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Quality of life of people with multiple sclerosis: Clinical and psychosocial determinants

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Abstract

Multiple sclerosis (MS) is an unpredictable, inflammatory, chronic, potentially disabling, neurological disease which is very common in young adults. It is of unknown origin there is no available curative treatment as of yet. Consequently, studying the quality of life (QOL) of people with MS people is an important aspect in assessing the impact of the disease on their daily lives. Through a cross-sectional, quantitative study, we enquired a random sample of 54 Portuguese MS patients, mostly female (61.1%), married (72.2%), aged between 20 and 67 years (M=42.11; SD=11.728), employed (37.0%), in which the mean age at onset was 33 years. The following are the measurement instruments used: the Multiple Sclerosis Quality of Life scale (MSQoL-54) (Vickrey, Hays, Harooni, Myers & Ellison, 1995), Portuguese version by Pedro and Pais-Ribeiro (2008); the Barthel Index (Mayoney FI & Barthel DW, 1965), Portuguese version by Araujo, Pais-Ribeiro, Oliveira and Pinto (2007); the Stress Vulnerability Scale (23QVS) (Vaz Serra, 2000) and the Social Support Scale (SSS) (Ferreira & Matos, 2000). The variables that showed a statistically significant effect on QOL were: age group, employment status, job satisfaction, age at onset of disease, associated diseases, sequelae of the disease, rehabilitation programme, degree of dependency/functional capacity, vulnerability to stress and social support. We believe that all who deal daily with people with this condition need to enter this subjective world where it becomes imperative to identify issues and needs not flagged by health professionals, but perceived by sufferers.

Keywords: Multiple Sclerosis; Quality of Life; Dependence Degree; Stress; Social Support.

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1. Introduction

Due to the increase of disabling diseases which little by little limit individuals’ activity, we have witnessed a major focus of research in medicine, more specifically, in the field of neurological diseases.

Accordingly, and because MS is an unpredictable chronic and disabling autoimmune inflammatory disease, it requires person-centered (Sá & Lamb, 2008) monitoring as well as their families. This has been generating interest in the scientific community.

It is a disease with little known etiology, which usually arises through a bout with a relapse, even without a curative treatment. It is irreversible, progressive and with multiform manifestations, requiring monitoring by a specialized multidisciplinary team.

This disease affects over 400,000 individuals in North America, approximately 500,000 in Europe and at least 1 to 2.5 million worldwide (McKeown, Mitchell et al., 2005 cited in Mimoso, 2007). It is estimated that in Portugal there are over 5,000 carriers (Portuguese Society of Multiple Sclerosis, 2010).

Although they vary from individual to individual, the most common clinical manifestations of this disease are: fatigue (53-92%); motor disorders, visual impairment (optic neuritis is the most common neurological symptom), sensory disorders, cognitive impairment, cerebellar changes, changes in the autonomic nervous system and mental changes (Oliveira, Santos, Fenelon & Penha-Silva, 2007; Pedro & Pais-Ribeiro, 2010; Rodrigues, 2008; Sá & Cordeiro, 2008; Soares, 2006).

Diagnosis currently allows four types of MS to be distinguished, namely: relapsing-remitting MS (the most common form, affecting 80% of MS patients); secondary progressive MS; primary-progressive MS (the rarest and most serious type) and benign MS (Bruno, 2005; Garcia & Coelho, 2009; Oliveira, Santos, Fenelon & Penha-Silva, 2007; Soares, 2006).

Standard therapy consists of three areas different intervention area: the treatment of exacerbation relapses; therapy designed to alter the natural course of the disease and symptomatic therapy (Ferro & Pimentel, 2006; Sá & Cordeiro, 2008).

After an MS diagnosis, individuals change their entire functional dynamics; their behaviour changes, both personally and within the family. They try to adapt to a new reality, leading to changes in QOL. The study of QOL thus becomes essential to determine new strategies for promoting health and well-being.

There are a number of studies on the relationship between MS and QOL, concluding that there is a strong relationship between the disease’s progression and QOL (Pedro & Pais-Ribeiro, 2010).

Knowing the functional evolution determines individuals’ level of (in)capacity, there are several authors who report this level as influencing QOL. In the study by Benedict et al. (2005) individuals who reported a worse QOL had higher levels of disability.

As in MS, all neurological diseases cause biopsychosocial consequences. The deterioration of the symptoms and the lack of a cure make MS a very stressful condition and adjustment problems are more prevalent. Cruz, Monteiro, and Ferreira Mendes (2004), analyzing the relationship between the vulnerability to stress variable and QOL, showed the existence of an inverse relationship.

QOL may also be influenced by social support, which may enhance well-being, allowing family relationships to be maintained as well as work and social relationships (Smith, 2006). In Machado et al. (2010) half of the respondents reported no changes in the home environment, the remaining claim deteriorating relations, including changes in marital status.

2. Problem Statement

After a diagnosis of MS, all individuals change; their behavior changes and they try to adapt to their new reality, automatically changing their QOL. Under this assumption, it is essential to identify and evaluate potential problems, in order to follow the evolution of the disease and individual adapting strategies (Martinez-Matin, 2001). There are several factors that can alter QOL; they may be physical, psychological or social (Hernández, 2000).
3. Research Questions

Understanding the impact of MS is especially with understanding how each individual perceives his health condition, the different variables affecting their QOL and the strategies they adopt to cope with change, or the progressive worsening of their condition. From this perspective, the problem of this study focuses on the following question: “What factors influence the quality of life of the person with MS?”

4. Purpose of the Study

The aim of this study to achieve two objectives: (i) to know the perception of quality of life, vulnerability to stress and social support in people with MS, and (ii) to evaluate the influence of socio-demographic factors and clinical variable in QOL, as well as understand the relationship between QOL, vulnerability to stress and social support.

5. Research Methods

This is a quantitative, descriptive, correlational, cross-sectional and non-experimental study. We considered QOL of the of the person with MS the dependent variable and the following independent variables: a set of socio-demographic variables (gender, age, area of residence, marital status, household composition, family cohabitation, academic qualifications, employment status and satisfaction, occupation and operationalization of job changes due to the illness), and the clinical variables (disease duration, age at disease onset, associated disease(s), disease sequelae, participating in a rehabilitation programme, therapeutic regimen instituted, compliance with medical prescription and degree of dependence) and psychosocial variables (vulnerability to stress and social support).

Participants

The non-probability, accidental or convenience sample, consisted of people with a definite MS diagnosis, recruited in February, 2013 in a session on “Treating Multiple Sclerosis,” held at the University of Minho – Portugal and also by people with MS who attended, a self-help meeting held by the association, “Friends of MS of Aveiro – Portugal” in February, 2013. The following were considered inclusion criteria: ability to read and write; being over 18, with a definite diagnosis of MS, being at different stages of the disease; having the disease for at least one year; not having any other serious debilitating disease at the time of data collection; not presenting a problem affecting cognitive capacity and oral expression.

Fifty-four individuals with MS participated in this study (21 men and 33 women) with a mean age of 42.11 years. All respondents were volunteers and were fully informed when signing the respective consent form.

Instrument

The data collection instrument (DCI), based on the nature of the phenomena intended for study and its psychometric properties included: a socio-demographic and clinical questionnaire (which seeks characterize the socio-demographic and clinical aspects of the MS patients); the Multiple Sclerosis Quality of Life Scale (MSQoL-54) (Vickrey, Hays, Harooni, Myers & Ellison, 1995), Portuguese version by Pedro and Pais-Ribeiro (2008); the Barthel Index (Mayoney FI & Barthel DW, 1965), Portuguese version by Araújo, Pais-Ribeiro, Oliveira and Pinto (2007); the Vulnerability to Stress Scale (23QVS) (Vaz Serra, 2000) and the Social Support Scale (SSS) (Matos & Ferreira, 2000).

To measure the QOL of people with MS we used the Multiple Sclerosis Quality of Life Scale (MSQoL-54), consisting of 54 items, combining items of the generic quality of life scale, the 36-Item Health Survey (SF-36), with other relevant items (18 items) and specific to MS, which usually express symptoms of the disease. The 54 items of MSQoL-54 are spread over scales that assess different dimensions of health-related QOL: physical functioning (10 items), physical performance (4 items), bodily pain (3 items), general health (5 items), vitality (5 items), social functioning (3 items), emotional performance (3 items), mental health (5 items), distress (4 items), cognitive
functioning (4 items), sexual functioning (5 items), general quality of life (2 items) and health transition (1 item). Scoring the MSQoL-54 consists of the sum of the items in each dimension. A low score in the physical functioning, physical performance, emotional performance, cognitive functioning, distress and general quality of life dimensions means more limitations or worse functioning in these dimensions. A low score in the bodily pain, mental health, vitality, general health, social functioning, sexual functioning and health transition dimensions means less pain and better functioning in these dimensions. The MSQoL-54 presents alphas between 0.75 and 0.96 except social function (0.68).

The person with MS’s degree of dependency/functional capacity was evaluated through the Barthel Index. It is an instrument used internationally to assess the level of independence of the subject in performing ten basic activities of daily living: eating, grooming, using the toilet, bathing, dressing and undressing, sphincter control, walking, transferring from chair to bed and climbing up and down stairs. This instrument has a high degree of reliability, with Cronbach’s alpha of 0.92. The overall score of the scale ranges between 0 and 100 points, varying inversely with the degree of dependence, so the higher the score the less the degree of dependence.

Vulnerability to stress was measured by the Stress Vulnerability Scale (23QVS), which is a unidimensional scale consisting of 23 Likert-type questions. Through the scale it is possible to identify various dimensions that account for vulnerability to stress, such as perfectionism and intolerance to frustration; inhibition and functional dependence; the lack of social support; adverse life conditions; the drama of existence; subjugation and deprivation of affection and rejection. A value of 43 is a cut-off point, above which the person is shown to be vulnerable to stress. The 23QVS has a good internal consistency, with a Cronbach coefficient of 0.824 for all items.

Evaluation of social support was carried out with the aid of the Social Support Scale (SSS) by Matos and Ferreira (2000). This scale consists of 16 questions and its aim is to study the quantitative and functional aspects of social support, assessing the availability of emotional, instrumental and informational support. The scale has a multidimensional structure, wherein the scores range between 16 and 80, and the higher score, the better the social support. Cronbach values all lie above 0.8, showing a good internal consistency.

**Procedures**

The data were processed using the Statistical Package for the Social Sciences (SPSS) version 17.0 for Windows with descriptive measures and the parametric and non-parametric tests, to interpret the results.

The study was approved by the Superior School of Health of Viseu’s Ethics Committee. Permission to use the scales was granted by the authors and data collection was authorized by those responsible for the institutions involved.

**6. Findings**

The sample consisted of 54 MS patients, mostly female (61.1%) living in urban areas (63.0%), married (72.2%), with a household mainly consisting of two people (37.0%), and living mainly with children and spouse (40.7%). Mean age was 42.11 years (SD=11.728) with the predominant age group between 32 and 43 years (33.3%). As for academic qualifications, 27.8% of subjects had basic education (2nd cycle [6 years of schooling]), followed by the 3rd cycle [9 years of schooling] with 25.9%. As for employment status, 37.0% are working but 18.5% are unemployed.

Regarding length of diagnosis, the study showed that the mean number of years of participants’ illness is nine, ranging between 1 and 26 years (SD=6.4). Participants’ mean age at onset is 33 years. Only two of the participants have an associated disease (gastrointestinal and endocrine). As for the therapeutic regimen established, the most commonly used drug (for eight subjects – 14.8%) was Copaxone®. Of all participants, 37 related disease sequelae; and imbalance (18.5%), difficulty in mobility (11.1%) and fatigue (11.1%) are the most commonly referred sequelae. Of all the participants, only 48.1% did not participate in a rehabilitation program.

Through the analysis with the Barthel Index instrument, 92.6% of respondents show a degree of independence in their basic activities of daily life. The mean Barthel Index is 97.96 (with 100 being the highest amount allowed by the scale) (Dp=4.710).
Regarding the overall QOL score and its respective dimensions (physical functioning, physical functioning, bodily pain, general health, vitality, social functioning, role emotional, mental health, distress, cognitive functioning, sexual functioning and general quality of life), we note that on average respondents perceived their state of health as most affected in terms of the vitality (\(=43.70\)) general health (\(=43.50\)) dimensions. While social functioning (\(=66.82\)), general quality of life (\(=62.85\)) and sexual functioning (\(=61.11\)) were the health status dimensions least perceived as less compromised.

Comparing males and females in the different dimensions using Student’s t test, it was found that there is no statistically significant difference in any of the dimensions. With respect to health transition, the majority (55.6%) indicated that their health is approximately equal compared to a year ago.

As for vulnerability to stress and related factors (perfectionism and intolerance frustration, inhibition and functional dependence, lack of social support, adverse living conditions, the drama of existence; subjugation and deprivation of affection and rejection), we can infer that in our sample the mean values were relatively low. The mean score found in the total sample was 41.9. Considering the cut-off point, it was found that the subjects are not vulnerable to stress, considering themselves able to deal with their current situation.

Regarding social support and related factors (informational support, emotional support, instrumental support and overall value): in the information support dimension, the values range between 8 and 30 (possibly varying between 6 and 30); in the emotional support dimension, the values range between 8 and 25 (possibly varying between 5 and 25); in the instrumental support dimension, the values range between 12 and 25 (possibly varying between 5 and 25). Perceived social support has a mean value of 61.41 (SD=11.984) on the measurement scale.

Inferential analysis between the socio-demographic variables and the quality of life of people with MS reveals that gender and QOL suggest that male subjects do not differ in a statistically significant way from females (p>0.05).

There are considerable statistically significant differences between the age group and physical functioning (p=0.002) and sexual functioning (p=0.008). MS patients aged between 20 and 31 years have a greater ability to perform all types of physical activity, including the most demanding, with minor limitations for health reasons; and MS patients aged between 56 and 67 years are the ones who express less satisfaction with their sexual activity and functioning.

Regarding academic qualifications we may infer that the total of the results does not show significant effects on the various QOL assessment dimensions (p>0.05).

Considering the effect of the employment status variable, only one significant effect is revealed, and even that at the threshold of statistical significance for the physical functioning dimension (p=0.047). Performing Tukey Post-Hoc Tests revealed the existence of significant differences between the class of employed people (M=57.75) and retired individuals (M=41.11) with a significance value of p=0.049.

In the marital status variable, we can see that there is homogeneity in the mean QOL scores in all dimensions, without statistical significance.

Employment status reveals that people with MS who are who are satisfied with their employment situation have a higher general QOL (statistically significant difference in the general quality of life dimension, with p=0.023).

Inferential analysis of the clinical characteristics and QOL revealed that the time of the course of the disease does not present statistically significant differences with QOL. The results obtained by Pearson correlation for age at onset of the disease, on the other hand, express two statistically significant and negative relationships between age at onset of the disease and the physical functioning (p=0.002) and sexual functioning (p=0.027) dimensions.

Subjects that have no associated disease tend to manifest higher levels of QOL in all dimensions. However, these differences only show statistical significance in the bodily pain (p=0.023) and cognitive functioning dimensions (p=0.012).

Implementing a therapeutic regimen does not influence QOL and respective dimensions (p>0.05).

In the context of sequelae of the disease variable, there is only a significant effect in the physical functioning dimension (p=0.015), showing that people with MS, who do not have disease sequelae yet, have higher physical functioning (M=64.41; Dp=26.21), compared to patients who already have sequelae (M=47.03; Dp=22.13).

With regards to the influence of the rehabilitation programme variable, the results affirm that there is only a significant difference in the mental health dimension (p=0.016), featuring a state of peace, happiness and calm.
As for the relationship between degree of dependency/functional capacity and QOL, they reveal the existence of significant associations (p>0.05) between the degree of dependence and the physical functioning (r =0.366) and social functioning (r=0.327) dimensions; hence, the higher the functional capacity of the person with MS, the their QOL.

Regarding the relationship between vulnerability to stress and QOL, there are significant influences between QOL and all factors of vulnerability to stress. We can infer that the lower the vulnerability to stress, the greater the QOL of the person with MS.

As well as vulnerability to stress, there also are significant influences between QOL and all factors of social support. It is worth noting that all relationships have positive r values, indicating that the higher the informational support, emotional support and instrumental support, the higher the QOL.

7. Conclusions

QOL is a subjective and preferably multidimensional measure whose domains emerge in the physical, psychological or social realms. This is a current issue that needs special attention, especially for health professionals given the importance their intervention can contribute to enhancing well-being and maintaining a good QOL status.

Currently most authors are unanimous in considering that there is a relationship between MS and QOL, concluding that there is a strong correlation between disease progression and QOL. The impact of this disease is also found on various aspects of the individual’s life (Dilorenzo, Halper & Picone, 2003, Pittock et al., 2004, Rotstein, Barak, Noy & Achiron, 2000 cited in Pedro & Pais-Ribeiro, 2010).

From this study, it can be concluded that the population’s profile is: married, employed, females, with a mean age of 42 years, residing in urban areas without chronic diseases associated, with disease sequelae already, with an average of age of 33 years at the onset of disease.

Within the scope of the socio-demographic and clinical variables there are employed MS patients, aged between 20 and 31 years, younger at disease onset, without sequelae, with a reduced degree of dependence, who have a better physical functioning; the ones with associated disease report greater bodily pain and better cognitive functioning; the ones with high functional capacity report better social functioning; the ones doing rehabilitation have better mental health; the MS patients who are between 56 and 67 years old and older at the onset of the disease manifest worse sexual functioning; those with job satisfaction have better overall QOL.

There is a relationship between QOL and the vulnerability to stress dimensions: perfectionism and intolerance to frustration; inhibition and functional dependence; lack of social support; adverse living conditions; the drama of existence; subjugation and deprivation of affection and rejection. There is also a relationship between QOL and all social support factors (informational support, emotional support, instrumental support and overall value).

Just as in several studies related to QOL in MS, our study confirmed that MS patients have impairments in QOL compared to healthy people in all areas, with the most pronounced in the physical domain.

To sum up, this study was designed with the expectation of contributing to improving reflection and care, to minimise effects of the disease so as to enhance the welfare of the individual and family. In this sense, rethinking intervention strategies and priorities, (re)equating (new) forms of support, reorganising and maximising existing resources, as well as learning more appropriate ways to deal with potentially problematic situations of life seem to be simple tasks when facing the potential benefits.

It is fundamental to act, preventing other problem situations and favouring QOL of individuals who live with the disease, as well as all those around them. We reinforce the need for a multidisciplinary team in monitoring and rehabilitating patients with MS and their immediate families (because it is probably these who play or will play the role of caregivers in the present or in the future), taking special care with the physical, psychological and social aspects.

References


