



INFLUENCE OF THE PROFILE OF THE PERSON WITH MULTIPLE SCLEROSIS IN THE QUALITY OF LIFE

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ABSTRACT

Multiple Sclerosis (MS) is a chronic neurological disease, it reaches mainly young adults. A modified immunological response creates a demyelination in Central Nervous System (CNS) resulting in an ample variety of signals and neurological symptoms. The great disability, functional and mental impairment influences directly in the social life and wellbeing of the MS patients meaning a great impact in quality of life. The aim of this study was evaluate the influence of profile in quality of life in patients with MS. Thirty five patients from São Paulo and surroundings were recruited, the profile was evaluated by a structuralized questionnaire, the quality of life by Functional Assessment of Multiple Sclerosis Quality of Life. Social and economic profile demonstrated little influence in quality of life which was more affected by functional impairment and severity of the symptoms.

Key-words: demyelinating diseases, sickness impact profile, quality of life.

INTRODUCTION

Multiple Sclerosis (MS) is a chronic autoimmune disease, it reaches mainly young adults between 16 and 60 years old¹ causing progressive physical and cognitive disability. Its etiology and physiopathogeny are not well established yet. It is believed that in genetically predisposed individuals an anomaly occurs in the immunological response^{2,3}.

The clinic forms are relapsing-remitting (RR) MS, primary-progressive (PP) MS, secondary-progressive (SP), MS and

relapsing-progressive (RP) MS⁴.

Expanded disability status scale (EDSS) developed by Kurtzke⁵ is widely used to designate the Multiple Sclerosis incapacity degree. It varies from 0 to 10, where 0 is the absence of deficit or symptoms and 10 is death due to MS. Scores < 3 reflect light incapacity, 3 to 6,5 moderate incapacity and > 6,5 severe incapacity.

MS has a bigger impact in quality of life than in expectation of life⁶, causing great impact in patients wellbeing and social life. The decline of standard of life, the exclusion from society

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and leisure activities are very stressful for relatives⁷. Kobelt et al⁸ show a strong relationship between quality of life, functional impairment and costs.

So, the aim of this study was evaluate the influence of profile in quality of life in patients with MS.

METHODS

All participants agreed with the study through the signature of a informed consent document with all information concerning the study and data.

Thirty five people with Multiple Sclerosis from São Paulo and surroundings were invited to take part in the study by telephone or e-mail. Due to great difficulty to access the patients cadastral map from big centers, the alternative to localize patients was through the contact with friends, relatives and people from Internet sites.

The inclusion standards used were: medical diagnostic, and preserved mental capacity. The exclusion standards used were: people with associated neurological syndrome and severe incapacity.

The patients were interviewed by a structuralized questionnaire which included demographic, professional and economical data, disease symptoms, medicine and treatment data.

The quality of life was evaluated through the “Escala de Determinação Funcional da Qualidade de Vida em Pacientes com Esclerose Múltipla (DEFU)”⁹, portuguese version

validation of Functional Assessment of Multiple Sclerosis quality of life – FAMS¹⁰.

DEFU has 53 items divided in seven groups: mobility, symptoms, emotional condition, personal satisfaction, thoughts and fatigue, social and familiar condition, attached, but, only 44 items are used to obtain scores, the score obtained in the “attached” group shows important clinical and social information, but they shouldn’t be part from the total score. DEFU score varies from 0 to 176 and higher ones show a better quality of life⁹.

The results obtained were presented in tabular form and statically analyzed by Bio Estat for significance level.

The participants and the results above were grouped according to the following characteristics: school level, fatigue among related symptoms and as the most annoying symptom, EDSS less than 3, between 3 and 6,5 and bigger than 6,5, income and changes in leisure activities and work. The scores from the group with EDSS bigger than 6,5 was considered not significant because we were unable to accomplish the statistic test with $n=2$.

The correlation among the sub-groups scores and DEFU total score was determined through Spearman’s correlation, determining wich sub-groups directly contribute for total score.

RESULTS

Among 35 MS evaluated patients, 66% were female, 34% male. The average age was 41,69 years old, (from 16 to 65 years old). Due to race 77,14% considered themselves white, 2,86 % black, 17,14% half black and half white and 2,86% asiatic.

The subjects were MS patients for 8,01 years \pm 5,99. 40% in average and had medium EDSS 3,59 \pm 2,57.

Due to school level there was only 2,86% who didn't finish "1st degree", 8,57 finished "1st degree", 5,71% didn't finish "2nd degree", 25,71% finished "2nd degree", 11,43% didn't finish College and 45, 71% finished College. The participants were divided into groups belonging to "1st degree" and "2nd degree" or College finished or not.

According to their income the obtained results were: 11% less than R\$ 500,00, 37% R\$ 1.000,00 to R\$ 2.000,00, 14% R\$ 2.000,00 to R\$ 3.000,00, 18% R\$ 3.000,00 to R\$ 5.000,00 and 20% more than R\$ 5.000,00.

Due to leisure activities, 57,14% of the patients had it reduced after MS diagnostic, and 42,86% just kept the same leisure activity level.

Job or occupation was the most disturbed activity. 31% were retired, 6% stopped working,

were under medical discharge, 9% reduced working hours and 14% worked under some kind of adaptation. These categories were grouped in just two groups, one with some kind of occupation or job (42,86%) and another one with retired people or people who weren't working at all.

Due to leisure activities, 57,14% of the patients had it reduced after MS diagnostic, and 42,86% just kept the same leisure activity level.(table 1).

DISCUSSION

Some international research have evaluated MS's people quality of life and correlated it with usual MS characteristics like: functional changes⁷, intestinal, vesicular and sexual problems¹¹ and change in social and familiar life¹².

Patti et al¹³ observed in her study a great connection between a higher degree at school and higher scores at FAMS. In our study, although the group with bigger schooling presents total DEFU scores bigger than the group with lower degree at school, this result is not significant. Fatigue is among the most frequent symptoms in MS's groups¹⁴. In our sample, the group who considers fatigue the most annoying symptom,presents the lowest scores inside the sub-groups related to symptoms and emotional condition.

11% considered themselves unemployed, 6%

Table 1. Comparison of sample characteristics with Functional Assessment of Quality of Life in Patients with Multiple Sclerosis (DEFU)

DEFU	TTL	MOB	SYM	EC	PS	TF	SFC
1° grau	111 ± 10,89	14,75 ± 4,99	22,50 ± 3,00	22,50 ± 4,36	17,50 ± 5,97	14,75 ± 12,34	19,00 ± 6,83
2° grau	119,66 ± 32,38	17,18 ± 6,16	16,82 ± 7,17	21,09 ± 7,92	21,64 ± 6,87	21,64 ± 9,15	21,18 ± 5,44
superior	120,45 ± 34,62	17,45 ± 5,08	18,75 ± 7,81	22,00 ± 6,14	20,90 ± 7,11	20,85 ± 9,83	20,50 ± 6,72
present	123,50 ± 26,58	16,85 ± 5,11	20,90 ± 5,51	22,65 ± 7,00	20,15 ± 7,00	21,05 ± 8,49	21,90 ± 5,12
first symptom	95,70 ± 31,42	15,30 ± 6,00	11,40 ± 6,69*	18,70 ± 5,54*	19,10 ± 7,06	13,90 ± 9,41	17,30 ± 7,09*
Incapacity degree	127,12 ± 28,49	19,88 ± 3,43	19,65 ± 6,95	22,47 ± 4,84	21,59 ± 5,17	21,94 ± 9,54	21,59 ± 5,40
(EDSS)	110,25 ± 35,12	14,56 ± 5,84*	17,63 ± 7,80	20,75 ± 8,09	19,44 ± 8,51	18,56 ± 10,56	19,31 ± 7,27
3 - 6,5	134,07 ± 30,54	18,60 ± 5,41	21,87 ± 5,35	22,93 ± 7,00	22,93 ± 6,80	24,73 ± 9,33	23,00 ± 5,48
not altered	107,85 ± 28,06	15,90 ± 5,12*	16,10 ± 7,38*	20,90 ± 6,01	19,10 ± 6,57*	17,15 ± 9,08*	18,70 ± 6,20*
reduced	136,87 ± 22,82	20,00 ± 3,00	20,20 ± 5,65	23,67 ± 4,95	24,53 ± 5,00	25,60 ± 7,31	22,87 ± 5,57
active	105,75 ± 31,06	14,85 ± 5,70*	17,35 ± 8,21	20,35 ± 7,15	17,90 ± 6,75*	16,50 ± 9,79*	18,80 ± 6,21
retired	102,25 ± 41,89	15,50 ± 9,26	17,25 ± 6,24	16,00 ± 12,68	14,75 ± 9,71	20,75 ± 6,55	18,00 ± 3,16
Income							
< 500,00	-	-	-	-	-	-	-
R\$ 500,00 a R\$ 1000,00	113,25 ± 27,22	16,33 ± 4,42	19,83 ± 5,92	21,75 ± 5,07	18,91 ± 5,63	16,33 ± 11,10	20,08 ± 6,52
R\$ 1000,00 a R\$ 2000,00	108,00 ± 49,56	15,40 ± 7,23	15,60 ± 11,70	20,60 ± 8,02	21,40 ± 8,71	17,00 ± 10,42	18,00 ± 10,07
R\$ 2000,00 a R\$ 3000,00	133,60 ± 18,26	19,20 ± 5,02	17,00 ± 7,48	24,20 ± 4,76	23,00 ± 5,57	26,60 ± 3,58	23,60 ± 1,14
R\$ 3000,00 a R\$ 5000,00	134,14 ± 26,89	18,71 ± 4,46	20,00 ± 8,39	25,29 ± 4,31	23,71 ± 5,74	23,14 ± 10,19	24,29 ± 4,11
> R\$ 5000,00							

Mann-Whitney test *p<0,05

Income - compared through Kruskal-Wallis test; *p<0,05

Legend: TTL= total, MOB= mobility, SYM= symptoms, EC= emotional condition, PS= personal satisfaction, TF= thoughts and fatigue, SFC= social and familiar condition.

The symptoms related to the disease are described in Table 2.

Table 2. Current symptoms

Symptoms	F	%
Fatigue	30	12,20
Disturbance of balance	28	11,38
Disturbance of gait	26	10,57
Diplopy	5	2,03
Another optics disturbances	8	3,25
Intestinal and vesical problems	12	4,88
Fecal incontinence	4	1,63
Urinary incontinence	8	3,25
Tremor	9	3,66
Pain	10	4,07
Burning	7	2,85
Tingling	21	8,54
Palsy	4	1,63
Espasticity	11	4,47
Sensibility loss	13	5,28
Cognitive disturbance	10	4,07
Emotional disturbance	15	6,10
Speak disturbance	8	3,25
Sexual disturbance	13	5,28
Others	4	1,63

The group that considers fatigue the worst symptom DEFU total score is related to emotional condition, personal satisfaction, thoughts and fatigue and social and familiar condition. Meanwhile in the fatigue's group with exception of the emotional condition, these correlations also occur, including mobility, so it means that fatigue not only has impact in physical aspects of the disease, but is strongly related to changes in the psychic condition of people with MS. These results corroborate Aronson's¹⁵ who found correlation between fatigue and deterioration of quality of life.

Montel and Bungener¹⁶ indicated strong

relationship among the development of the emotional condition, how the patient handles with the disease and quality of life. One of the ways to evaluate the development of the disease is through EDSS. The same authors confirm that high EDSS scores are related to worse quality of life concerning emotional aspects. Aronson¹⁵ observed that people with most severe symptoms present less satisfaction concerning quality of life.

Comparing EDSS group lower than 3 with EDSS between 3 and 6,5 it showed that only the mobility sub-group presented difference statistically significant.

Comparing EDSS group lower than 3 with EDSS between 3 and 6,5 it showed that only the mobility sub-group presented difference statistically significant. This result agrees with observations by Pfaffenberger et al¹⁷, whose study with 2299 patients from Austria, verified that those with higher EDSS scores present a higher risk concerning reduction in quality of life due to their mobility.

In both groups occurred correlation among all DEFU sub-groups and total score. The sub-group which presented a higher level of significance were: emotional conditions, personal satisfaction, thoughts and fatigue and familiar and social condition.

These results suggest involvement of psychic aspects in defining limits in quality of life. Montel and Bungener¹⁶ accomplished study in France with 135 patients related high EDSS scores to worst quality of life concerning psychic and physical aspects.

Aronson¹⁵ related a high degree of interference in social activities as a factor of a reduction in quality of life. He yet suggested that maintenance of social activities by MS patients can be an essential factor to prevent or delay patient's internment.

In our study the group who succeed in keeping their leisure activities presented higher scores in all DEFU subgroups: mobility, symptoms, personal satisfaction, thoughts and fatigue, and social and familiar condition, presented significative statistic differences. Our results coincide with Aronson's¹⁵, where the reduction

of leisure activities had harmful effect over patient's quality of life.

DEFU total score has correlation with all sub-groups in the group without any change in leisure activity. The group who presented reduction in leisure activities surprisingly did not presented correlation with mobility and symptoms sub-groups, indicating physical restriction, meaning that reduction of leisure activities is related more to psychic factors than emotional condition, personal satisfaction, thoughts and fatigue and familiar and social condition.

Morales et al¹⁴ observed in his study that the majority of MS patients is retired or not working, likewise our study, where 57,13% of the patients were part of this groups.

The group of active patients presented bigger scores in all DEFU groups, with significant statistic difference in groups concerning mobility, personal satisfaction and thoughts and fatigue.

Patti et al¹³ verified that quality of life of those who still work is significantly higher than the others. The results demonstrate still that the patient of Multiple Sclerosis must keep the job since he is a predictor of vitality and cognitive function. Kobelt et al⁸ also checked that great part of MS patients leave work before retirement on account of the progression of the disease.

His studies show that the functional compromising, the costs, and the quality of life are strongly connected.

So much for the group of assets all that for the group of pensioners there was significant correlation between DEFU total score and all its sub-groups. Aronson¹⁵ also correlated a better quality of life to a bigger income.

For groups with an income up to R\$ 500,00, DEFU is highly correlated to mobility sub-group, emotional condition and personal satisfaction. For groups with an income up to R\$ 3.000,00, DEFU total score is correlated to personal satisfaction, thoughts and fatigue, and social and familiar condition. In the group whose income is R\$ 3.000,00 to R\$ 5.000,00, the sub-groups emotional condition, thoughts and fatigue and social and familiar condition.

We observed that in any belt of income, the group of thought and fatigue maintains correlation with total score while mobility only correlates with total score in the group with an income bigger than R\$ 5.000,00. It suggests that independently of the belt of income all the sub-groups can be affected and present decreases in quality of life.

Quality of life is an extremely important factor, as important as the search for new therapies is to identify how the MS patients have their daily life affected and break from there to try to create measures to improve the daily life of these patients. Besides identifying what the real necessities of the patients are at this moment. In this sense, the studies on quality of life are extremely important and they can contribute to create new policies and social measures.

We suggest that new researches are carried out with more patients and with the support of the great centers in curing the difficulties faced in this work.

CONCLUSION

We observed in this study that the social and economical profile of MS patient demonstrated little influence in quality of life, most affected by factors related to functional impairment and severity of symptoms.

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2) Os autores declaram a não existência de conflitos de interesse.