# Psychosocial Adjustment and Adherence to Medication in Patients with Myasthenia Gravis

Myestenia Gravis Hastalarında Psikososyal Uyum ve İlaç Uyumu

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#### ABSTRACT

**Objective:** This descriptive study was conducted to determine psychosocial adjustment and adherence to medication of myasthenia gravis (MG) patients in two different tertiary centers between July 2015 and November 2016.

**Methods:** This study was completed with 54 MG patients. Data was collected using the Introductory Information Form, the Modified Morisky Scale and the Psychosocial Adjustment to Illness Scale - Self-Rating Scale (PAIS-SR) in Turkish.

**Results:** In this study, it was determined that 48.1% of the patients achieved a good level of psychosocial adjustment to MG. It was found that the patients' medication adherence (59.3%) was moderate. No statistically significant relationship was found between patients' psychosocial adjustment to their disease and adherence to medication (p<0.05).

**Conclusion:** The present study demonstrated the psychosocial adjustment of MG patients to be at a good level and adherence to medication of patients was moderate. This study found that MG patients' psychosocial adjustment does not affect their medication compliance.

Keywords: Myasthenia gravis, psychosocial adjustment, medication adherence

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## ÖZET

**Amaç:** Bu tanımlayıcı çalışma, Myestenia Gravis (MG) hastalarının psikososyal uyum ve ilaç uyumlarını belirlemek amacıyla Temmuz 2015 - Kasım 2016 tarihleri arasında iki farklı üçüncü basamak hastanede yapılmıştır.

Yöntem: Çalışma 54 MG hastası ile tamamlanmıştır. Veriler, tanıtıcı bilgi formu, Modifiye Morisky Ölçeği ve Hastalığa Psikososyal Uyum Ölçeği (PAIS-SR) kullanılarak toplanmıştır.

**Bulgular:** Bu çalışmada hastaların %48.1'inin MG'ye iyi düzeyde psikososyal uyum sağladığı belirlenmiştir. Hastaların ilaç uyumunun (%59.3) orta düzeyde olduğu saptanmıştır. Hastaların hastalığa psikososyal uyumları ile ilaç uyumları arasında istatistiksel olarak anlamlı bir ilişki bulunamamıştır (p<0.05).

**Sonuç:** Bu çalışma, MG hastalarının hastalığa psikososyal uyumlarının iyi düzeyde olduğunu ve ilaç uyumlarının orta düzeyde olduğunu göstermiştir. Ayrıca çalışmada, MG hastalarının psikososyal uyumunun ilaç uyumunu etkilemediğini sonucuna ulaşılmıştır.

Anahtar Sözcükler: Myastenia gravis, psikososyal uyum, ilaç uyumu

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#### INTRODUCTION

Chronic diseases are disorders that persist for a long time and can affect person's usual functional abilities. Myasthenia gravis (MG) is among the chronic diseases that are generally characterized by progressive physical decline and that require long-term pharmacological treatment (1). MG is a neuromuscular disease characterized by muscle weakness and fatigue that change during the day and increase with physical activity toward evening (2,3). Symptoms commonly experienced by MG patients are ptosis, diplopia, fatigue, aphonia, difficulties with chewing and swallowing, and oropharyngeal muscle weakness that causes solid food to stick in the throat and regurgitation of fluids through the nose (3,4).

Fatigue and muscle weakness experienced in MG complicate the daily living activities and social life of MG patients (5). Along with the physical symptoms, psychological and social problems caused by a disease have also negative effects on patients' life (5,6). Due to their disease, MG patients have difficulty finding a job or can be dismissed from their current job because they cannot work. Patients can suffer from fear, anxiety, and depression sometimes cut off communication with those around them (7,8,9,10). MG can affect not only patients' physical health but also affects their psychology and their professional, family, and social lives; therefore, it is important to assess these patients psychosocially. Whereas psychosocial adjustment to disease can be influenced by factors imposed by the disease and its treatment, the course of disease can have a positive or negative effect on psychosocial adjustment (11). Adherence to treatment is among areas that require adjustment to disease. Starting a treatment program and completing it, taking medicines at the suggested dose and for the suggested time are elements of the adjustment to treatment, and thus, to disease (12). Adherence to medication becomes difficult as a result of factors such as patients' fears about the medication, the course of disease, adverse effects from the medication, problems experienced in following the medication regime, inadequate social support, inadequate information about the treatment, attitudes of patients and those around them toward medication, and pressure about the treatment (12). MG patients' adjustment to changes that occur in their lives along with the disease is important in terms of their adjustment to treatment (11). There are studies assessing patients' psychosocial adjustment to various chronic diseases, but not to MG (11-14). However, these studies have not examined adherence to medication. There is therefore a need for studies that assess both MG patients' psychosocial adjustment to their disease along with adherence to medication. This study aimed to determine the psychosocial adjustment to the disease and adherence to medication in MG patients.

#### **MATERIAL and METHODS**

#### Patient samples

This descriptive study was conducted with MG patients who applied to the neurology outpatients clinics and inpatient in the neurology services of Ankara University Faculty of Medicine, Ibni Sina Hospital and Hacettepe University Faculty of Medicine, Adult Hospital. The study population included all those patients. The study sample was determined by power analysis to require 54 MG patients; it was conducted between July 2015 and November 2016.

#### Ethical considerations

The participants' mean disease duration was  $7.5\pm7.4$  (min:1- max:39) years. Duration of disease in 48.1% of the patients was less than 10 years, and 42.6% had at least one chronic disease in addition to MG. Of them, 25.9% had hypertension, 11.1% diabetes mellitus and 3.7% had hyperlipidemia, 3.7% had osteoporosis, 3.7% had asthma. Of participants, 53.7% had a history of thymectomy, and almost all (92.6%) used pyridostigmine.

For the present study, which was conducted according to Helsinki Declaration principles, the researcher obtained written permission from Hacettepe University, Non-Interventional Clinical Studies Ethics Committee (GO-15/371-35) and from the head physician's department of relevant hospitals. After volunteer participants were informed about the study, their consents were obtained.

#### Data collection

Data was collected using the Introductory Information Form, the Modified Morisky Scale (MMAS) and the Psychosocial Adjustment to Illness Scale - Self-Rating Scale (PAIS-SR). Patients were briefly informed by the researchers about the purpose of the study. The researchers collected data from inpatient participants in their rooms, and from outpatients clinics in medical examination rooms using a face-to-face interview. The forms were completed within approximately 20 to 25 minutes. The Introductory Information Form includes 15 questions (12 closed- and 3 open-end) about participants' demographic, social, and medical characteristics.

The Morisky Medication Adherence Scale (MMAS) was developed by Morisky et al. (15) and its Turkish validity and reliability analyses was performed by Yilmaz (16). The scale was used to determine the medication compliance level of the patients. Responses question are 'yes' or 'no.' The scale was scored "high" (all questions were answered no), moderate (1 or 2 questions answered yes), or low (>2 questions answered yes).

The Psychosocial Adjustment to Illness - Self-Rating Scale (PAIS-SR) was developed by Derogatis and Lopez; it measures psychosocial adjustment to disease (17). Turkish validity and reliability analyses of this scale was performed by Adaylar (18). This scale comprises 46 questions in 7 sub-dimensions: health care orientation; vocational environment; family environment; sexual life; extended family relationships; social environment; and psychological distress. In studies conducted using PAIS-SR, a psychosocial adjustment score under 35, 35 to 51, and over 51 are adjudged to be a good, moderate, or poor level of psychosocial adjustment, respectively.

#### Statistical analysis

The study data were analyzed using the SPSS 21.0 (Statistical Package for Social Sciences) software. This study used descriptive statistical methods (numbers, percentages, means, standard deviation, medians). The Mann Whitney U Test and Kruskal Wallis Test were used because the study data did not meet parametric test assumptions. This study used Spearman's correlation test to assess the relationship of scales to each other.

#### RESULTS

The mean age of participating patients was 44.0±17.3 years; 64.8% were female. Of MG patients, 74.1% were married, 35.2% were high school graduates, 83.3% were unemployed, and 72.2% had moderate levels of economic circumstances. Table 1 also shows MG patients' psychosocial adjustment to disease and adherence to medication by their demographic characteristics. This study did not find a statistically significant difference between participants' demographic characteristics and their mean score on PAIS-SR and MMAS, but determined a statistically significant difference between their occupational status and PAIS-SR mean score. It was found that unemployed participants had higher mean scores of PAIS-SR than employed participants and that this difference was statistically significant (p=0.040).

Also, 12.9% used antidepressants without a psychiatric diagnosis of them. In all, 29.6% of participants had received some education, and 35.6% had obtained some information about the disease (Table 2). There was no statistically significant difference between patients' disease duration, their status having an additional chronic disease, and their mean scores on PAIS-SR and MMAS (p>0.05).

Table 1. Characteristics of MG patients (n=54).							
	n %		PAIS-SR		MMAS		
			Mean±SD P-value		Mean±SD P-value		
Age (years) (44.1 ± 17.3)							
≤43	27	50.0	34.6 ± 16.2		$2.8 \pm 0.9$		
≥44	27	50.0	44.7 ± 20.1	0.083	$3.2 \pm 0.8$	0.097	
Gender							
Female	35	64.8	39.6 ± 19.5		$2.9 \pm 0.8$		
Male	19	35.2	39.6 ± 17.9	0.935	$3.2 \pm 0.8$	0.137	
Marital status							
Married	40	74.1	42.2 ± 19.9		$3.1 \pm 0.8$		
Unmarried	14	25.9	32.3 ± 13.2	0.110	2.7 ± 0.8	0.161	
Education level							
Primary school	4	7.4	39.0 ± 21.5		$2.5 \pm 1.2$		
Secondary school	16	29.6	38.6 ± 21.6	0.850	3.3 ± 0.7	0.383	
High school	19	35.2	46.6 ± 15.3		$2.7 \pm 1.0$		
University	15	27.8	32.1 ± 17.6		3.1 ± 0.7		
Employed status previously							
Worked	9	16.7	28.4 ± 17.7		$3.1 \pm 1.0$		
Have not worked	45	83.3	41.9 ± 18.4	0.040*	$3.0 \pm 0.8$	0.649	
Income level							
Good	12	22.2	30.9 ± 15.2		$3.2 \pm 0.7$		
Medium	39	72.2	40.3 ± 18.2	0.117	$2.9 \pm 0.9$	0.432	
Low	3	5.6	65.6 ± 16.1		$3.0 \pm 0.0$		
People who live together							
Alone	1	1.9	38.0± 0.0		$4.0 \pm 0.0$		
Family	50	92.9	40.2 ± 19.4	0.814	$3.0 \pm 0.8$	0.150	
Relatives	3	5.6	31.3 ± 5.5		2.3 ± 0.5		
Total	54						

PAIS-SR = The Psychosocial Adjustment to Illness - Self-Rating Scale, MMAS = The Morisky Medication Adherence Scale.

\*p < 0.05.

 Table 2. Characteristics of individuals with regard to illness and treatment.

	n	%	PAIS-SR		MMAS		
			Mean±SD P-value		Mean±SD P-value		
Disease duration (7.5 ± 7.42 years) (min:1- max:39)							
≤10 year	42	70.7	39.4 ± 18.3	0.875	$3.0 \pm 0.8$	0.782	
≥11 year	12	29.3	40.6 ± 18.8		3.0 ± 0.9		
Other chronic illness status							
Yes	23	42.6	43.1 ± 19.9	0.306	$3.1 \pm 0.9$	0.409	
None	31	57.4	37.1 ± 17.8		$2.9 \pm 0.8$		
Thymectomy							
Yes	29	53.7	40.2 ± 19.3	0.665	$3.1 \pm 0.8$	0.257	
None	25	46.3	39.1 ± 18.5		$2.9 \pm 0.9$		
Medication*							
Cholinesterase inhibitors	50	92.6					
Glucocorticoids (methyl prednisolone, prednisolone, prednisone vb.)	18	33.3					
Ciclosporin	5	9.3					
Intravenous Immunoglobulin therapy	5	9.3					
Azathioprine	11	20.4					
Other drugs	22	40.7					
Status of receiving training		20.6		0.040		0.045	
Yes	16	29.6	37.6 ± 21.6	0.343	$2.8 \pm 0.8$	0.345	
None	38	70.4	40.5 ± 17.7		$3.1 \pm 0.8$		

PAIS-SR = The Psychosocial Adjustment to Illness - Self-Rating Scale, MMAS = The Morisky Medication Adherence Scale

\*Percentages do not sum to 100% due to multiple answers.

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The participants' mean score on PAIS-SR was 39.6±1.8. Participants' mean scores on the sub-dimensions on the PAIS-SR scale showed that participants had higher scores on the sub-dimensions of health care orientation, vocational environment, sexual life, social environment, and psychological distress (Table 3). Assessment of MG patients' psychosocial adjustment to disease based on the

PAIS-SR scale determined that of the study patients, 48.2%, 29.6%, and 22.2% had good, poor, and moderate levels of adjustment to their disease, respectively. Among the MG patients 9.3%, 35.2%, and 5.6% had moderate, good, and poor levels of adherence to medication. After determining the relationship between MG patients' psychosocial adjustment and adherence to medication, no statistically significant was found (p>0.05) (Table 4).

#### Table 3. The Score Averages of the MG on the Psychosocial Adjustment to the Illness Scale- Self-Report and on Its Subscales.

PAIS-SR Subscales	MinMax.	Mean±SD
Orientation to healthcare	0-24	8.0 ± 3.9
Vocational environment	0-18	6.5 ± 3.5
Domestic environment	0-24	5.83 ± 4.4
Sexual relationships	0-18	6.1 ± 5.5
Extended family relationships	0-15	1.9 ± 2.1
Social environment	0-18	6.5 ± 5.7
Psychological distress	0-21	$6.3 \pm 4.1$
PAIS-SR total	0-138	39.6 ± 1.8
Psychosocial Adjustment Level	n	%
Well adjusted (score of <35)	26	48.2
Moderately adjusted (score between 35 and 51)	12	22.2
Poorly adjusted (score of >51)	16	29.6

# Table 4. The relationship between the Psychosocial Adjustment to the Illness Scale- Self-Report and the Morisky Medication Adherence Scale.

MMAS		Orientation to healthcare	Vocational environment Vocational environment	Domestic environment		Sexual relationships	Extended family relationships	Social environment	Psychological distress	PAIS-SR total	
	r * 0.266		-0.101	0.108	0.037		-0.151	0.0 36 0.7	0.204	-0.092	
	p 0.052		0.487	0.465	0.817		0.290	96	0.138	0.507	

\* Spearman's rank-correlation coefficient

## DISCUSSION

#### MG patients' psychosocial adjustment to disease

The present study determined that participants' mean score on PAIS-SR was 39.6±1.8, and 48.2% of the MG patients had good levels of adjustment to disease. MG patients did not report psychiatric diseases. 12.9% of MG patients used antidepressant drugs. Published studies reported that the course of disease is affected by psychosocial factors and that in 35% of patients, there is a relationship between psychosocial stress and the onset of disease (19). Many studies of MG patients reported that patients frequently experience psychosocial problems and that many patients have some psychiatric diseases such as anxiety and depression (9,10). A study by Doering et al. (1993) determined that 41% of 44 MG patients had at least one psychiatric diagnosis, and that their most common diagnosis was depression (20). Lundeen et al. (2004) conducted a study to determine the frequency of anxiety in MG patients and found that 55% of patients had anxiety disorders (21). Kotan et al. (2016) studied MG patients and determined that as the levels of depression and anxiety increase, patients' psychosocial adjustment to disease deteriorate (22). The same study found that MG patients who had a psychiatric disease such as anxiety or depression had lower levels of adjustment to disease (22). It is possible that the present study result may be associated with patients in the sample not being previously diagnosed with a psychiatric disease. And that a major part of participants was living with their family. Because different studies conducted with patients having chronic diseases reported that patients' adjustments to disease increase by having a partner and family as social support systems (23,24). Similarly, another study on MG showed that as patients received higher levels of support from their friends or someone special, their psychosocial adjustment to disease also increased (22).

In the present study, MG patients' sub-dimension scores on the PAIS-SR scale showed that participants had difficulty in the health care orientation area. Koopman et al. (2016) reported that independence levels of patients in activities of daily living increase, their mental well-being and quality of life (QoL) is affected positively (25). The study by Mourão et al. (2016) found that in MG patients, the intensity of symptoms, steroid dose used, and depression and anxiety level have negative effects on patients' quality of life (QoL) (26). Because that MG is a chronic disease, is treated with long-term medication, medicines used have adverse effects, the symptoms of disease have a negative effect on daily life and QoL, symptoms fluctuate during a day, and the patient's orientation to health care may deteriorate. The present study determined that the sub-dimension having the highest level of adjustment among sub-dimensions of PAIS-SR scale is the relationships with extended family. Basta et al. (2012) determined that low social support was associated with lower levels of disease acceptance in MG patients (9). Similarly, Kotan et al. (2016) found that as social support increased, patients' adjustment to disease also increased (22). In studies conducted with patients having a chronic disease other than MG have reported that the more perceived support that patients had, the better psychosocial adjustment they experienced (14,23,24). Family structure and its characteristics, the family's attitude, and information and practices about the disease may have an effect on a patient's orientation period. That family members accept the disease, plan their own lives according to the disease, and encourage patients to make new adjustments in their lives is adjudged to play an important part in patients' adjustment to disease.

In the present study, the difference between MG patients' demographic and medical characteristics and their mean score on the PAIS-SR Scale was not found to be statistically significant. Only unemployed participants had a higher mean score of PAIS-SR than employed participants at a statistically significant level. MG patients may withdraw from society because they experience fatigue, have difficulties with talking, swallowing, and a change in facial expression, and they may suffer from anxiety. Because of these problems that they experience, patients need to change jobs or leave their current job (27). Also as a result, patients are detached from active working life because of insufficient control of symptoms, hospital stay, need to go to the hospital for years, bias for intractable and uncommon diseases from others (28). Similarly, patients who have never worked before need to stay at home because of these symptoms; therefore, they experience problems such as social isolation, anxiety, and depression. This makes their adjustment to disease difficult (14).

### MG patients' adherence to medication

The present study found that of MG patients; 59.3% had moderate and 35.2% had good levels of adherence to medication. Studies have assessed patients' adherence to medication for chronic diseases, including hypertension (29), diabetes (30), asthma (31), epilepsy (32) and stroke (33) and psychiatric diseases (12) as well. In these studies in the literature, it is seen that there are differences in drug compliance levels of patients. This is possibly associated with that patients encounter fewer problems in their activities of daily living when they take their medicines regularly, and that they are informed about what would be if they do not take their medicines regularly in MG. This study found no statistically significant difference between MG patients' demographic characteristics and their mean score on MMAS. Similarly, in the literature, studies report that patients' adherence to medication does not differ according to demographic characteristics such as patients' age, gender, educational status, marital status, occupational status and income level (29,34). The findings of the present study are in line with the literature.

The present study determined that MG patients had good levels of psychosocial adjustment to disease and of adherence to medication. However, there was no statistically significant relationship between MG patients' psychosocial adjustment and adherence to medication. A study conducted with MG patients determined that symptoms patients experience are obviously affected by psychosocial stressors that have a negative effect on response to treatment (35). Literature reviews showed a relationship between the presence of social support and patients' adjustment to treatment and higher levels of healthy living behaviors (36,37). These reviews also showed a relationship between an increase in symptoms resulting from psychosocial stress, and a decrease in response to treatment. The results of the present study differ from the literature. Therefore, it is suggested that adherence to medication should not be discussed as a determinant factor in terms of psychosocial adjustment. Further studies should take into consideration that an increase in psychosocial adjustment does not mean an increase in the adherence to medication; patients should also be assessed in terms of their adherence to medication regardless of the level of their psychosocial adjustment.

The study has some limitations. First one, the symptoms of patients with MG and the severity of these symptoms have not been questioned. Other limitations included the small sample size and the use of only two centers. Therefore, the findings of the present study are not generalizable for all patients with MG. It is recommended that to study on larger sample and to assessment the symptoms of patients and the severity of these symptoms.

#### **Conflict of interest**

No conflict of interest was declared by the authors.

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