Psychosocial Adjustment and Adherence to Medication in Patients with Myasthenia Gravis

Myestenia Gravis Hastalarında Psikososyal Uyum ve İlaç Uyumu

Güler Duru Aşiret¹, Sevgisun Kapucu², Tuğçe Türten Kaymaz³, Can Ebru Bekircan-Kurt⁴

¹ Nursing Department, Faculty of Health Sciences, Aksaray University, Aksaray, Turkey
² Faculty of Nursing, Hacettepe University, Samanpazari Ankara, Turkey
³ Nursing Department, Faculty of Health Sciences, Duzce University, Düzce, Turkey
⁴ Neurology Department, Faculty of Medicine, Hacettepe University, Ankara, Turkey

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 uymalarını belirlemek amacıyla Temmuz 2015 – Kasım 2016 tarihlerinde 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 uymalarının (%59.3) orta düzeyde olduğu saptanmıştır. Hastaların hastalığa psikososyal uyumları ile ilaç uymaları arasında istatistiksel olarak anlamlı bir ilişki bulunamamıştır (p<0.05).

Sonuç: Bu çalışma, MG hastalarının hastalığa psikososyal uyumlarının iyi düzeyde olduğunu ve ilaç uymalarının orta düzeyde olduğunu göstermiştir. Ayrca çalışmada, MG hastalarının psikososyal uyumunun ilaç uymasını etkilemediğini sonucuna ulaşılmıştır.

Anahtar Sözcükler: Myastenia gravis, psikososyal uyum, ilaç uyumu

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ORCID IDs: G.D.A.0000-0002-9635-1539, S.K.0000-0003-3908-3846, T.T.K.0000-0003-4723-8174, C.E.B. 0000-0003-2355-6979

Address for Correspondence / Yazışma Adresi: Güler Duru Aşiret, Nursing Department, Faculty of Health Sciences, Aksaray University, Aksaray, Turkey E-mail: gulerduru@gmail.com

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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, aphony, 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 outpatient clinics and inpatient in the neurology services of Ankara University Faculty of Medicine, Ibnî Sîna 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±4.1 (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 additional chronic disease, 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 patients’ 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 some information about the disease.
Table 1. Characteristics of MG patients (n=54).

|                           | n    | %   | PAIS-SR Mean±SD | P-value | MMAS Mean±SD | P-value |
|---------------------------|------|-----|-----------------|---------|---------------|---------|
| **Age (years)** (44.1 ± 17.3) |      |     |                 |         |               |         |
| ≤43                       | 27   | 50.0| 34.6 ± 16.2     | 0.083   | 3.2 ± 0.8     | 0.097   |
| ≥44                       | 27   | 50.0| 44.7 ± 20.1     | 0.083   | 3.2 ± 0.8     | 0.097   |
| **Gender**                |      |     |                 |         |               |         |
| Female                    | 35   | 64.8| 39.6 ± 19.5     | 0.935   | 3.2 ± 0.8     | 0.137   |
| Male                      | 19   | 35.2| 39.6 ± 17.9     | 0.935   | 3.2 ± 0.8     | 0.137   |
| **Marital status**        |      |     |                 |         |               |         |
| Married                   | 40   | 74.1| 42.2 ± 19.9     | 0.110   | 2.7 ± 0.8     | 0.161   |
| 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     | 0.850   | 3.3 ± 0.7     | 0.383   |
| 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     | 0.850   | 3.7 ± 1.0     | 0.161   |
| University                | 15   | 27.8| 32.1 ± 17.6     | 0.850   | 3.1 ± 0.7     | 0.161   |
| **Employed status previously** |      |     |                 |         |               |         |
| Worked                    | 9    | 16.7| 28.4 ± 17.7     | 0.040*  | 3.0 ± 0.8     | 0.649   |
| Have not worked           | 45   | 83.3| 41.9 ± 18.4     | 0.040*  | 3.0 ± 0.8     | 0.649   |
| **Income level**          |      |     |                 |         |               |         |
| Good                      | 12   | 22.2| 30.9 ± 15.2     | 0.117   | 2.9 ± 0.9     | 0.432   |
| Medium                    | 39   | 72.2| 40.3 ± 18.2     | 0.117   | 2.9 ± 0.9     | 0.432   |
| Low                       | 3    | 5.6 | 65.6 ± 16.1     | 0.117   | 3.0 ± 0.0     | 0.150   |
| **People who live together** |      |     |                 |         |               |         |
| Alone                     | 1    | 1.9 | 38.0± 0.0       |         | 4.0 ± 0.0     |         |
| Family                    | 50   | 92.9| 40.2 ± 19.4     | 0.814   | 3.0 ± 0.8     | 0.150   |
| Relatives                 | 3    | 5.6 | 31.3 ± 5.5      | 0.814   | 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 Mean±SD | P-value | MMAS 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 ± 0.8     | 0.782   |
| ≥11 year                  | 12   | 29.3| 40.6 ± 18.8     | 0.875   | 3.0 ± 0.9     | 0.782   |
| **Other chronic illness status** |      |     |                 |         |               |         |
| Yes                       | 23   | 42.6| 43.1 ± 19.9     | 0.306   | 3.1 ± 0.9     | 0.409   |
| None                      | 31   | 57.4| 37.1 ± 17.8     | 0.306   | 2.9 ± 0.8     | 0.409   |
| **Thymectomy**            |      |     |                 |         |               |         |
| Yes                       | 29   | 53.7| 40.2 ± 19.3     | 0.665   | 3.1 ± 0.8     | 0.257   |
| None                      | 25   | 46.3| 39.1 ± 18.5     | 0.665   | 2.9 ± 0.9     | 0.257   |
| **Medication**            |      |     |                 |         |               |         |
| Cholinesterase inhibitors | 50   | 92.6|                 |         |               |         |
| Glucocorticoids (methyl 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** |      |     |                 |         |               |         |
| Yes                       | 16   | 29.6| 37.6 ± 21.6     | 0.343   | 2.8 ± 0.8     | 0.345   |
| None                      | 38   | 70.4| 40.5 ± 17.7     | 0.343   | 3.1 ± 0.8     | 0.345   |

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.
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       | Min.-Max. | 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 ± 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.

| PAIS-SR Subscales       | MMAS Orientation to healthcare | MMAS Vocational environment | MMAS Domestic environment | MMAS Sexual relationships | MMAS Extended family relationships | MMAS Social environment | MMAS Psychological distress | PAIS-SR total |
|-------------------------|-------------------------------|-------------------------------|--------------------------|--------------------------|-----------------------------------|-------------------------|-----------------------------|---------------|
| r                       | 0.266                         | -0.101                       | 0.108                    | 0.037                    | -0.151                            | 0.0                     | 0.204                       | -0.092        |
| p                       | 0.052                         | 0.487                        | 0.465                    | 0.817                    | 0.290                             | 0.96                    | 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 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 and found that 55% of patients had anxiety disorders (21). Kotan et al. (2016) (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, 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 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.

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