

Quality of life in relapsing-remitting multiple sclerosis

Nuray Dayapoglu¹, Mehtap Tan²

ABSTRACT

Objective: To describe quality of life (QOL) and the factors that affect QOL in people with multiple sclerosis (MS).

Methodology: The sample consisted of 60 MS patients from neurology outpatient clinics of Yakutiye Hospital in eastern Turkey; they were included in the study between December 2008 and June 2009.

Results: The mean score of the physical health composite of QOL was 46.25 ± 23.95 , of mental health composite was 46.63 ± 24.34 . QOL was affected by factors such as age, gender, education, employment status, income level, place of residence and duration of illness. There is a negative and significant correlation between the fatigue severity and the areas of QOL, such as, physical health and mental health. Also, there is a negative and significant correlation between depression and QOL.

Conclusions: Reduction of depressive symptoms and fatigue may be the decisive factors in improving QOL. Increased use of active coping strategies may put patients at risk of decreased fatigue and depressive symptoms.

KEY WORDS: Multiple sclerosis, Quality of life, Fatigue, Depression.

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INTRODUCTION

Multiple Sclerosis (MS) is a chronic demyelinating disease of the central nervous system characterized by disturbances in nerve conduction and manifested by various clinical features. This disease affects a significant part of life and is a significant health problem that causes limitations in individuals' physical, emotional, social and cognitive functioning.¹

Characteristically, MS strikes between the ages of 20-40 and affects approximately one million adults, mostly women, worldwide. In industrialized countries, prevalence rates vary between 15-145 per hun-

dred thousand.² It is estimated that the prevalence of MS in Turkey is about 30-40 in hundred thousand, and the total number of MS patients is 35 thousand.³

The QOL is a complex concept and it expresses a totality. One of the most important factors encompassed within this concept is health. However, many factors such as economic status, profession, education, and residence in which an individual lives can all contribute in determining QOL level in addition to one's health status.⁴

People with MS often complain of poor exercise tolerance and exertion fatigue that limit their daily living activities. Fatigue is the most frequently reported symptom of persons with MS, with surveys reporting prevalence rates of up to 92%⁵ and brings about lower QOL.⁶

Depression is more common in MS than in other chronic illnesses or neurological disorders. It can result from individual reactions to MS-related disability and symptoms, as well as, from the disease process itself.⁷ Lifetime prevalence estimates of depression in MS patients are high, typically falling around 50%.⁸

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In the past, only few authors have investigated the influence of MS-related depression and fatigue on QOL. Most studies have showed that the disability status had a limited influence on QOL⁹⁻¹¹ whereas depression^{12,13} and fatigue^{6,14} were clearly associated with reduced QOL scores in patients with MS.

Although in recent years there has been an increase in research to evaluate QOL and the effect QOL in MS there has been a limited number of studies conducted in Turkey on this subject. We believe this study will provide a foundation for future research on this subject in Turkey.

The aim of this study was twofold. First, to assess whether there are relations in the QOL and fatigue and depression between of MS patients. Secondly, to assess whether patients' QOL and sociodemographic (age, gender, marital status, education, employment status, place of residence, income level, duration of disease) factors are associated.

METHODOLOGY

Patients: This descriptive research was conducted with a total of 60 MS patients who applied to the Neurology Polyclinic of Yakutiye Hospital between May-November 2008 and meet the research criteria. The site of this research, Yakutiye Hospital, is the largest hospital in eastern Turkey.

The questionnaires were filled by the researchers through face to face interviews with patients. Each interview lasted around 10-15 minutes.

Inclusion criteria were as follows;

- * have clinically definite MS diagnosis according to Poser's criteria
- * be relapsing-remitting MS"
- * be Expanded Disability Status Scale (EDSS) score 0-4.0
- * be able to read and understand the questionnaire
- * be over age 18 year

To obtain a homogeneous population of MS patients, only patients with both a low neurological disability (EDSS 0- 4.0), and a relapsing-remitting MS were included. EDSS was rated by an experienced neurologist.

Measures: A five-part survey was used for data collection. The questionnaires included Individual Information Questionnaire, Expanded Disability Status Scale (EDSS), Multiple Sclerosis Quality of Life-54 (MSQOL-54) for Health Status, Fatigue Severity Scale (FSS), and Beck Depression Inventory (BDI).

Individual Information Questionnaire: Individual Information Questionnaire included age, gender,

marital status, education, occupational status, income, place of residence, health insurance, and disease duration.

Expanded Disability Status Scale (EDSS): The EDSS is the standard measure of disease progression and the degree of neurological impairment in clinical practice and clinical trials. The EDSS divides functioning into eight functional systems: pyramidal, cerebellar, brainstem, cerebral, bowel and bladder, sensory, visual, and other; impairment in each system is graded and then summed across the eight systems. The EDSS measures the extent of neurological deficit with higher scores meaning greater deficit. Scores for the total scale can range from 0 (no neurological abnormality) to 10 (death from multiple sclerosis).¹⁵
Multiple Sclerosis Quality of Life-54 (MSQOL-54): MSQOL-54 was developed by Vickrey et al¹⁶ and was adapted by Idiman et al¹⁷ for use especially with Turkish people. The 54 items of the questionnaire are distributed into 12 multi-item scales, two single-item scales, and physical and mental health composite scores, which are calculated as a weighted sum of selected scales. The sub-scales include physical function, physical role limitation, emotional well-being, emotional role limitation, energy, health perception, social function, change in health, health distress, cognitive function, sexual function, satisfaction with sexual function, overall QoL, and pain. Higher scores indicate better QOL. Previous research has shown high internal consistency reliability estimates and test-retest correlation coefficients. In this study, total cronbach's alpha for MSQOL- 54 was 0.77. The alpha parameters of single items Cronbach were determined as 0.70 for physical health and 0.89 for mental health.

Beck Depression Inventory (BDI): BDI was developed by Beck et al¹⁸ and was adopted by Hisli¹⁹ for use especially with Turkish people. BDI was used to assess depressive symptoms. The scale is 21 items; four-point scale ranging from rarely or none of the time (0) to most or all of the time (3) and highest total score is 63. Higher scores indicating increasing depression. The BDI demonstrates high internal consistency, with Cronbach's alpha coefficients of 0.86 and 0.81 for psychiatric and non-psychiatric populations respectively. The Cronbach's alphas for patients were found as 0.92 for this study.

Fatigue Severity Scale (FSS): The presence and severity of fatigue were assessed by means of the FSS. It consists of nine items, each rated on a seven-point scale, which has five equidistant anchor points: strongly disagree (1), rare (between 2 and 3), sometimes (4), frequently (between 5 and 6) and strongly

agree (7). The scale is scored by computing the average rating for the nine items, with higher scores indicating increasing fatigue severity.²⁰ Armutlu et al.²¹ documented test-retest reliability of .89 for the FSS. The internal reliability in the present study was 0.97 in the patients.

Statistical Analysis: The data were assessed through percentage distribution, Mann-Whitney-U Test, Kruskal Wallis variance analysis and Pearson's correlation analysis. P values less than 0.05 was considered as significant.

Ethical Considerations: Permission to undertake this study was obtained from the presidency of the main neurology discipline at Ataturk University, and informed consent was obtained from each participant. The patients were informed about the purpose of the research.

RESULTS

The mean score of the physical health composite of QOL was 46.25 ± 23.95 , of mental health composite was 46.63 ± 24.34 (Table-I).

The age range of patients were 20–69 years. The mean age was 34.6 years (S.D., 12.5) and 60% of the group was female, 71.7% were married, 48.3% were primary school graduates, 65.0% were unemployed, 71.7 had less income than expenditures, 63% lived in city, and 55.0% had duration of illness of 1-4 years. (Table-II). All of the patients were covered by health insurance. The sample had a mean EDSS score of 2.30 (S.D., 1.6).

Age and place of residence revealed significant correlation with physical health composite score ($P < 0.05$). Older patients reported poor QOL than younger ones on the physical health composite. City resident patients reported better physical health composite. Men showed significantly higher scores on the MSQOL-54 dimensions of physical health ($P < 0.001$) and mental health ($P < 0.001$). Marital status revealed no significant correlation with both composite scores ($P > 0.05$) (Table-II).

Employed MS patients displayed higher scores than those unemployed on the MSQOL-54 dimensions of physical health ($P < 0.001$) and mental health ($P < 0.001$).

The highest mean scores for physical health and mental health components were determined in those with higher income, those with university education and the difference between them was statistically significant ($P < 0.001$) (Table-II).

Disease duration showed significant inverse relationship to QOL. Longer duration of disease was associated with reduced scores on physical health

($P < 0.001$), mental health ($P < 0.05$).

Mean score for fatigue severity was 4.61 ± 1.93 . There was significant negative correlation between fatigue and both components of MSQOL-54 ($r = -0.796$, $p < 0.01$ for physical health composite and $r = -0.671$, $p < 0.01$ for mental health composite).

Mean score for depression was 19.56 ± 15.01 . There was significant negative correlation between BDI and both components of MSQOL-54 ($r = -0.739$, $p < 0.01$ for physical health composite and $r = -0.763$, $p < 0.01$ for mental health composite) (Table-III).

DISCUSSION

At the end of the research, mean scores of MS patients in physical health and mental health areas of the QOL were found to be low. This is in accordance with the previous researches.^{9,13} Individuals with chronic disease experience physical and social restrictions of the disease for a long period of time, and they may lose their job, independence, social power and self-esteem because of the disease.³

In the study it was determined that as MS individual's age increased their physical health mean score decreased. In studies by Solaria et al.⁹ and Larsen et al.²², it was also determined that as MS individuals' age increased they experienced the poor physical health composite. The reason for this result is probably due to functional changes that occur with age as well as physical effects of a chronic illness on the individual.

When examining gender differences, we found men scoring higher than women on the QOL dimensions of physical and mental health. This has also been reported by Miller and Dishon²³ and Pfenning et al.²⁴ The reason why women have poor QOL than men may be a result of the household responsibilities that women are expected to fulfill (housework, childcare, etc.) more than men.

In this study it was determined that as the education level of the patients advanced, the physical and mental health composite scores increased. These results are in accordance with the results of previous researches.¹³ It is suggested that this finding may be a result of those with higher education using more people for help. Consequently the group with a low

Table-I: Distributions regarding of MSQOL-54 physical and mental health composite scores

MSQOL-54	Min-Max	X \pm SD
Physical health composite score	8-94	46.25 \pm 23.95
Mental health composite score	5-99	46.63 \pm 24.34

Table-II: Relationships between MS individuals' characteristics and Quality of Life Scale mean scores (n=60)

Characteristics	n	%	MSQOL physical		MSQOL mental	
			X±SD	P value	X±SD	P value
Age						
20-30	26	43.3	54.42±21.89	KW=6.085	51.23±23.36	KW=3.505
31-41	19	31.7	43.94±21.12	df = 2	47.36±23.66	df = 2
42 and above	15	25.0	35.00±23.39	P<0.05	37.73±26.02	P> 0.05
Gender						
Female	36	60.0	37.00±21.43	MWU=203.500	38.36±21.11	MWU=219.500
Male	24	40.0	60.12±20.92	P<0.001	29.04±23.95	P<0.001
Marital Status						
Married	43	71.7	45.95±25.52	MWU=358.500	44.55±25.63	MWU=284.000
Unmarried	17	28.3	47.00±20.12	P>0.05	51.88±20.47	P>0.05
Education						
Primary school	29	48.3	33.51±20.23	KW=15.788	34.17±18.77	KW=15.757
Secondary/ High school	19	31.7	55.26±22.30	df=2	57.42±25.30	df=2
University	12	20.0	62.75±18.88	P<0.001	59.66±20.89	P<0.001
Occupation						
Unemployed	39	65.0	65.23±17.22	MWU=132.500	63.52±20.87	MWU=155.500
Employed	21	35.0	36.02±20.69	P<0.001	7.53±21.16	P<0.001
Income level						
Income < expenditure	43	71.7	38.41±21.81	MWU=130.500	38.72±20.18	MWU=132.000
Income > expenditure	17	28.3	66.05±16.88	<0.001	66.64±22.83	P<0.001
Place of residence						
City	38	63.3	53.11±27.37	KW=7.739	49.65±23.67	KW=5.605
Town	9	15.0	50.31±23.91	df=2	54.00±25.60	df=2
Village	13	21.7	29.61±13.07	P<0.05	32.69±21.61	P>0.05
Duration of disease						
1-4 year	33	55.0	54.54±21.87	MWU=252.000	53.03±23.35	MWU=285.000
5 year and above	27	45.0	36.11±22.77	P<0.001	38.81±23.61	<0.05

educational level coped inadequately with disease symptom.

Employed patients scored significantly higher than unemployed patients of MSQOL-54 domains. Association between employment status and QOL was found in the past amongst MS patients.^{13,23} In these studies, as well as in ours, the unemployed group had lower scores on the physical and psychological components of QOL. Employment is important to persons with MS for the income earned, structure to daily lives and opportunity for social interaction, all of which directly or indirectly affect one's QOL.²³ When the mean scores of QOL of patients were examined with regard to their level of income, it was determined that patients whose income was greater than their expense had higher mean scores of physical health and mental health compared to patients whose income was less than their expense, and the difference in between was found to be statistically significant. This is in agreement with a previous

study.²⁵ According to the results, the increase in the QOL due to an increase in income level was related with the advantages of the patients being more comfortable, having some compensation for the economical burden of disease.

When mean scores taken from QOL with respect to place of residence were studied, patients residing in city demonstrated the highest mean scores of

Table-III: Correlation between MSQOL-54 physical and mental health composite scores with Beck depression and fatigue

Quality of Life Instrument (MSQOL-54)	Depression (BDI)		Fatigue (FSS)	
	r	P	r	P
Physical health composite score	-0.739	p<0.01	-0.796	p<0.01
Mental health composite score	-0.763	p<0.01	-0.671	p<0.01

physical health. Those living in cities probably have better opportunities to benefit from health services. In this study, which found a significant relationship between MS individuals' duration of illness and quality of life, as the duration of illness increased individual's level of QOL decreased. These results are in accordance with the results of previous researches.^{13,17,24} Other factors such as increasing age, other chronic illnesses occurring, the effect of long-term medication use and the psychological effects of illness, may play a role in this result.

A negative significant correlation was found between the depression and QOL. QOL decreased with the increase in depression. Similar results were also reported in the studies of Loberentanz et al.,⁷ Amato et al.¹² and Patti et al.¹³

A negative significant correlation was found between the fatigue and QOL. QOL decreased with the increase in fatigue. Fatigue is defined in the literature as a factor that has a negative effect on individuals' functional status and role performance and it has been determined to have a negative effect on individuals' QOL.^{6,14}

CONCLUSION

According to the results of this study, patients' physical and mental health mean scores were lower. The difference between the mean score of both components QOL according to gender, educational level, occupation, income level and duration of disease were found statistically significant. Age and place of residence revealed significant correlation with physical health composite score.

We found a negative correlation between the fatigue, depression and both components QOL. This study shows that fatigue and depression are associated with impaired QOL in MS patients. Our findings may have important implications towards the care of MS patients. The determination of the effect of fatigue and depression on QOL would increase the determination of more effective goals in care and in this way improve the individuals' QOL. Thus, our findings suggest that measures of MS related QOL should include assessment of fatigue and depression.

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