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Calidad de vida y estado de ánimo de un paciente con miastenia gravis

Quality of life and mood of a patient with myasthenia gravis

Qualidade de vida e humor de um paciente com miastenia gravis

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Resumen

La miastenia *gravis* (MG) es una enfermedad autoinmune, de origen desconocida y que repercute en la unión neuromuscular, lo que origina debilidad en la musculatura esquelética y, por lo tanto, tiene como característica la generación de fatiga. Esta sintomatología repercute en las actividades físicas de quienes la padecen y se suele contrarrestar con reposo (Suárez, 2000).

El objetivo de este trabajo es dar a conocer el seguimiento de un paciente con MG: su diagnóstico, el tratamiento y la evolución de esta enfermedad. La persona en cuestión fue diagnosticada desde los cinco años de edad, por lo que también se evalúa cómo esta enfermedad ha repercutido en su calidad de vida y estado de ánimo.

La presente investigación tiene un enfoque cuantitativo; el estudio es de tipo retro-prospectivo. Prospectivo porque se busca evaluar la calidad de vida y el estado de ánimo del paciente; retrospectivo porque se retoman los antecedentes de la evolución de la enfermedad por medio del expediente clínico.

Para cumplir con ello, se realizó la historia clínica del paciente: se revisó su estado de salud general, sus antecedentes patológicos y no patológicos, sus notas de evolución y se efectuaron estudios diagnósticos y de laboratorio; dichos instrumentos de evaluación se aplicaron en un solo momento. Se utilizó, además, el *test* de depresión de Hamilton, el cual sirve para evaluar a los pacientes que se cree puedan estar sufriendo un trastorno de ansiedad o depresión. También se aplicó el World Health Organization Quiality of Life Questionnaire (WHOQOL). Este *test* se centra en la calidad de vida percibida por la persona, aportando un perfil de la misma y dando una puntuación global de las áreas.

Entre los resultados se encontró que el paciente, un adulto joven de 21 años, presenta gastritis e insomnio. Además, debido a que desde los cinco años ha tomado pastillas para controlar la MG, sus dientes se fueron descalcificando y, en consecuencia, requirió del uso de dientes postizos. Con respecto a la aplicación del *test* de depresión de Hamilton, se descubrió que está sufriendo un trastorno de depresión severa. Sin embargo, siguiendo el resultado de la aplicación del instrumento de calidad de vida, el paciente cuenta una calidad de vida regular.

Palabras Clave: Miastenia gravis, Calidad de vida, Enfermería.

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Abstract

Myasthenia Gravis (MG) is an autoimmune disease of unknown origin that affects the neuromuscular junction originating weakness of the skeletal muscles, therefore, has as characteristic fatigue, impacting physical activities and improve with rest (Suárez, 2000).

The objective of this work is to present the follow-up of a patient who presents MG: his diagnosis, treatment and evolution of MG, which was diagnosed since he was five years old. And also evaluates how it has affected his quality of life and his state of cheer up.

The present investigation is with a quantitative approach; the study is Retro-Prospective type. Prospective because the aim is to evaluate the quality of life and the state of mind of a patient presenting MG; retrospective because the history of the evolution of the disease is taken up through the clinical file.

The patient's medical history was made, where his general health status, his pathological and non-pathological antecedents, evolution notes, diagnostic and laboratory studies were reviewed. Also it was used the Hamilton Depression Test, used to evaluate patients believed to be suffering from an anxiety or depression disorder, as well as the WHOQOL, focuses on the quality of life perceived by the person, providing a profile of the same and giving a global score of the areas.

The results showed that the patient, a 21-year-old man, is suffering from a severe depression disorder, however, in the result of the application of the quality of life instrument to the patient with MG, it was obtained with a quality of life regular.

Key words: Myasthenia gravis, Quality of life, Nursing.

Resumo

A miastenia gravis (MG) é uma doença autoimune de origem desconhecida que afeta a junção neuromuscular, que causa fraqueza nos músculos esqueléticos e, portanto, possui a característica de geração de fadiga. Esta sintomatologia afeta as atividades físicas daqueles que sofrem com isso e é geralmente neutralizada com o descanso (Suárez, 2000).

O objetivo deste trabalho é apresentar o seguimento de um paciente com MG: seu diagnóstico, tratamento e evolução desta doença. A pessoa em questão foi diagnosticada a

partir dos cinco anos de idade, por isso também é avaliado como esta doença tem impactado na sua qualidade de vida e humor.

A presente investigação tem uma abordagem quantitativa; o estudo é retroprospectivo. Prospectiva porque busca avaliar a qualidade de vida e o estado de espírito do paciente; retrospectiva, porque os antecedentes da evolução da doença são tomados através do arquivo clínico.

Para isso, foi realizada a anamnese do paciente: seu estado geral de saúde, seus antecedentes patológicos e não patológicos, suas anotações de evolução e estudos diagnósticos e laboratoriais foram revisados; Esses instrumentos de avaliação foram aplicados em um único momento. O teste de depressão de Hamilton também foi utilizado, que serve para avaliar pacientes que se acredita estar sofrendo de um transtorno de ansiedade ou depressão. O Quiality of Life Questionnaire da Organização Mundial da Saúde (WHOQOL) também foi aplicado. Este teste centra-se na qualidade de vida percebida pela pessoa, proporcionando um perfil da mesma e dando uma pontuação global das áreas.

Entre os resultados, verificou-sé que o paciente, um jovem adulto de 21 años, apresenta gastrite e insônia. Além disso, desde que tomou pílulas para controlar MG desde os cinco anos de idade, seus dentes foram descalcificados e, consequentemente, exigiu o uso de dentes falsos. Com relação à aplicação do teste de depressão de Hamilton, descobriu-sé que ele está sofrendo de um distúrbio grave de depressão. No entanto, seguindo o resultado da aplicação do instrumento de qualidade de vida, o paciente tem uma qualidade de vida regular.

Palavras-chave: Miastenia gravis, Qualidade de vida, Enfermagem.

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Introduction

According to Drachman (1994), myasthenia gravis (MG) is coincidentally one of the diseases known as autoimmune diseases because its target organ is known, antibodies have been identified and the mechanisms of cellular immunity involved in the disease are increasingly recognized. attack on the autoimmune system, as well as the thymus affectation at the origin of the disease.

It is important to mention that within the autoimmune problems genetic and environmental factors may prevail that make the patient more susceptible to acquiring these diseases, which may favor the presentation of more than one autoimmune process in the same patient. Therefore, one of the most important processes is the autoimmune pluriglandular syndrome in its two variants.

On the one hand, autoimmune pluriglandular syndrome type I occurs mainly in childhood and is inherited in an autosomal recessive manner and is not associated with any antigen specific to the major histocompatibility complex. Type II, on the other hand, originates in early adulthood and in mature age and in some families the susceptibility is hereditary with an autosomal dominant pattern; It is common that the diseases that compose it appear in multiple generations of a family. Many of the diseases of this syndrome are associated with the BB and DR3 antigens of the major histocompatibility complex (González, Pérez and Lloréns, 1997).

The origin of the problem is in the synaptic transmission that affects the clinical manifestations; are the antibodies directed against the nicotinic acetylcholine receptors of the postsynaptic membrane at the neuromuscular junction. The prevalence of MG is approximately 5 cases per 100 000 people (Suárez, 2000).

The term myasthenia comes from the Greek mys ('muscle') and asthenia ('fatigue' or 'fatigue'). The word gravis, on the other hand, is of Latin origin and can be translated as 'heavy', 'serious', 'hard' or 'marked'. Etiologically, myasthenia gravis implies the existence of marked muscular fatigue.

MG is an alteration defined by skeletal muscle weakness and easy fatigue that deteriorates with physical activity and improves with rest; the process is autoimmune and the symptoms

are mediated by antibodies against the acetylcholine receptor. (Tapia, Tapia and Tapia, 2009).

It was recognized for the first time as a unique clinical entity by Thomas Willis in the seventeenth century, but it was not until 1877 that Samuel Wilks, a London physician, made the first modern description of the disease. After several unsuccessful attempts to baptize her, it was in 1895, at a meeting of the Berlin Society of Physicians and Surgeons, that two cases were described under the name of pseudo-paralytic myasthenia gravis, when the first two words of that description passed to conform the name by which this disease is known today. Since then the advances in the understanding of this entity have not stopped, as well as the search for a definitive treatment for it.

According to Gamboa (2013):

> Patients with MG show weakness in extraocular muscles. More than 65% presents with diplopia and ptosis secondary to weakness of the ocular muscles. Less than 25% present bulbar weakness, with appearance of myasthenic facies, language difficulty, chewing and swallowing. The muscle weakness varies day by day in its distribution and intensity, usually worsens throughout the day and tends to improve with rest and the use of acetylcholinesterase inhibitors. There is also weakness in the flexor muscles of the neck, deltoids, hip flexors, extensors of the wrist and dorsiflexors of the foot (p. 651).

MG is caused by a defect in the transmission of nerve impulses to muscles. It occurs when normal communication between the nerve and the muscle is interrupted at the neuromuscular junction, the place where nerve cells connect with the muscles they control. Normally, when the impulses travel the nerve, the nerve endings secrete a neurotransmitter substance called acetylcholine. Acetylcholine moves through the neuromuscular junction and attaches to acetylcholine receptors. These are activated and generate a contraction of the muscle.

In MG, antibodies block, alter, or destroy acetylcholine receptors in the neuromuscular junction, which prevents muscle contraction from occurring. These antibodies are produced by the body's own immune system. Therefore, MG is an autoimmune disease, because the

immune system, which normally protects the body from external organisms, attacks itself by mistake.

The autoimmune form of MG is not transmitted by Mendelian inheritance, but the children of parents with MG are about 1000 times more likely to have the disease than the rest of the population (Howard, 2014).

Treatment

The first option is the pharmacological treatment of MG, which includes drugs such as pyridostigmine, corticosteroids, azathioprine, cyclophosphamide and immunoglobulin, among others (Bachmann et al., 2009). These bind to acetylcholinesterase and inhibit its action, as well as increase the amount of acetylcholine available in the neuromuscular junction. This leads to a greater synapse of acetylcholine by its receptors, which are found in the cellular membrane of the myasthenic muscle, and it manages to improve its contractility.

Timectomy

As for thymectomy, it has greater benefits in young adults (<40 years) with generalized MG, however, other patients benefit from it. It is important to mention that the benefits of thymectomy are not so obvious in patients with MG: there may be a delay of six months to several years in presenting results. In general, 85% of patients improve with thymectomy; 3 5% go into remission, without needing pharmacological treatment, and 50% reduce the medication requirements. It is not possible to distinguish radiologically patients with thymoma or thymic hyperplasia. In addition, these patients must undergo surgery, since the thymoma can invade adjacent structures in the mediastinum (Suárez, 2000, Chaudhuri and Behan, 2013).

The myasthenic crisis includes in its treatment assisted ventilation if the vital capacity decreases below 15 mg / kg. And, therefore, intubated the patient to stabilize respiratory function. Usually treatment with fluticasone propionate (FP) or intravenous corticosteroids (1 mg / kg / day) is started. The benefits in the patients are observed after the third day. One of the main causes that triggers myasthenic crises are respiratory infections (Suárez, 2000).

Objective

To make known the follow-up of a patient that presents MG on its diagnosis, treatment and evolution. The patient in question was diagnosed from the age of five, so it also aims to assess the way in which this disease has impacted on their quality of life and mood.

Materials and methods

The present investigation is of a quantitative and retro-prospective type. Prospective because it seeks to evaluate the quality of life and the mood of a patient who presents with MG and retrospective because the antecedents of the evolution of the disease were taken up through the clinical file.

In this line, a clinical history of the patient was made: his general condition, his pathological and non-pathological antecedents, his evolution notes and diagnostic and laboratory studies were carried out. It should be specified that the assessment instruments were carried out in a single moment and that the patient's home is located in the state of Hidalgo, Mexico.

Stages

First stage

Through observation, the patient's medical history was made, where his general health status, his pathological and non-pathological background, his evolution notes and diagnostic and laboratory studies were reviewed. At the same time, the collection of bibliographic information covering the etiology, symptomatology and technological advances on MG was undertaken.

Second stage

The Hamilton Test and the WHOQOL (1993) were applied to determine the mood and quality of life of the patient.

Instruments

Hamilton Test

The Hamilton Depression Test is used to evaluate patients who are believed to be suffering from an anxiety or depression disorder. According to the results obtained by it, the degree of severity of the disorder suffered will be diagnosed.

The interpretation of this test is simple. The total score ranges between 0 and 52 points (this being the maximum score). Most of the items present five possible answers (from zero to four) with the exception of some elements with lower weighting (which go from zero to two). Therefore, the total score has different cut-off points: a score of 0 to 7 means that the subject does not show depression; from 8 to 13 supposes the existence of a slight depression; from 14 to 18, a moderate depression; from 19 to 22, a severe one, and more than 23 is a very severe depression and suicide risk (Lobo *et al.*, 2002)

WHOQOL

WHOQOL (1993), It is also a test that focuses on the quality of life perceived by the person, providing a profile of it and giving a global score of the areas and facets that compose it.

It is based on a simple method that measures the perception that the person interviewed gives to each one of the mentioned dimensions. In other words, it is a semi-structured standard interview form that allows spontaneous answers from the user through three stages.

Statistic analysis

The instruments, the Hamilton test and the WHOQOL (1993), are evaluated with the help of the Excel program. This software facilitates the elaboration of tables that will allow to reach the results of the degree of depression and quality of life, and thus be able to elaborate the conclusions and suggestions of this investigation.

Results

The patient is part of a family of five: father of 51 years, mother of 50 years, daughter (1) of 29 years, daughter (2) of 25 years and son (3) of 21 years. According to the clinical history, the following results were reached.

The patient is a young adult with myasthenia gravidarum; He is 21 years old, he is of the masculine gender, his marital status is single and his schooling of degree; He is currently studying and his place of origin is Hidalgo, Mexico.

Among his family history, on the part of his paternal grandparents, the following was found: diabetes mellitus type II, hypertense, operated gall bladder and renal failure; paternal aunt with cerebral palsy. On the part of her mother: diabetes mellitus type 2, hypertension, diabetic retinopathy, operated on of appendicitis and ovarian cyst. On the part of his father: type II diabetes mellitus, operated on lipomas in the neck and extraction of extra bone in both feet. On the part of her sister (1): she also presents ocular MG. And on the part of her other sister (2): presents vitiligo and was operated on gallbladder.

The hygienic habits of the patient are a daily bath. Eat three meals a day; among these those that mainly consume are meat, fruits, vegetables and cereal. Maintains a water intake of approximately one liter per day.

Regarding the pathological personal history, he was diagnosed after five years with MG. According to the Osserman scale, the type of MG presented is group I: ocular myasthenia gravis

It is mentioned as a personal history that since the age of five he has taken pills to control MG. As a result of this intake, his teeth were decalcified and required the use of false teeth. In addition, it presents gastritis and insomnia.

His pathological personal history goes back to June 2000. At the age of five he has symptoms of right ptosis and diplopia, so he goes to the Social Security Institute of the State of Mexico and Municipalities (ISSEMYM), where he is diagnosed with facial paralysis and starts treatment with dexamethasone and multivitamins. With the taking of the treatment it presents improvement: the resolution of ptosis is carried out in seven days. He remains asymptomatic for a month. Subsequently, he presents with non-progressive left ptosis with ocular pruritus. He went to ophthalmology, where he was diagnosed with paralysis of the left

par III, and was referred to a neurologist for probable ocular myasthenia. Performing pirostigmine tests, it is positive: you are diagnosed with MG. They also perform a computed tomography (CT) of the mediastinum, reported as normal.

In January of 2001 it is valued for the first time by the immunology service; initiates management of methylprednisolone. The next day, the patient is started on immunosuppressants with azathioprine 50 mg / day and prednisone 10 mg. It continues with pyridostigmine, with which it presents adequate evolution. It is channeled to the National Institute of Pediatrics, where it remains one month hospitalized.

Treatments

Methylprednisolone (30 mg / kg / dose) in January 2011. Azathioprine 50 mg / day from Monday to Friday: started in January 2001 and was suspended in August 2013. Pyridostigmine: started with 60 mg / day; Currently it takes 120 mg every 4 hours per day. Prednisone: started with 40 mg / day; currently it takes 15 mg / day. Metrotexate: started with 20 mg / week in March 2011; Currently it takes 20 mg every Saturday and Sunday. Omeprazole: 20 mg / day, and folic acid

Evolution

Follow-up in the immunology outpatient clinic and in June 2001 a progressive decrease in prednisone was started at 10 mg / day, later at 5 mg / day until it was suspended in April 2002. Later, however, it was continued until March 2003 , where it was indicated with azathioprine; however, the neurologist at ISSEMYM indicated suspension of said medication. In 2011 he attended the immunology service of the National Institute of Pediatrics for ocular relapse with right palpebral ptosis. Treatment was started with metrotexate 5 mg Saturday and Sunday and folic acid 5 mg every 24 hours, restarting prednisone 40 mg / day, which presented improvement.

The last consultation in the National Institute of Pediatrics was on January 11, 2013, where it was found with improvement of ocular symptomatology, so that progressive steroid decrease began, continuing management with metrotexate and pyridostigmine.

Forecast

Good for life, reserved for the function.

Laboratory and cabinet studies

Antibodies anti acetylcholine receptor (2001)

January 22, 2000: T3T 1.28, total T4 6.83, TSH 1.42, free T3 2.61, free T4 1.9, thyroglobulin 1.12.

2001: Hb 14.4, Hto 42.4, leucos 8300, neutral 3600, lymphos 3900, monocytes 700, eosinophils 100, platelets 430 000. USG adrenal glands: without alterations.

January 2001: attended the National Institute of Pediatrics. Repetitive stimulation studies were performed and the result was negative; stress test, positive.

June 2011 with BH: Hb 15.2, Hto 44.8, leucos 7900, neutrophils 4600, lymphocytes 2200, monocytes 70, eosinophils 300, platelets 308 000. EGO: light straw, DU 1.020, PH 7.0, blood 25, erythrocytes 13, negative rest.

January 2013 with Hb 16.4, Hct 50, 13 700 leukocytes, 10 190 neutrophils, 2459 lymphocytes, 765 monocytes, eosinophils 232, VSG 5, TGO 19.6, TGP 62, GGT 41.4, DHL 212, PCR 0.49.

July 2014: the test acetylcholine antibodies performed by the National Institute of Medical Sciences and Nutrition Salvador Zubirán and sent for analysis of results to the Nichols Institute San Juan Capistrano, California, United States, yielded as result: acetylcholine antibodies 0.56 nmol / L high with values negative reference: <= 0.30 nmol / L, indeterminate 0.31 -0.49 nmol / L, positive:> = 0.50 nmol / L.

December 2014: the repetitive stimulation test of low frequency (3 Hz) was performed in the bilateral ulnar and ulnar nerve, capturing the abductor muscle of the fifth finger of the hand and superior fibers of the trapezium, respectively, with a train of 10 stimuli in ulnar and spinal; The first is compared with the fifth. Taking a basal stimulus, isometric contraction is performed for 30 seconds, recorded at minute one, three and five postejercicio and was obtained: repetitive stimulation test of low positive frequency.

December 30, 2015: is referred to the National Institute of Neurology in a study protocol for thymectomy, already protocolized and a candidate for thymectomy, so it is sent to the National Institute of Respiratory Diseases for thorax surgery with thymus scraping. They were sent for 3 months to continue their treatment.

January 2016, the National Institute of Respiratory Diseases was reoccurred to continue with the specialized treatment for thoracic surgery service.

March 2016: a muscle biopsy was performed.

In 2017: continued in protocol for thymectomy.

The suggested indications for the patient were: physical activity to tolerance; normal feeding.

Interrogation by apparatuses and systems

Signs and symptoms with the presence of diplopia. In the devices without cardiovascular, respiratory, skeletal alterations and endocrine system. In the digestive system with normal peristalsis, solid stools; in the nephrological system with toilet training, amber urine and metabolism. Skin and integuments with slight paleness in teguments, dryness in the dermis. Organs of the senses: present myopia

According to the physical examination, vital signs were obtained: T / A 110/60 ml hg, FC. 76 per minute, FR 20 per minute.

Physical appearance

With aligned appearance, adequate cleaning, ptosis and ocular weakness and obesity of the first degree -obtaining data by other physical examination methods, according to the patient's condition (palpation, percussion, auscultation, measurement). Patient with a height of 1.70 m, weight of 79 kg; He presented pallor of integuments, semi-hydrated oral mucous membranes, soft abdomen that could be depressible on palpation, airways permeable to auscultation, normal thoracic limbs, and full pelvic limbs.

Emotional aspect

The patient presents feelings of sadness due to intense fatigue when he performs physical activities and mentioned that his illness will limit him and he will not be able to have a partner, marry or have children.

With respect to the application of the Hamilton depression test that is used to evaluate the patient with myasthenia, it resulted in a severe depression disorder (see table 1)

Tabla 1. Depresión de un paciente con MG

Tipo	Puntaje	Resultado
Depresión muy severa	22-25	0
Depresión severa	19-22	21
Depresión moderada	14-18	0
Depresión ligera	8-13	0
Sin depresión	0-7	0

Fuente: Elaboración propia

In the WHOQOL application it was obtained that the patient with MG has a regular quality of life.

Tabla 2. Calidad de vida de un paciente con MG

Calidad	Puntaje	Resultado
Excelente	81-100	0
Buena	51 -80	0
Regular	31-50	50
Mala	0-30	0

Fuente: Elaboración propia

Discussion

MG is an autoimmune disease. Different authors agree that the majority of patients with MG have a good prognosis: muscular weakness tends to improve significantly and patients can lead almost a normal life. However, in this research on a patient with this disease it was shown that their quality of life is regular, and that it presents severe depression. So it is important to note that when a patient requests health services who provide it should not focus exclusively on the physiological part and leave aside the emotional part, as discussed in this study, where the patient manifests its limitation in making a daily life, including not having couple projects, as well as children

As mentioned by Hidalgo and Lépiz (2000), thymectomy is necessary for patients with MG who do not have only palpebral ptosis, with the expectation of improving their symptomatology, in any case reducing the requirement of medications and the progress of the disease. Similarly, the patient studied here carried out the thymectomy in order to control or stop his disease. Although this has not been the case, and although the surgical complications are minimal, the patient must be informed that there is a likelihood that there will be no improvement or that this could be long-term.

Conclusions

Concluding with this study, a 21-year-old patient with MG since the age of 5 years, it could be determined that both the quality of life and the state of mind are affected by a disease of this type. This, in part, as a result of suffering from the disease from a very early age, therefore, their self-esteem was deteriorating. It is attributed that since childhood he has relapsed in hospital visits and internments, that is, he did not lead a life as a normal child. In addition, they usually administered medications such as immunosuppressants, which, over time, deteriorated their dental health, dental wear was observed every day, another factor that markedly affected their quality of life. And coupled with the fact that he could not consume certain foods, he could not carry out sports or games that required a lot of physical effort, because, as already mentioned, the MG creates a muscular weakness, causes the muscles to weaken, and causes difficulty. respiratory All this despite the fact that on many occasions he stayed for long periods in hospitals. In short, he did not achieve a full childhood.

As for his state of mind, as already alluded to above, it deteriorated. It was considered important to request support from the psychologist service, as well as the indication of administration of antidepressants, in view of the severe depression that was obtained as a result of the tests applied.

Finally, it is intended that a thymectomy be programmed in order to eliminate the use of immunosuppressants, since the kidneys are affected. With thymectomy it is intended that the MG be controlled definitively and then be able to lead a normal life: perform daily activities.

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