Effectiveness of Educational Program on Fatigue and Activities of Daily Living among Myasthenia Gravis Patients

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Abstract

Background: Myasthenia gravis is the most prevalent medical disorder related to dysfunction of neuromuscular transmission. It mainly causes fluctuating muscle weakness, fatigability and decreasing activities of daily living. **Aim of study:** Was to evaluate the effect of education program on fatigue and activities of daily living among myasthenia gravis patients. **Study design:** A quasi- experimental design was used in the study. **Setting:** This study was conducted at neurological departments of Benha University Hospitals and Mansoura University. **Sample:** A purposive sampling was used in the current study and the sample size included (60 patients) with myasthenia gravis. **Tool of data collection: (I)** Patients' interviewing questionnaire, covering patients' demographic characteristics, medical and surgical history, their knowledge about myasthenia gravis. **(II)** Myasthenia gravis fatigue scale. **(III)** Activities of Daily Living, **(IV)** Myasthenia gravis Manual Muscle Test. **Results**: There was significantly improvement in patients' knowledge about disease, fatigue score, activities of daily living and manual muscle test post and at follow up compared to pre program where $p<0.001$. **Conclusion:** The educational program provided for studied myasthenia gravis patient has significantly increased their knowledge about disease and improved fatigue score, activities of daily living and muscle strength. **Recommendation:** Replication of this study is recommended on several clinical settings for generalizability of the research results to other hospitals.

Key words: Activities of Daily Living, Educational program, Fatigue, Myasthenia gravis.

Introduction

Myasthenia Gravis (MG) is an autoimmune disorder that affects neuromuscular transmission and is characterized by localized or generalized weakness and skeletal muscle fatigability. The attacks are both antibody-driven and linked to cellular immunological phenomena **(Piehl and Wolfe, 2020).**

Muscular weakness and fatigability are hallmarks of MG, which affects specific groups of muscles. This weakness typically varies from hour to hour and day to day, worsening with repeated activity and improving with rest. Muscle groups that are vulnerable include the ocular, bulbar, facial, limb, axial, and respiratory muscles **(Shelly, 2020).**

Myasthenic Crisis (MC) is a complication of MG that causes worsening muscle weakness and respiratory failure, necessitating intubation and mechanical ventilation. Myasthenic crisis affects 15-20% of myasthenic patients at some point in their lives **(Meel et al., 2020).**

Activities of Daily Living (ADL) are activities that are typically performed during the course of a normal day in an individual's life, such as eating, walking, or brushing teeth, but these activities are negatively impacted by fatigue and muscle weakness caused by myasthenia gravis disease, which decreases patients' physical activity, functional level, and dependency level **(Chakraborty, 2018).**

The neuroscience nurse faces a challenge when caring for a patient with muscle weakness caused by myasthenia gravis. Nursing interventions for the acute state of a myasthenia patient are described, including care for impaired breathing patterns, inability to clear the airway, impaired communication, altered nutrition, self-care deficits, and impaired vision **(Malik and Almadani, 2019).**

The nurse plays a role in improving the physical condition of patients and their independence in daily activities by assessing the degree of functional impairment and the need for assistance in ambulation (getting up, walking), as well as self-service activities (self-care, bathing, changing a bed, etc.) **(Serrano, 2020).**

Significance of the study:

Most patients with myasthenia gravis develop generalized weakness, such as weakness of limb muscles, within the first two years of disease onset. Bulbar muscles, which are required for speaking, chewing, and swallowing, can also be involved **(Salci, 2018).**

The global prevalence of MG is 100–200 per million populations, affecting over 700,000 people worldwide. Life-threatening MG crises occur in about 15–20% of patients, usually within the first two years of diagnosis **(AL-Zwaini and AL-Mayahi, 2019).**

Respiratory muscles can also be affected in up to 20% of cases, resulting in a myasthenic crisis in which patients must be ventilated artificially **(Andersen, 2019).** Fatigue is a common symptom of myasthenia gravis, and it has been reported by 70%–85% of patients. **(Hasan et al., 2018).**

In Benha University Hospital, the prevalence of myasthenia gravis patients in neurological departments was 43 patients according to Annual statistical data from neurological department at Benha university hospital, 2019. Although, according to annual statistical data in neurological department at Mansoura University Hospital, the prevalence of myasthenia gravis patients in neurological departments was 73 in female and 3 in males; with total prevalence were 76 patients through this year.

Aim of the Study:

The study aimed to evaluate the effect of education program on fatigue and activities of daily living among myasthenia gravis patients.

Research hypotheses:

Hypothesis (1): The mean knowledge score of patients with myasthenia gravis who are exposed to an educational program would be higher than before.

Hypothesis (2): The mean fatigue score of patients with myasthenia gravis who are exposed to an educational program would be decreased than before.

Hypothesis (3): The score of muscle strength among patients with myasthenia gravis post program would be highly significantly than before.

Hypothesis (4): Dependency level in activity of daily living among patients with myasthenia gravis who are exposed to an

educational program would be significantly enhanced than before.

Subjects and Method

Study design:

Quasi-experimental research design was utilized to conduct this study.

Setting:

This study was conducted at neurological departments of Benha university Hospitals mainly and at neurological departments at Mansoura University Hospitals.

Subjects:

A purposive sampling was used in the current study and the sample size included (60 patients) with myasthenia gravis who were admitted to the above mentioned settings within 6-9 months.

Tools of data collection:

The following four tools were used for data collection:

Tool (I): Patients' interviewing questionnaire:

This tool was developed by the researcher and composed of three parts:

Part I: Patients' demographic characteristics.

Part II: Health history which include:

A. **Past history** such as (Previous hospitalization, previous neurologic problems, previous surgery, medication and allergy).

B. **Present medical history** such as (Diagnosis, its symptoms, frequency of symptoms and chronic diseases).

Part III: Patients' knowledge Assessment:

This tool was developed and adopted from previous research references after reviewing related literature by the researcher to assess patients' knowledge about prevention and management of myasthenia gravis.

The knowledge score was categorized as following:

- **Poor:** for those who had a score<50.0%.
- **Average:** for those who had a score 50.0% to 75.0%.
- **Good:** for those who had a score >75.0%.

Tool (II): Myasthenia gravis fatigue scale (MGFS):

The MG fatigue scale encompasses sensations ranging from tiredness to an overwhelming, debilitating, and sustained sense of exhaustion that impairs one's ability to engage in physical, functional, social, and mental activities. This Fatigue Scale is used to assess fatigue in myasthenia gravis patients **(Burns et al, 2008).**

Scoring system of fatigue scale:

MG fatigue scale comprises a 19-item, which scored as following, each item is graded on a 4 point symptom severity scale (0 = normal, 1= mild, 2= moderate and 3= severe), with the total score ranging from 0 to 40 **(Burns et al, 2008).**

Tool (III): MG Activities of Daily Living Scale:

The MG-ADL requires no special equipment or training and can be administered in 10 minutes. The MG-ADL test domains include ocular (2 items), oro-pharyngeal (3 items), respiratory (1 item), and extremity/limb (2 items) (**Muppidi et al., 2017).**

Scoring system:

MG Activities of Daily Living (MGADL) Scale consists of an eight-item questionnaire, with each item graded on a four-point symptom severity scale (0 = normal, 1 = mild, 2 = moderate, and 3 =

severe), and a total score ranging from 0 to 24 **(Wolfe et al., 1999)**.

Tool (IV): MG Manual Muscle Test:

Evaluates the strength or function of 30 muscle groups commonly affected by MG. **(Sanders et al., 2003).**

Scoring system:

The MMT evaluates the strength in 12 bilateral muscle groups and 6 ocular or axial (eg, neck flexors) muscles, that are usually affected in MG. Each muscle is scored from 0 (normal strength) to 4 (paralysis), and the total score is the sum of each muscle, where higher scores indicate more strength (less disease severity) (**Birnbaum et al., 2018).**

Validity and Reliability: Tool (I) was tested for its validity by a jury composed of five experts from (Medical -Surgical Nursing Department) at Benha Faculty of Nursing to ensure the applicability, relevant and replication.

Reliability of tool I was tested for its internal consistency using Cronbach's Alpha test, the coefficient value was (0.805).

Pilot study:

A pilot study was done to assess the applicability and clarity and replicated of the interview questionnaire form. It will conduct on (10%) about (6) cases of myasthenia gravis patients. These subjects will not be included in the study sample.

Ethical consideration

1. The consent was obtained verbally and written from participants to share in the study after explanation of the aim and nature of the study to them.
2. The patient had the right to withdraw from the study at any time.
3. They assured that any information taken from them will be confidential and used for the research purpose only.
4. The patients assured that the result will be used as a component of the research only.

Field work:

This educational program was applied through the following four phases that include assessment, planning, implementation, and evaluation.

Assessment phase:

During this phase, an interviewing questionnaire was applied by the researcher to obtain baseline data using the prepared study tools (**Tool I, II, III and IV**).

Planning phase (program development):

In this phase, the researcher identified the important needs and health services for target group, set priorities, and defined goals and objectives which the content of the educational program was developed.

Implementation phase:

During this phase, the researcher applied this program for patients, after the providing comprehensive explanation through series of teaching sessions that scheduled by the researcher and patients divided into small groups for each session. The researcher used colored pictures and simple booklet.

The program was explained to patients in eight sessions. The duration of each session was 30 minutes minimally/ session and five patients were included in the session.

Evaluation phase:

After completion of the one month exercises training program, the researcher evaluated the effect of exercises training

program on studied patients' muscles strength, dependency level in performing the activities of daily and the patients' knowledge about disease and its management using the assessment tool immediately at the end of program (post) and after one month (follow up).

Statistical analysis:

All statistical analyses were performed using SPSS for windows version 20.0 (SPSS, Chicago, IL). Data were tested for normality of distribution prior to any calculations. All variables with continuous data showed normal distribution and were expressed in mean ± standard deviation (SD). Categorical data were expressed in number and percentage. Chi-square test was used for comparison of variables with categorical data. The reliability (internal consistency) of the questionnaires used in the study was calculated. Statistical significance was set at $p<0.05$.

Results:

Table (1) shows that, the mean age was 38.9 ±11.3 in the studied patients. The majority of patients' age was 41.7% in the studied patients that ranged between 30 to 39 years. Regarding gender, more than half 61.7% of the studied patients were females. Regarding level of education, the table reveals that slightly less than one half 40.0% of studied patients had moderate education.

The table also, illustrates that, slightly less than one half 40.0% of studied patients had physical work. Regarding marital status, the table shows that the majority of patients 55.0% were married.

Table (2) shows that, the majority of the studied patients 70% had previous hospitalization and more than half 60% of the studied patients had neurologic diseases. Regarding chronic disease, the table shows that most of studied patients 45.0% have hypertension disease and were taken anti-hypertensive medication and majority of studied patients 70% had past surgical history.

Figure (1) represents that 58.3% of the studied patients post program and 51.7% of them at follow up registered good knowledge compared to 95% of them registered poor knowledge pre program with a statistically significant difference where $P<0.0001$.

Figure (2) illustrates that 56.7% of the studied patients hadn't fatigue post program and 46.7% of studied patients hadn't fatigue at follow up compared to 55% of them had severe fatigue pre program with a statistically significant difference where $P<0.0001$.

Figure (3) represents that 63.3% of the studied patients post program and 78.3% of them at follow up had normal activities of daily living compared to 50% of them had severe impairment in their activities of daily living pre program with a statistically significant difference where $P<0.0001$.

Figure (4) shows that majority of the studied patients 80.0% post program and 86.7% of them at follow up had normal muscles compared to 75.0% of them had severe muscles weakness pre program with a highly statistically significant difference where $P<0.0001$.

Table (3), illustrates that, there is high significant difference in correlation between Total patient knowledge, MG Fatigue scale, MG-ADL and Manual muscle test at follow up, where $p<0.001$.

Table 1. Frequency distribution of the studied group according their socio-demographic characteristics.

Socio-demographic Variables	N (60)	%
Age (years)		
18 – 29	8	13.3
30 – 39	25	41.7
40 – 49	15	25.0
50 or more	12	20.0
Mean ±SD	**38.9 ±11.3**	
Gender		
Male	23	38.3
Female	37	61.7
Level of education		
Read and write	16	26.7
moderate education	24	40.0
College/University	20	33.3
Marital status		
Married	33	55.0
Single	4	6.7
Divorced	11	18.3
Widowed	12	20.0
Occupation		
Physical work	24	40.0
Administrative work	6	10.0
Intellectual work	6	10.0
Retarded	13	21.7
House wife	11	18.3

Table 2. Frequency distribution of the studied group regarding health history data:

Variables	N (60)	%
A) Past Medical History		
Previous hospitalization		
Yes	42	70.0
No	18	30.0
Previous neurologic problems		
Yes	36	60.0
No	24	40.0
Chronic diseases		
None	8	13.3
Diabetes	13	21.7
Spinal injuries	10	16.7
Hypertension	27	45.0
Heart diseases	2	3.3
Medication		
Insulin	13	21.7
Anti-hypertensive medication	27	45.0
Antibiotics	18	30.0
Cardiac medication	2	3.3
B) Past surgical history		
Yes	42	70.0
No	18	30.0

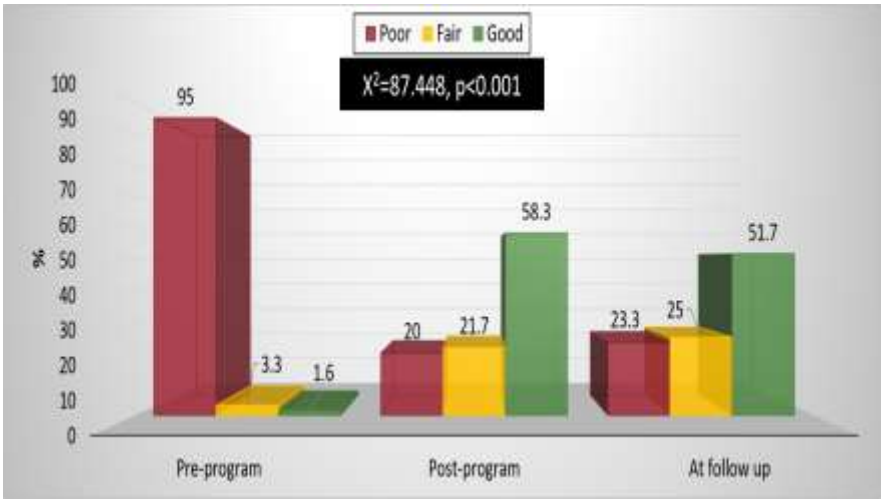

Figure 1: Comparison of the total patients' knowledge regarding MG among pre-program, post-program and at 3 months after implementation (follows up):

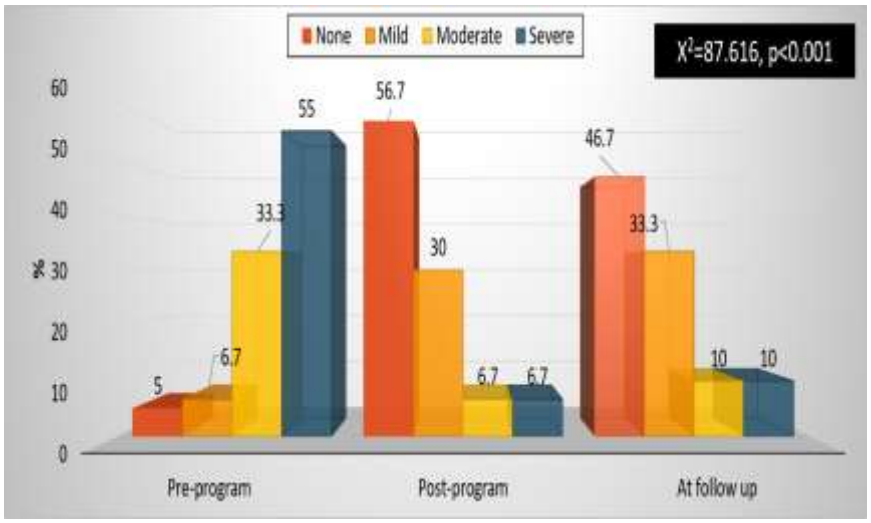

Figure 2. Comparison of the myasthenia gravis Fatigue Scale between pre-program, post-program and at 3 months after implementation (follows up): n=60.

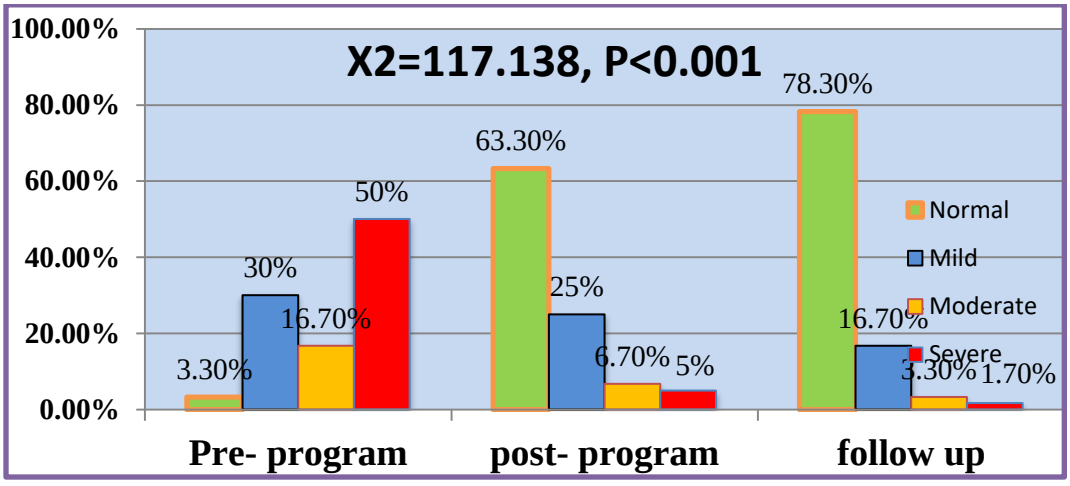

Figure 3: Comparison of Myasthenia Gravis Activities of Daily Living (MG-ADL) scale between pre-program, post-program and at 3 months after implementation (follows up): n=60.

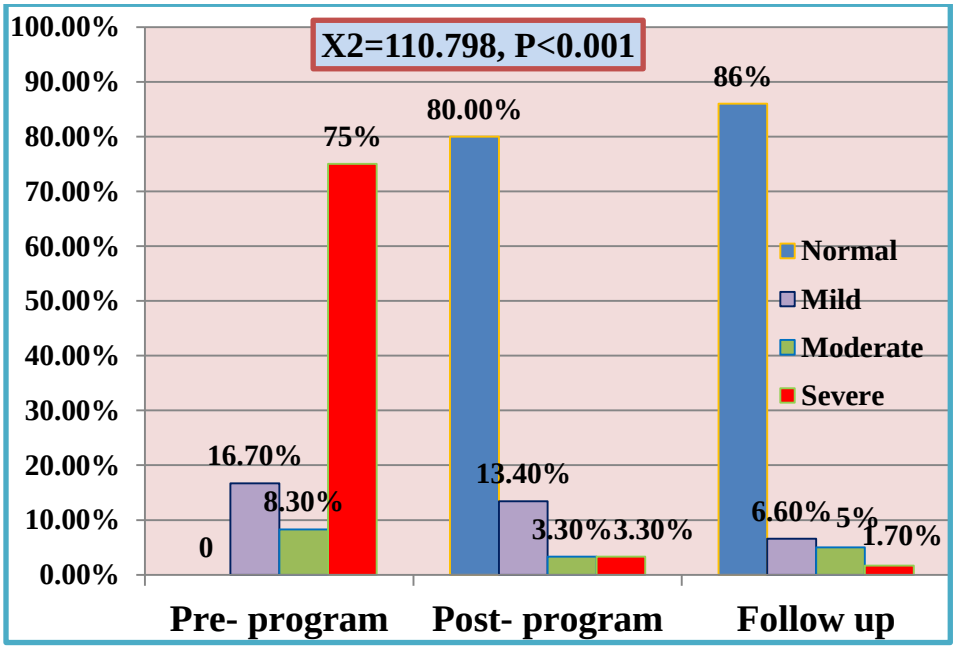

Figure 4. Comparison of Myasthenia Gravis muscle test between pre-program, post-program and at 3 months after implementation (follows up): n=60.

Table 3. Correlation between Total patient knowledge and MG-practice, MG-Fatigue, MG-ADL and MG-muscle testing at follow up. (n=60)

	Poor (n=16)		Fair (n=13)		Good (n=31)		Chi square	
	N	%	N	%	n	%	X^2	P
MG-ADL scale								
Normal	3	18.8	13	100.0	31	100.0		
Mild impairment	10	62.5	0	0.0	0	0.0		
Moderate	2	12.5	0	0.0	0	0.0	45.638	<0.001
Severe impairment	1	6.2	0	0.0	0	0.0		
MG-muscle testing								
Normal	4	25.0	13	100.0	31	100.0		
Mild weakness	7	43.7	0	0.0	0	0.0		
Moderate weakness	3	18.8	0	0.0	0	0.0	41.25	<0.001
Severe weakness	2	12.5	0	0.0	0	0.0		
MG-Fatigue scale								
None	0	0.0	0	0.0	28	90.3		
Mild	6	37.5	11	84.6	3	9.7		
Moderate	4	25.0	2	15.4	0	0.0		
Severe	6	37.5	0	0.0	0	0.0	65.315	<0.001

Discussion

Myasthenia gravis is a potentially fatal chronic autoimmune disorder characterized by circulating autoantibodies directed against skeletal muscle neuromuscular junction (NMJ) components. The muscle weakness typically worsens with continued activity, improves with rest, and ranges in severity from mild ocular muscle weakness to severe generalized muscle weakness **(Lorenzoni et al., 2020).**

Concerning to **socio-demographic characteristics,** the findings of the present study illustrated that the mean age for the studied patients was 38.9 ±11.3. This result agreed with **Alanazy, (2019)** whose study was about "Prevalence and associated factors of depressive symptoms in patients with myasthenia gravis", who mentioned that, the mean age of studied patients was 38.0 ± 16. 0.

As regard to level of education; the current study result showed that the majority of studied patients had (moderate and high education level) which increase studied patient response and participation to study. Similarly, this study was agreement with **Harris et al., (2019)** whose study was about "Employment in refractory myasthenia gravis: A Myasthenia Gravis Foundation of America Registry analysis", who revealed that majority of studied patient had high educational level.

Regarding to past history of patients; the current study illustrated that the majority of the studied patients had previous hospitalization. This result was in the same line with **Salci, (2018)** whose study was about "functional exercise capacity evaluated by timed walk test in myasthenia gravis", who stated that most of the studied sample was hospitalized. This could be return to presenting chronic disease for most of studied patients that required pervious hospitalization.

Regarding to studied patients' knowledge about myasthenia gravis disease; the present study revealed that, there was improvement in their knowledge level post program and at follow up compared to pre program.

This was in agreement with **Hamed and Imbrahim, (2021)** whose study was about "Effect of Self- Care Management Strategy on Self- Efficacy for Patients with Myasthenia Gravis", who found that there was decrease in Patients' knowledge score about myasthenia gravis pre program implementation. But there was increase in total knowledge score after one month and after three months of program implementation.

This improvement in knowledge level was return to the positive impact of educational program that providing structured clear and simple informational and educational materials about myasthenia gravis.

Concerning Patients' fatigue scale; the current study showed that majority of studied patients had sever fatigue pre program while more than half of studied patients had no fatigue post program and at follow up (3 months after implementing program) fatigue with statistical significant difference. This result was in same line with **Ruiter et al., (2021)** whose study was about "Prevalence and associated factors of fatigue in autoimmune myasthenia gravis", who found that most of studied patients had sever fatigue before disease treatment due to

disease severity, while after treatment program minority of studied patients had severe fatigue with statistical significant difference. This improvement in patients' fatigue score was in response to positive effect of implementing nursing educational and intervention program and good following of patients to exercise training program in physiotherapy center and at home.

Concerning to patients' Activities of Daily Living (MG-ADL) scale; the current study illustrated that there was improvement in studied patients' (MG-ADL) post program and at follow up compared to preprogram with a statistical significant difference. These findings were in the same line with **Hamed and Ibrahim, (2021)** who stated that the majority of studied patients had improvement in their activities of daily living after one month and three months from implementing the management strategy compared to pre management strategy.

In accordance to patients' MG manual muscle test; the present study showed that majority of the studied patients post program and at follow up had normal muscles compared to majority of them had severe muscles weakness pre program with a highly statistically significant difference. This study was compatible with **Lueangaram and Sirin, (2021)** whose study was about "Radiological Characteristics of Extraocular Muscles in Myasthenia Gravis Patients With Ocular Manifestations: a Case-Control Study." who presented that the muscle weakness of MG studied patients was relived after implementing of the exercise program compared to before implanting the program with statistically significant differences.

The current study showed that there was high significant difference in correlation between Total patient knowledge, MG Fatigue scale, MG-ADL and Manual muscle test pre and post program. This study was in the same direction with **McPherson et al., (2020)** whose study was about " Correlation of Quantitative Myasthenia Gravis and Myasthenia Gravis Activities of Daily Living scales", who stated that there were correlation coefficients and highly confidence intervals to study the relationships between patient knowledge about myasthenia gravis, fatigue scores and the MG-ADL, manual muscle test.

This high correlation was attributed to the positive effect of the theoretical and practical program sessions that introduced by the researcher to whole participant patients during the study that significantly improved patients' knowledge and increased the independency level as a result of reliving the weakened muscles, increasing functional ability and activity level.

Conclusion

The educational program provided to studied myasthenia gravis patients was effective in improving knowledge, activity of daily living, decrease of fatigue level and increase muscle strength post program and at follow up compared to preprogram.

Recommendations:

1. Myasthenia gravis patients should be encouraged for training of exercise program to improve muscle weakness, fatigue, dependency level and activities of daily living. Furthermore,
2. Replication of this study is recommended on several clinical settings for generalizability of the research results to other hospitals.
3. Each patient should receive individualized duration and number of the sessions and hence of the program for more positive effects.

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تأثيرالبرنامج التعليمي على الشعور بالتعب وأنشطة الحياة اليومية علي المرضى الذين يعانون من الوهن العضلي

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يعتبر الوهن العضلي هو أحد أمراض المناعة الذاتية حيث يسبب ضعف شديد في العضلات و الشعور بالتعب والإرهاق و قلة أنشطة الحياة اليومية لذلك تم تصميم هذا البرنامج التعليمي والتدريبي لمساعدة مرضي الوهن العضلي. لذا هدفت هذه الدراسة إلى تقييم تأثير البرنامج التعليمي على الشعور بالتعب وأنشطة الحياة اليومية علي المرضى الذين يعانون من الوهن العضلي. وقد أجريت هذه الدراسة في أقسام المخ والأعصاب بمستشفي جامعة بنها بشكل رئيسي وفي أقسام المخ والأعصاب بمستشفي جامعة المنصورة. تم تطبيق هذه الدراسة علي جميع المرضي المتاحين (٦٠ مريض) في قسم الأعصاب خلال تسعة أشهر و تم عمل اختبارأولي لهم قبل تطبيق البرنامج و بعد تطبيق البرنامج لتقيم تأثيره عليهم. حيث كشفت النتائج أن أكثر من نصف المرضى الخاضعين للدراسة زادت معرفتهم عن المرض و ايضا أكثر من نصف المرضى لم يعانوا من التعب و أكثر من ثلاثة أرباع المرضي لديهم أنشطة عادية للحياة اليومية بعد البرنامج و في فترة المتابعة مقارنة بقبل البرنامج مع وجود فرق إحصائي كبير. كما اوصت الدراسة بتشجيع مرضى الوهن العضلي على اتباع البرنامج التمريني لتحسين ضعف العضلات ، والتعب ، ومستوى أنشطة الحياة اليومية كما يوصى بتكرار هذه الدراسة في عدة أماكن سريرية لتعميم نتائج البحث على مستشفيات أخرى.