. Patients with myasthenia gravis and a psychiatric diagnosis were also found to have lower scores in general health, vitality, social functioning, emotional role and mental health domains of SF-36 compared with those patients without a psychiatric diagnosis. Four of these five domains (vitality, social functioning, emotional role and mental health) belong to mental health indicating that having a psychiatric diagnosis is related with decrement mostly in mental aspects of HRQoL [32]. Supporting literature data; mostly emotional and mental aspects of QoL (emotional role limitations, emotional well-being, health perceptions, social function, cognitive function, health distress and mental health composite) were more negatively affected in patients with a psychopathology in the present study. In the presence of psychopathology, the effects of chronic illness and of treatment could be perceived more negatively resulting with more decrement in HRQoL.

### Limitations

There are some limitations of the present study. Cross-sectional design is a major limitation which

does not allow to infer causality but only to show associations. Secondly, our study does not have a control group consisting of healthy individuals or patients with another chronic disease. Thirdly, personality disorders which could have a significant impact on psychosocial features were not evaluated in our study.

### CONCLUSION

We have shown a high prevalence of psychopathology in MS patients. Psychopathology has a significant impact on quality of life, perceived social support and psychosocial adjustment. Quality of life is reduced especially in emotional and mental domains if the patient had a psychiatric diagnosis. Social support is an important predictor of at least some domains of QoL and effects psychosocial adjustment. We suppose that our results may have a practical implication. We believe that psychiatric disorders should be carefully evaluated and treated in patients with MS in order to reduce disease burden. Psychiatric consultation should be considered as a key element of approach to MS. Interventions to increase social support should be considered in psychosocial therapeutic protocols. Prospective studies investigating the effects of psychiatric interventions on MS outcomes are needed to verify those findings.

### Authorship declaration

All authors listed meet the authorship criteria according to the latest guidelines of the International Committee of Medical Journal Editors, and all authors are in agreement with the manuscript.

### Author contributions

Concept - VOK, ZK, BA, ÖT; Design - VOK, ZK, BA; Supervision - ÖT, ÖFT, SK; Resources and materials - ZK, BA, AS, ÖFT; Data collection and processing - VOK, BA, ÖT, AS; Analysis interpretation and literature search - GÖ, VOK, ZK, ÖT, BA; Writing manuscript - VOK, ZK; Critical review - ÖFT, SK.

### Conflict of interest

The authors disclosed no conflict of interest during

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