Assessment of the Myasthenia Gravis Patients' Quality of Life

Ocena jakości życia wśród pacjentów z miastenią

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Abstract

Introduction. Myasthenia gravis is an immune-mediated disease associated with a disorder of the neuromuscular junction. MG belongs to the group of chronic diseases with variable clinical courses. Patients struggling with this disease must remain under the constant care of a neurologist and take medications regularly. Talking about myasthenia gravis, we can divide it into two forms: ocular and generalized. In patients with the generalized form, a lower level of quality of life can be observed. As patients age, their quality of life increases. This may be due to the fact that younger people, leading a more active life, find it more difficult to accept disabilities resulting from the disease.
Aim. The aim of the study is to present the specificity of the functioning of patients with myasthenia gravis.
Material and Methods. To write the above work, an analysis of the literature and a diagnostic survey were used, an original questionnaire consisting of three parts and six ready-made scales was used.
Results. The study showed that the quality of life of patients with myasthenia gravis is reduced. A lower level of quality of life can be observed among women, younger people and those suffering from the general form of this disease. Myasthenia gravis negatively affects the daily functioning of patients. The negative impact of physical, mental and general fatigue as well as the degree of everyday life difficulties due to fatigue on the quality of life of patients with MG was also demonstrated. In the case of myasthenia gravis, however, we must distinguish between fatigue and muscle fatigue.
Conclusions. Myasthenia gravis and the problems faced by people with this disease is a topic rarely discussed in scientific works. The quality of life of this group of patients is significantly reduced, which contributes to the occurrence of anxiety and depression among this group of patients. The biggest problem among MG patients is fatigue, which has a significant impact on their quality of life. More attention should be paid to the problem of quality of life and more research related to this topic should be carried out in the future. **(JNNN 2023;12(2):74–83)**
Key Words: activity of daily living, fatigue, myasthenia gravis, quality of life

Streszczenie

Wstęp. Miastenia jest chorobą o podłożu immunologicznym, związaną z zaburzeniem złącza nerwowo-mięśniowego. MG należy do grupy chorób przewlekłych, o zmiennym przebiegu klinicznym. Pacjenci borykający się z tą chorobą muszą pozostać pod stałą opieką lekarza neurologa oraz regularnie przyjmować leki. Mówiąc o miastenii możemy ją podzielić na dwie postaci: oczną oraz uogólnioną. U pacjentów z postacią uogólnioną można zaobserwować niższy poziom jakości życia. Wraz z wiekiem pacjentów, ich jakość życia wzrasta. Może się to wiązać z tym, iż osobom młodszym, prowadzącym bardziej aktywne życie trudniej zaakceptować niepełnosprawności wynikające z choroby.
Cel. Celem pracy jest przedstawienie specyfiki funkcjonowania pacjentów z miastenią.
Materiał i metody. Do przygotowania pracy wykorzystano analizę piśmiennictwa oraz sondaż diagnostyczny, użyto autorskiego kwestionariusza ankiety, składającego się z trzech części oraz sześciu standaryzowanych narzędzi.

Wyniki. Przeprowadzone badanie wykazało, że jakość życia pacjentów z miastenią jest obniżona. Niższy poziom jakości życia można zaobserwować wśród kobiet, ludzi młodszych oraz cierpiących na postać ogólną tej jednostki chorobowej. Miastenia wpływa negatywnie na codzienne funkcjonowanie pacjentów. Wykazano również negatywny wpływ zmęczenia fizycznego, psychicznego, ogólnego oraz stopnia utrudnienia życia codziennego poprzez zmęczenie na jakość życia pacjentów z MG. W przypadku miastenii musimy jednak rozróżnić zmęczenie od męczliwości mięśni.
Wnioski. Miastenia oraz problemy z jakimi borykają się osoby z tą chorobą jest tematem rzadko poruszanym w pracach naukowych. Jakość życia tej grupy pacjentów jest znacznie obniżona, co sprzyja występowaniu lęku i depresji wśród tej grupy pacjentów. Największym problemem wśród pacjentów z MG jest zmęczenie, które ma znaczny wpływ na poziom jakości ich życia. Należałoby zwrócić większą uwagę na problem jakości życia oraz przeprowadzić więcej badań związanych z tym zagadnieniem w przyszłości. **(PNN 2023;12(2):74–83)**
Słowa kluczowe: aktywność dnia codziennego, zmęczenie, myasthenia gravis, jakość życia

Introduction

Myasthenia gravis (MG) is an acquired autoimmune disease that belongs to the group of diseases of the neuromuscular junction. This disease is associated with excessive fatigue of skeletal muscles, which is caused by impaired neuromuscular transmission [1].

MG is a rare disease, its incidence is estimated at 5–12 cases per 100.000 people. The disease affects both women and men. Two peaks of incidence can be observed: in women between the 2nd and 3rd decade of life, and in men after 50 years of age. Myasthenia gravis is not a hereditary disease, however, an increased incidence of autoimmune diseases such as rheumatoid arthritis, multisystem lupus and thyroid diseases are observed among family members of the patient [1,2].

There are two forms of myasthenia gravis: ocular and generalized. Regardless of the form of the disease, most patients experience generalized fatigue and reduced tolerance to physical exercise [3]. In the initial period, the symptoms of the disease may be non-specific. The main feature of myasthenia gravis is muscle fatigability. It manifests itself mainly as fatigue, which worsens with repeated activities and improves with rest. Symptoms are also more severe in the evening [1,2,4]. Eye muscle weakness is the most common first symptom of MG. It is caused by weakness of more than one extra ocular muscle. It manifests itself as: asymmetrical drooping of the eyelids, which may be accompanied by periodic or permanent double vision [4]. Generalization usually occurs in the first two years of the disease. Myasthenia gravis affects the facial and bulbar muscles, which is associated with paralysis and dysphagia. The weakening of the masseter muscle results in difficulty in chewing. As the disease progresses, the limbs are affected as proximal muscle weakness. The upper limbs are usually more affected. Reduced neck muscle tension may cause "droopy head syndrome" [2,4]. In case of exacerbation of symptoms, when the diaphragm muscles are so weakened that they require ventilator support, we talk about a "myasthenic crisis". The risk of crisis is approximately 15% for each patient [1,4].

Patients with myasthenia gravis have problems performing everyday activities due to fatigue of skeletal muscles. Very often they isolate themselves from society, and because society does not understand the symptoms of the disease, they feel lonely and rejected. They are often accompanied by fear of the possibility of myasthenic crisis [5].

In patients with myasthenia gravis, a decrease in almost all components of the quality of life is observed. The quality of life is largely related to the physical fitness of patients and anxiety as a feature. Being part of support groups may have a positive impact on the emotional and social functioning of patients with MG, and thus improve the quality of life of this group of patients. Support groups are, in a way, a source of information about the disease [3]. Decreased quality of life in patients with MG is very often associated with depression. This may be due to poor physical condition and limited activity [6]. Moreover, compliance with therapeutic recommendations (adherence) and coping with stress may be important for the quality of life of patients with myasthenia gravis [5,7]. Appropriate nursing interventions also improve the quality of life of patients with MG, which also allows for better daily functioning. In the case of chronic diseases, such as myasthenia gravis, cooperation with the patient's family is also important [5].

Nursing staff play an important role in the treatment of a patient with myasthenia gravis at every stage of the disease. Health education and support for the patient and his or her relatives are extremely important. If the patient is hospitalized, the nurse takes part in diagnostics, pharmacotherapy and rehabilitation of the patient. She/he conducts careful observation, monitoring the neurological and general condition of a patient with myasthenia gravis. Due to the specific functioning of patients with MG, the nursing team should have an appropriate level of knowledge and experience in providing care for this group of patients. Health education of patients influences compliance with therapeutic recommendations in this group of patients.

The aim of the study is to present the specific functioning of a patient with myasthenia gravis.

Material and Methods

The study was conducted at the neurological outpatient clinic for patients with myasthenia gravis at the Adult Neurology Clinic of the UCK in Gdańsk, from December 2022 to March 2023. During this period, the research was conducted once a week, with the consent of the UCK Management and the Independent Bioethics Committee for Scientific Research at the Medical University of Gdańsk (resolution no. 769/2022). Respondents gave informed, written consent to participate in the study.

Table 1 shows the characteristics of the study group. 67 people took part in the study, most of whom were women (61.2%). 26 men (38.8%) took part in the study. The average age of the respondents was 53 years. The youngest person was 18 years old, the oldest 81. Most of the respondents declared secondary education (62.7%). Almost 40% of respondents are still working. Most respondents (38.8%) live in rural areas. The vast majority of respondents are married (74.6%). Nearly 90% of patients assess their socioeconomic status as average. Analysing clinical data, the study showed that almost 75% of respondents were people with generalized myasthenia gravis. However, the ocular form was declared by 25.4% of respondents. Most respondents had suffered from myasthenia gravis for over 10 years (43.3%). The smallest group consisted of people suffering from the disease for less than a year (9%). More than half of the

Table 1. Characteristics of the study group

Variable	N	%
1	2	3
Gender		
Women	41	61.2
Men	26	38.8
Education		
Primary	3	4.5
Secondary	42	62.7
Higher	22	32.8
Professional work		
Yes	25	37.3
No	3	4.5
Pension	19	28.4
Retirement	20	29.9
Place of residence		
Village	26	38.8
City up to 100,000 inhabitants	14	20.9
City from 100,000 to 500,000 inhabitants	15	22.4
City over 500,000 inhabitants	12	17.9

Table 1. Continued

1	2	3
Marital status		
Single	10	14.9
Married	50	74.6
Divorced	5	7.5
Widow/Widower	2	3.0
Socioeconomic status		
Low	8	11.9
Average	59	88.1
For how many years have you had myasthenia gravis?		
<1 year	6	9.0
From 1 to 5 years	22	32.8
From 6 to 10 years	10	14.9
>10 years	29	43.3
What form of myasthenia do you have?		
Ocular	17	25.4
Generalized	50	74.6
What therapy for myasthenia gravis do you use?		
Cholinesterase inhibitors	62	64.6
Non-steroidal immunosuppressive drugs	13	13.5
Immunoglobulins administered intravenously	1	1.0
Intravenous infusion of immunoglobulins	1	1.0
I do not take any medications	2	2.1
Other	17	17.7
What symptoms of myasthenia do you have?		
Diplopia	32	12.3
Strabismus	3	1.1
Drooping eyelids	41	15.7
Change of facial expressions	21	8.0
Jaw drop	3	1.1
Weakening in biting, chewing and swallowing	31	11.9
Head drop	14	5.4
Weakness of the lower limb muscles when walking	46	17.6
Weakness of hand muscles while performing everyday activities	43	16.5
Falls while running	10	3.8
Respiratory disorders	14	5.4
Other	3	1.1
Descriptive statistics	Min	Max
Age	18	81

patients participating in the study were people taking cholinesterase inhibitors — 64.6%. When asked about the symptoms, patients most often indicated: drooping eyelids (15.7%), weakness of the lower limb muscles (17.6%), weakness of the hand muscles while performing everyday activities (16.5%) and diplopia (12.3%). The average value of the overall assessment of health and well-being of the surveyed respondents is 6.09 (determined on a Likert scale from 0 to 10 points, where a higher number of points means a higher assessment of health and well-being).

Two research methods were used to prepare this work. They are: literature analysis and diagnostic survey [8]. To conduct the study, an original survey questionnaire was used, consisting of three parts. The first part included questions about the socio-demographic data of the respondents. The second part concerned the clinical condition in the context of myasthenia gravis, including the duration of the disease, the form of myasthenia gravis, the therapy used and the symptoms. The third part included questions regarding the assessment of the patient's health condition and well-being.

The assessment of activities of daily living in myasthenia gravis was based on the MG-ADL (Myasthenia Gravis Activity of Daily Living) questionnaire. This tool helps assess the functional capacity of daily activities in patients with MG. It consists of eight items, two of which assess visual impairment, three bulbar, one respiratory, and two related to limb impairment. Each item receives a score from 0 to 3. Therefore, the total scoring range is 0 to 24 points. The more points a patient receives, the more dependent she/he is in everyday activities. The questionnaire made it possible to determine in which of the eight examined areas there was the smallest/greatest problem in the patient's functioning [9].

Myasthenia Gravis Quality of Life 15 (MG-QoL15) is a short 15-item disease-specific questionnaire designed to assess aspects of quality of life in myasthenia gravis. Fifteen items are from the larger 60-item version of Myasthenia Gravis Quality of Live (MGQoL), and were selected on the basis of responsiveness and reliability. When completing the sheet, the respondent, answering each item, selects the appropriate answer on a Likert scale from 0 to 4 points (0 — not at all, 1 — a little, 2 — slightly, 3 — significantly, 4 — very much). In this questionnaire, the respondent can obtain a maximum of 60 points. When assessing the quality of life, the average for the population is given. There are no specific cut-off points. However, higher scores indicate a lower quality of life for patients [10].

The HADS-M scale (Hospital Anxiety and Depression Scale — Modified Version) is a tool used to assess anxiety, depression and irritability in hospitalized patients. The authors of the original version are A. Zigmond and R. Snaith. The Polish version was developed by de Walden-Gałuszko and Majkowicz. The questionnaire contains two independent subscales to assess anxiety and depression. Each subscale consists of seven statements. The questionnaire was enriched with two statements regarding the level of irritation. Answers are given on a 4-point Likert scale (0–3). The final score for each subscale ranges from 0 to 21 points. For two questions regarding aggression, the score ranges from 0 to 6 points. Results in the range of 0–7 indicate regularity, the range of 8–10 points indicates a borderline level, while the range of 11–21 is considered incorrect [11–13].

The Mini-COPE Inventory for Measuring Coping with Stress is a scale used to assess the level of coping with stress. Respondents answer 28 questions that concern typical behaviour of people in very difficult situations. The respondent answers on a four-point scale: 1=I almost never do this, 2=I rarely do this, 3=I often do this, 4=I almost always do this. It is a tool used to examine adults — healthy and sick. All statements covered by the above tool consist of 14 strategies, which are divided into 4 categories and corresponding scales: active coping, helplessness, seeking support, avoidance behaviours. Strategies: turning to religion, acceptance, sense of humour are separate categories. This tool allows you to assess which strategies are the most frequently used [11,14].

The Adherence in Chronic Disease Scale (ACDS) consists of 7 questions with 5 suggested answer options for each question. Questions 1 to 5 refer to behaviours that directly determine adherence. However, questions number 6 and 7 refer to situations and views that may directly affect the level of adherence. This tool is intended for examining adults struggling with a chronic disease. The results reflect the level of implementation of the pharmacological therapeutic plan. The patient can score from 0 to 28 points on this scale. A score below 20 points indicates a low level of adherence. 21–26 points are interpreted as an average level. However, 27 points and more mean a high level of adherence. Only achieving a high level of adherence means proper compliance with therapeutic recommendations [15].

Each patient received an original survey questionnaire and five standardized clinimetric tools.

All statistical calculations were performed using the IBM SPSS 23 statistical package and the Excel 2016 spreadsheet. Qualitative variables were presented using counts and percentages, and quantitative variables were characterized using the arithmetic mean and standard deviation. The significance of differences between more than two groups was checked with the Kruskal–Wallis test and one-way analysis of variance ANOVA (in case of obtaining significant results, Bonferroni post hoc tests were used), and between the two groups the Mann–Whitney U test and Student's t-test for independent samples. In order to determine the relationship between

the strength and direction between the variables, correlation analysis was used by calculating Pearson's correlation coefficients. In all calculations, the level of significance was p≤0.05.

Results

Table 2 presents strategies for coping with stress using the Mini-COPE scale. It has been shown that among patients with myasthenia gravis, the most frequently chosen strategy for coping with stress is acceptance (4.55).

Table 2. Strategies for coping with stress according to the Mini-COPE* scale (N=67)

Descriptive statistics	Min	Max	M	SD
Active coping	67	6.00	4.06	1.10
Helplessness	0	3.67	1.44	0.78
Seeking support	0	6.00	3.81	1.37
Avoidant behaviour	0	6.00	2.65	1.18
Turning to religion	0	6.00	1.94	1.98
Acceptance	0	6.00	4.55	1.43
Sense of humour	0	6.00	2.14	1.46

*Mini-COPE — Inventory for measuring coping with stress; Min — minimum value; Max — maximum value; M — average; SD — standard deviation

Table 3 shows the level of anxiety, depression and irritability according to the HADS-M scale. Among the respondents, the level of anxiety (6.59) and depression was within normal limits. It has been shown that the most common phenomenon among anxiety, depression and irritability is anxiety (6.59). Irritation was declared the least frequently (2.74). Table 3 shows the level of anxiety, depression and irritability according to the HADS-M scale.

Table 3. Level of anxiety, depression and irritability according to the HADS-M* scale (N=67)

Descriptive statistics	Min	Max	M	SD
Anxiety	0	19	6.59	4.26
Depression	0	15	4.58	3.47
Irritation	0	6	2.74	1.70

*HADS-M — Hospital Anxiety and Depression Scale — Modified Version; Min — minimum value; Max — maximum value; M — average; SD — standard deviation

Table 4 shows the level of quality of life of the surveyed respondents. It has been shown that the average quality of life level of patients with myasthenia gravis is 21.01, with a lower score on the MG-QoL scale indicating a higher level of quality of life.

Table 4. Quality of life in patients with myasthenia gravis according to the MG-QoL 15* scale (N=67)

| How true has each of the following statements been over the past few days?				
Answers	Min	Max	M	SD
I am frustrated of myasthenia gravis	0	4	1.70	1.23
I have vision problems	0	4	1.90	1.32
I have vision problems due to myasthenia gravis	0	4	1.69	1.42
I limited my social activity due to myasthenia gravis	0	4	1.39	1.36
Myasthenia gravis limits my ability to enjoy hobbies and other activities	0	4	1.87	1.38
I have problems meeting the needs of my family due to myasthenia gravis	0	4	1.13	1.24
I have to take myasthenia gravis into account in my plans	0	4	2.33	1.12
Myasthenia gravis had a negative impact on my professional skills and work	0	4	2.10	1.55
I have difficulty speaking due to myasthenia gravis	0	4	0.78	1.03
I have problems driving due to myasthenia gravis	0	4	0.76	1.13
I have a low mood due to myasthenia gravis	0	4	1.31	1.05
I have problems walking due to myasthenia gravis	0	4	1.42	1.27
I have problems moving in public places due to myasthenia gravis	0	4	0.94	1.04
I feel overwhelmed due to myasthenia gravis	0	4	1.15	1.16
I have problems taking care of myself (hygiene and appearance)	0	3	0.55	0.84
Descriptive statistics				
Quality of life	0	51	21.01	12.04

*MG-QoL 15 — Myasthenia Gravis Quality of Life 15; Min — minimum value; Max — maximum value; M — average; SD — standard deviation

In turn, taking into account independence in activities of daily living, the average assessment of activities of daily living among patients with MG is 5.22.

One of the examined areas of functioning of patients with myasthenia gravis was compliance with therapeutic recommendations. Adherence was at an average level among the respondents (21–26 points). Unfortunately, almost 24% of patients declare a low level of adherence ≤20.

Analysing the relationship between the quality of life and sociodemographic data, a relationship between the variables was demonstrated. A statistically significantly lower level of quality of life occurs among women (t(65)=2.95; p<0.05), while the lowest quality of life is achieved by people on disability pension F(2.61)=4.98; p<0.05. Pearson's correlation analysis showed that as the age of the respondents increases, the quality of life index decreases (quality of life increases), (r=–0.26; p<0.05). There were no statistically significant differences between the respondent's quality of life and education (t(62)=1.21; p>0.05), place of residence (F(2.61)=4.98; p<0.05), marital status (H(2)=3.67; p>0.05) and economic status (Z=0.24; p>0.05).

Figure shows the relationship between age and the quality of life of patients with myasthenia gravis. According to the chart below, an increase in the quality of life among patients with myasthenia gravis can be observed with age.
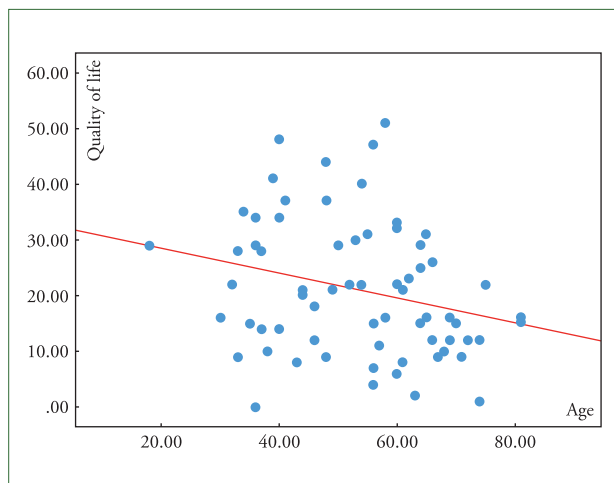
Figure. Age and quality of life in patients with myasthenia gravis

During the analysis carried out regarding the correlation of quality of life and clinical variables, a relationship was demonstrated. A statistically significantly lower level of quality of life occurs among people suffering from generalized MG (Z=2.28; p<0.05), taking non-steroidal and immunosuppressive drugs (Z=2.01; p<0.05) and having symptoms of: diplopia (t(65)=2.24; p<0.05), changes in facial expressions (t(65)=5.51; p<0.001), weakening of biting, chewing, swallowing (t(65)=3.28; p<0.05), weakness of the lower limb muscles (t(65)=3.70;

p<0.001) and weakness of the hand muscles (t(65)=3.65; p=0.001). No statistically significant differences were observed between the respondents' quality of life and the duration of the disease (H(3)=0.73; p>0.05), taking medications: cholinesterase inhibitors (Z=0.96; p>0.05) and eyelid ptosis (t(65)=0.53; p>0.05).

Table 5 below shows the impact of clinical variables on the quality of life of patients with MG. The analysis showed a significantly lower level of quality of life among people suffering from the generalized form, taking non-steroidal and immunosuppressive drugs and having symptoms of: diplopia, changes in facial expressions, weakness of biting, chewing, swallowing, weakness of lower limb muscles and weakness of hand muscles.

To analyse the impact of assessing health and well-being on the quality of life of patients, the Pearson correlation test was used. Negative and positive, statistically significant correlations between variables were obtained. In interpretation, this means that with an increase in the assessment of good health today (r=–0.48; p<0.001), total acceptance of the disease (r=–0.49; p<0.001), disease control (r=–0.39; p=0.001) and effectiveness in fulfilling all tasks (the quality of life index decreases) — the level of quality of life among the surveyed respondents increases.

However, as the impact of the disease and treatment on life increases (r=0.53; p<0.001) and the feeling of loneliness increases (r=0.39; p=0.001) (the index increases) — the level of quality of life of the surveyed people decreases.

There were no statistically significant correlations between the respondents' quality of life and: the degree of understanding the disease (r=–0.13; p>0.05), worry about the disease (r=0.04; p>0.05), optimism (r=–0.17; p>0.05) and religiosity (r=0.07; p>0.05).

The research shows that with the increase in the assessment of good health today, total acceptance of the disease, disease control and effectiveness in fulfilling all tasks — the level of quality of life among the surveyed respondents increases. However, as the impact of the disease and treatment on life increases and the feeling of loneliness increases, the level of quality of life of the surveyed people decreases, as shown in Table 6.

Taking into account the impact of anxiety, depression and irritability on the quality of life, the Pearson correlation test was used. Positive, statistically significant correlations between variables were obtained. In interpretation, this means that as anxiety (r=0.52; p<0.001) and depression (r=0.58; p<0.001) increase (the index increases) — the level of quality of life of the surveyed respondents decreases.

There were no statistically significant correlations between respondents' quality of life and irritability (r=0.13; p>0.05).

Table 5. Clinical variables and quality of life among patients with myasthenia gravis

Clinical variables	Quality of life *higher value=worse quality of life			Statistic value	p
	N	M	SD		
Duration of the disease					
<1 year	6	18.83	6.96		
From 1 to 5 years	22	22.63	12.53	0.73 (df=3)	0.864[a]
From 6 to 10 years	10	20.20	12.88		
>10 years	29	20.51	12.59		
Form of MG					
Ocular	17	15.17	10.36	2.28	0.022[b]
Generalized	50	23.00	12.02		
Drugs: cholinesterase inhibitors					
No	5	25.40	11.28	0.96	0.333[b]
Yes	62	20.66	12.12		
Drugs: non-steroidal immunosuppressive drugs					
No	54	19.55	11.79	2.01	0.045[b]
Yes	13	27.07	11.56		
Symptoms					
Diplopia					
No	35	17.94	10.02	2.24 (df=65)	0.028[c]
Yes	32	24.37	13.27		
Drooping eyelids					
No	26	22.00	11.89	0.53 (df=65)	0.598[c]
Yes	41	20.39	12.24		
Change of facial expressions					
No	46	16.45	8.66	5.51 (df=65)	0.000[c]
Yes	21	31.00	12.54		
Weakness in biting, chewing and swallowing					
No	36	16.86	10.48	3.28 (df=65)	0.002[c]
Yes	31	25.87	12.06		
Weakness of the muscles of the lower limbs					
No	21	13.61	9.15	3.70 (df=65)	0.000[c]
Yes	46	24.39	11.76		
Weakness of the hand muscles					
No	24	14.41	8.93	3.65 (df=65)	0.001[c]
Yes	43	24.69	12.06		

*a — Kruskal–Wallis test; *b — Mann–Whitney U test; *c — Student's t-test; N — number of observations; M — average; SD — standard deviation; p — statistical significance

To analyse the relationship between the quality of life and the daily activities of patients with MG, the Pearson correlation test was used. A positive, statistically significant correlation between the variables was obtained. In interpretation, this means that as the difficulties in everyday activities increase (the index increases) — the level of quality of life of the respondents decreases (r=0.54; p<0.001).

In relations to the relationship between ways of coping with stress and quality of life, the Pearson correlation test was used. A negative, statistically significant correlation between the variables was obtained. In interpretation, this means that as the search for support increases (the index decreases) — the level of quality of life of the surveyed respondents increases (r=–0.26; p<0.05). There was no statistically significant relationship

Table 6. Assessment of one's own health and well-being and the quality of life of patients with MG* (N=67)

Quality of life	r	p
How do you rate your health today?	–0.48	0.000
To what extent do you accept your illness?	–0.49	0.000
To what extent do you think you have control over your disease?	–0.39	0.001
To what extent do you understand your disease and the treatment process?	–0.13	0.284
To what extent is the disease a concern for you?	0.04	0.727
To what extent do the disease and its treatment affect your life?	0.53	0.000
How optimistic are you?	–0.17	0.162
How lonely are you?	0.39	0.001
How spiritual/religious are you?	0.07	0.553
How do you rate your effectiveness in fulfilling the tasks associated with all these roles?	–0.52	0.000

*MG — Myasthenia Gravis; r — Pearson's correlation coefficient; p — statistical significance

Table 7. Anxiety, depression, ADL*, coping with stress and compliance with therapeutic recommendations, and the quality of life of patients with myasthenia gravis (N=67)

Quality of life	r	p
Anxiety	0.52	0.000
Depression	0.58	0.000
Irritability	0.13	0.276
Activity of daily living (ADL*)	0.54	0.000
Active coping	–0.15	0.215
Helplessness	0.18	0.131
Seeking support	–0.26	0.033
Avoidant behaviour	0.12	0.323
Turning to religion	–0.06	0.618
Acceptance	–0.09	0.441
Sense of humour	–0.06	0.615
Adherence level	–0.04	0.716

*ADL — Activities of Daily Living; r — Pearson's correlation coefficient; p — statistical significance

between the quality of life of the respondents and coping with stress through: active coping (r=–0.15; p>0.05), helplessness (r=0.18; p>0.05), avoidance behaviour (r=0.12; p>0.05), turning towards religion (r=–0.06; p>0.05), acceptance (r=–0.09; p>0.05) and a sense of humour (r=–0.06; p>0.05).

Taking into account compliance with therapeutic recommendations, there was no statistically significant relationship between the subjects' quality of life and the level of adherence (r=–0.04; p>0.05).

From the presented results, it can be concluded that an increase in the level of anxiety and depression, an increase in difficulties in performing everyday activities and an increase in the search for support is associated with an increase in the level of quality of life of the surveyed respondents. The remaining factors examined and the level of adherence do not significantly affect the quality of life of patients with myasthenia gravis. All the above results are presented in Table 7.

Discussion

Our own research constitutes an important contribution to the scarce literature on the specific functioning of patients with myasthenia gravis. In addition to sociodemographic and clinical data, various areas of life of patients with MG were analysed, such as: daily activities, quality of life along with the assessment of health and well-being, anxiety, depression and irritability, compliance with therapeutic recommendations (adherence) and strategies for coping with stress.

It has been shown that a low level of quality of life predominates among women with MG. This is the first study to demonstrate the impact of gender on the quality of life of patients with MG. The lowest assessment of the quality of life can be observed among patients on disability pensions. This may be due to the fact that in the case of these patients the income is not very high and medications for myasthenia gravis must be taken regularly, which forces people on disability pensions to spend money on this treatment. As a result of the analysis of the literature on the subject, the author did not find any other studies indicating the impact of the pension on the quality of life.

Our own research has shown the impact of MG on the quality of life. The analysis shows that people suffering from the generalized form have a lower level of quality of life than people struggling with the ocular form of MG. This may be due to the increase in difficulties in performing everyday activities in the above group of patients, which, as the results show, reduces the level of quality of life.

Additionally, it has been reported that some medications may affect quality of life. Respondents indicate that non-steroidal and immunosuppressive drugs negatively affect the quality of life.

Symptoms such as diplopia, changes in facial expressions, weakness in biting, chewing and swallowing, weakness of lower limb muscles and weakness of upper limb muscles reduce the quality of life of patients with MG. This may be caused by the above-mentioned symptoms making it difficult to perform daily activities.

Depression and anxiety are common in MG and adversely affect the quality of life of patients. Bilińska and Sitek noted that without taking into account the clinical picture, the severity of depression may be overestimated. The diagnosis of depression requires cooperation between a psychiatrist and/or psychologist and a neurologist [3].

Our results indicate that a lower level of quality of life can be observed in younger people suffering from MG than in older people. This may be related to the fact that younger people are more physically and professionally active, which is why they are more affected by limitations resulting from the disease. The above results are consistent with the study by Kumar R. et al. from 2016 [16]. However, Basta et al., using the SF-36 questionnaire, showed that the higher the age of the patients, the lower their quality of life [17].

Among the items assessing physical activity in the MG-QoL-15, a small number of patients reported difficulties in performing personal care activities or moving around in public places. Most also reported no significant impairments in speaking or driving. The reasons for obtaining such answers may vary. First, optimal treatment, which included in particular symptomatic treatment, was associated with improved physical strength and helped overcome difficulties in routine activities such as eating or walking. Secondly, social support can address difficulties in having to navigate public spaces or drive a car, or even in having to meet family needs. Moreover, patients can "adapt" to MG by voluntarily reducing physical activity. The presented results are consistent with data from 2016 presented by Kumar R. et al. [16].

It is worth noting that the presented study also assessed the level of adherence among patients with myasthenia gravis. In the study group it is at an average level (68.66%). There is no data in the literature regarding compliance with therapeutic recommendations in this group of patients. Due to the chronic nature of myasthenia gravis, adherence is an important variable determining the effectiveness of the therapy [18,19].

Conclusions

1. Female gender, low socioeconomic status and generalized form of myasthenia gravis have a negative impact on the quality of life of patients with this disease.
2. The most frequently chosen strategy for coping with stress by patients with MG is acceptance.
3. Non-steroidal and immunosuppressive drugs negatively affect the respondents' quality of life.
4. Symptoms such as diplopia, changes in facial expressions, weakness in biting, chewing, swallowing, weakness of the lower limb muscles and weakness of the upper limb muscles make it difficult for patients to perform everyday activities, which contributes to a reduction in their quality of life.
5. The impact of myasthenia gravis on physical and professional activity may cause a decrease in the quality of life among the younger group of patients with myasthenia gravis.
6. The majority of respondents had an average level of adherence.

Implications for Nursing Practice

The obtained results of our own research are consistent with the data presented in the literature, although there is little research in this area. The results presented in this work may become an inspiration to set the direction for further research and expand the issues discussed in this work. They constitute an important contribution to the assessment of the functioning of patients with myasthenia gravis. At the same time, the implications for nursing practice may significantly contribute to improving the quality of care for patients with myasthenia gravis.

It remains an open question to assess the impact of myasthenia gravis on patients' daily lives over the duration of the disease. An interesting perspective for the future would be to conduct prospective studies of the quality of life of patients with MG in correlation with other variables. One area that requires further analysis is undoubtedly adherence among MG patients.

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