86 - QUALITY OF LIFE AND MULTIPLE SCLEROSIS - REVIEW OF LITERATURE

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Introduction

The loss of the capacity of movement not only has a physical effect on the patient, but also a psychological effect, therefore there is an abrupt change of the self-image: from a young, healthyl and capable person, to a sick and incapable person [1]. The evaluation of the quality of life (QDV) started to be added in the randomly clinical assays, as a third dimension to be evaluated, beyond the effectiveness of the modification of the illness for the effect of drugs, as of security, like in the case of its adverse reactions [2]. The Multiple Sclerosis is a demyelinating illness that attacks the Central Nervous System. The illness generally attacks young adults at the height of their personal and professional lives, being considered an incapacitating illness [3]. Thus, in the last three decades, instruments, generic and specific have appeared in the health area. The most important one being the change of an evaluation based on the measure of objective parameters to another takes in to account the subjective perception of the individual of his proper condition. Not less important, but decurrent of that one, was the change of an evaluation based on the impression of the researcher to that one where the judgment is given by the proper individual, that is the only one that feels and can evaluate, objective and subjectively, his own situation. The lack of a specific clinical treatment, the uncertainty about the prognostic in long time and the frequent difficulty in establishing a real diagnosis make complicates the psychological state of the patient more complicated [1]. A form to follow the repercussion of the injuries in the daily life of the patient is making use of the Scales of Functional Systems, one of the most spread out is EDSS (Expanded Disability Status Scale) proposed for Kurtzke [4]. The objective of the study is to evaluate the quality of life of patients with MS and describe the main factors that interfere with the quality of life of the patients.

Methodology

It was carried through a revision of specialized literature, in the data bases Pubmed, High-wire Press, Cochrane and Scielo. The key words used had been: quality of life and Multiple Sclerosis. A total of 219 (two hundred and nineteen) citations were found. After the crossing of the researchers it was observed that they had similar citations in the data bases Pubmed and High-Wire Press, thus after carrying through the verification of duplicity they came to a total number of 121 (one hundred and twenty and one) citations. After that the searched in the site Periodicos Capes and selected 20 citations was carried through.

Results

The total number of patients evaluated in the studies it was of 2668. The average age found in the evaluated studies was 46,6 years (SD ± 4,8). The ratio of the female gender was 68%. The average of duration of the illness was 11,06 years (SD ± 4,97). Despite having found new criteria diagnosing (Mc Donald et al., 2001) [5] the majority of analyzed articles uses the Poser criteria (1984) as referencial for determination of the illness [3]. It can also be notice that the EDSS is still sufficiently used as observed in 13 of the 17 revised studies. The Sf-36 scale was the most used to evaluate the quality of life (29%), followed by the MSQoL-54 scale (18%).

Discussion

The patient with MS suffers important repercussions in his quality of life since the exact moment the diagnosis is confirmed, as for example, Janssens et al. (2003) had observed that after 3 months after diagnosis, 34% of patients and 40% of the partners had had, clinically, high levels of anxiety and 36% of patients and 24% of the partners had presented severe levels of stress [6]; even social-economical impacts, as evidenced that each patient generates an annual cost of 53.250 EUR, direct costs (drugs and personal assistant) represent 67%, while the indirect costs (loss of production) represent 33%. A patient with severe disorder costs 4,9 times more than one with light disorder [7]. Confirming the previous data Reynolds and Prior (2003) had evidenced that almost all the patients with MS were involved in activities of health [8]. For Mccabe and Judicibus (2005) that had evaluated the costs and the economic pressure a patients with MS in Australia the financial disadvantage is predicted for depression, anxiety, levels of fatigue and QoL [9].

In comparison with healthy individuals, the QoL in patients with MS is reduced in relation to general people [10]. In a comparative study with 1049 healthy individuals, the patients with MS present significant reduction of the QoL, with exception to the patients who have light disorder [11]. These findings had also been observed in the study of Benedict et al. (2005) that besides observing minor QoL in relation to the general individuals found dysfunction in 45% of the patients [12].

Among the factors that interfere in the quality of life of the MS patient presents fatigue, depression, anxiety, alteration in the cognitive function and duration of the illness. There is a strong association between the estimate of QoL and the experience of fatigue [13]. The fatigue, the dysfunctions, and the reduction of the quality of sleep has a main impact in the physical aspect [11]. There is no difference in the severity of the fatigue in patients with light, moderate or severe incapacity stage [14], showing that the patients with MS suffer with the fatigue presence, independent of the stage of the illness. The occurrence of depression, anxiety and the alteration in the cognitive function also interfere with the QoL, according to the increase of the severity of the illness cognitive average values diminish and emotional they increase, evaluated by scales of anxiety and depression (MMSE, Hamilton Rating Scale will be Depression and Hamilton Rating Scale for Anxiety) [15] and for other scales [12]. The depression strongly influences the QoL [10]. In the study of Fruehwald et al. (2001) the author observed that the depression is the greatest factor of risk for reduction of the QoL, besides observing there was no correlation with the duration of the illness and the emotional state [16]. Lobentanz et al. (2004) also observed that the depressive state is the main factor that influences the QoL [11]. Some authors had also associated the QoL with the duration of the illness, being the related QoL directly connected with the time of illness, thus being a more severe and gradual MS, a minor QoL of the patient [16]. Benito-Leon, Rivera-Navarrese and Morales (2002) add that beyond the time of duration, the more severe and gradual the illness worse the QoL [7.15].

There are several scales of evaluation of quality of life, the most used are the Short Form-36 and the Multiple Sclerosis Quality of Life - 54 (MSQoL-54), being the first one generic and the second one specific for the one MS and derived from the first one. The SF-36 is the only one that has already it been translated and validated into the Portuguese language [18], in addition to its easy application and it can identify to eight important concepts of health [19]. The EDSS is strongly used in the physical and quality of life evaluation, despite of several criticism for being highly influenced by the motor function of the inferior members [20]

and having low capacity of evaluating the function of the superior member and the cognitive state [21], thus then, its recommended to currently use Multiple Sclerosis Functional Composite (MSFC), that is composed by three scales for motor evaluation, to evaluate the dysfunctions of the illness, for that has been proved to be more sensitive in relation to the quality of life of than the EDSS [14] and more sensitive in detecting functional alterations [21]. Moreover, there is a significant correlation between the MSFC and the MSQoL-54.

The Qualiveen scale was used for evaluation of the quality of life of patients with urinary disorders and observed moderate to strong correlation of the type, number of symptoms and severity of the incontinence, besides demonstrating a weak correlation with the EDSS, supporting the use of the scale in this population of patients of MS with urinary disorders [20]. In relation to treatment, it was observed a significant improvement with the use of pulsoterapy of metilprednisolona in day 5 and day 30, with EDSS presenting 4,72 in day 0 and 2,94 in day 30; the MSFC from 0,03 to 0,95 and the MSQoL-54 from 67 to 76 [21]. On the other hand, the treatment with interferon 1-beta after one year did not show to alteration in the QoL [22]. With physical activity in ergometric bicycle during 8 weeks of training one observed lower lactate levels with the same load of work, showing the effect of the training. The QoL increased significantly in the trained group and no effect was observed in the immune-endocrine parameters, and neurothophic factors and the author concludes that the aerobic exercise of low intensity not only increases the QoL but also the motor coordination and the physical capacity of patients with MS [23].

Conclusion

The evaluation of the QoL requires multifactorial evaluation and we can observe that in patients with MS some aspects are involved such as: duration of illness, fatigue, depression and physical alterations. In relation to the general population, patient with MS present significant reduction in the quality of life. Amongst the most used instruments for gauging the QoL in MS, the SF-36 scale is more widely used followed by the MSQoL-54, that is a specific scale and derivative of the first one. In relation to the factors that influence the QoL, we can notice that the MS patient needs multiple and interdisciplinary approach, since the drugs, psychological and physical treatments are directly related to the risk factors for reduction of the QoL.

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QUALITY OF LIFE AND MULTIPLE SCLEROSIS - REVIEW OF LITERATURE

Abstract

The evaluation of the quality of life (QoL) started to be added in the clinical assays as a third dimension to be evaluated, in view of the necessity to follow the evolution of the illness and its repercussions in well-being of the patient, mainly in chronic illnesses as the Multiple Sclerosis (MS). The MS is a demyelinating illness that attacks the Central Nervous System. The illness generally attack young adults at the height of their personal and professional lives, being considered an incapacity illness and therefore brings disastrous consequences in self-esteem and the social-economical capacity of the patients. The evaluation of the QoL requires multifactorial evaluation and we can observe that in patients with MS some aspects are involved such as: duration of illness, fatigue, depression and physical disorders. In relation to the general population, patient with MS present significant reduction in the quality of life. Amongst the most used instruments for gauging QoL in MS, the Sf-36 scale is more widely used followed by the MSQoL-54, that is a specific scale and derivative of the first one. In relation to the factors that influence the QoL, we can perceive that this patient needs a multiple and interdisciplinary approach, since the drugs, psychological and physical treatments are directly related to the risk factors for reduction of the QoL.

Keywords: Quality of Life; Multiple Sclerosis and depression.

QUALITÉ DE LA VIE ET DE LA SCLÉROSE EN PLAQUES - EXAMEN DE LA LITTÉRATURE

Abstrait

L'évaluation de la qualité de la vie (QV) a commencé à être ajoutée dans les analyses cliniques comme une troisième dimension à évaluer, en raison de la nécessité pour suivre l'évolution de la maladie et de ses répercussions dans le bien-être du patient, principalement dans des maladies chroniques comme sclérose en plaques (SP). La SP. est une maladie demyelinating qui attaque le système nerveux central. De maladie adultes d'attaque généralement les jeunes à la taille de leurs vies personnelles et de professionnel, étant considéré une maladie d'incapacité et apporte donc des conséquences désastreuses dans l'amour-propre et la capacité social-économique des patients. L'évaluation du QV exige l'évaluation multifactorielle et nous pouvons observer que dans les patients avec la SP. quelques aspects sont impliqués comme: durée de maladie, de fatigue, de dépression et de désordres physiques. Par rapport à la population générale, patient présentant la réduction significative actuelle de SP. de la qualité de la vie. Parmi les instruments les plus utilisés pour mesurer QV dans la SP., la balance SF-36 plus largement est répandue suivie du MSQoL-54, qui est une balance et un dérivé spécifiques du premier. Par rapport aux facteurs qui influencent le QV, nous pouvons percevoir que ce patient a besoin d'un multiple et les traitements d'approche d'interdisciplinaryl, depuis les drogues, psychologiques et physiques sont directement liés aux facteurs de risque pour la réduction du QV.

Mots-clés: Qualité de la vie; Sclérose en plaques et dépression

CALIDAD DE LA VIDA Y LA ESCLEROSIS MÚLTIPLE - REVISIÓN DE LA LITERATURA

Resumen

La evaluación de la calidad de la vida (CV) comenzó a ser agregada en los análisis clínicos como un tercio dimensión que se evaluará, en la vista de la necesidad para seguir la evolución de la enfermedad y de sus repercusiones en el bienestar del paciente, principalmente en enfermedades crónicas como la Esclerosis Múltiple (EM). El EM es una enfermedad desmielinizante que ataca el sistema nervioso central. De la enfermedad es del adulto joven del ataque generalmente en la altura de su vida personal y profesional, siendo considerado una enfermedad de la incapacidad y por lo tanto trae consecuencias desastrosas en autol-imagen y la capacidad socio-economica de los pacientes. La evaluación del CV requiere la evaluación multifactorial y puede observar que en pacientes con el EM algunos aspectos ellos estén implicados como: época de la enfermedad, de la fatiga, de la depresión y de disfunciones físicas. En lo referente a la población en general, paciente con el EM presentan la reducción significativa en la calidad de la vida. Entre los instrumentos usados más para calibrar de CV en EM, la escala SF-36 más extensamente se utiliza seguida del MSQoL-54, que es una escala específicos y derivado de primer. En lo referente a los factores que influencian el CV, podemos percibir que este paciente necesita al acercamiento del multi y interprofessional, por lo tanto el tratamiento de la droga, psicologico y físico se relacionan directamente con los factores del riesgo para la reducción del CV.

Palabras claves: Calidad de la vida; Esclerosis múltiple y depresión

QUALIDADE DE VIDA E ESCLEROSE MÚLTIPLA REVISÃO DE LITERATURA

Resumo

A avaliação da qualidade de vida (QDV) começou a ser acrescentada nos ensaios clínicos como uma terceira dimensão a ser avaliada, tendo em vista a necessidade de acompanhar a evolução da doença e suas repercussões no bem-estar do paciente, principalmente em doenças crônicas como a Esclerose Múltipla (EM.). A E.M. é uma doença desmielinizante que acomete o Sistema Nervoso Central. A doença geralmente acomete adultos jovens no auge de sua vida pessoal e profissional, sendo considerada uma doença incapacitante e por isso traz conseqüências desastrosas na auto-estima e na capacidade sócio-econômica dos pacientes. A avaliação da QDV requer avaliação multifatorial e podemos observar que em pacientes com EM vários aspectos estão envolvidos como: tempo de doença, fadiga, depressão e alterações físicas. Em relação à população saudável, pacientes com EM apresentam significativa redução na qualidade de vida. Dentre os instrumentos mais utilizados para a aferição de QDV em EM., a escala SF-36 é a mais amplamente utilizada seguida da MSQoL-54, que é uma escala específica e derivada da primeira. Em relação aos fatores que influenciam a QDV, podemos perceber que este paciente necessita de uma abordagem multi e interdisciplinar, pois o tratamento medicamentoso, psicológico e fisioterapêutico estão diretamente relacionados com os fatores de risco para redução da QDV.

Palavras-chave: Qualidade de vida; Esclerose Múltipla e depressão.