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STUDY OF THE RELATIONSHIP BETWEEN PHYSICAL DISABILITY AND QUALITY OF LIFE OF PATIENTS WITH MULTIPLE SCLEROSIS IN THE IBN-SINA HOSPITAL IN RABAT

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Background:

Multiple sclerosis (MS) is a chronic inflammatory disease affecting the central nervous system and is a chronic disease leading to a reduced quality of life. The objective of the study is the assessing of physical disability in patients with MS and its impact on QoL; the aim is to facilitate the treatment of patients with this pathology.

Material/ Methods:

75 patients with multiple sclerosis from the Neurology and Neurogenetic Department of the Ibn Sina University Hospital, Rabat, Morocco were studied. The data was collected using a kit composed of several tools including a sociodemographic and clinical questionnaire, the Expanded Disability Status Scale (EDSS), and quality of life SEP-59.

Results:

Of the 75 MS patients in the study, females accounted for 77.3% (n = 58) (the female/male ratio being 3.4). The mean age of the population was 38.29±13.31 years, Relapsing remitting is most present at 65.3% (n=49), while 56% (n=42) were married. We determined that the average EDSS was 4.067 (SD 1.829) with 54.3% (n = 34) of the patients displaying a moderate level of disability (EDSS between 4 and 6.5). We found that of the role limitations - mental and physique, energy, overall quality of life, emotional well-being, distress, sexual satisfaction, sexual function were the QoL scales affected most (SEP-59). Furthermore EDSS is significantly associated with QoL SEP-59.

Conclusions:

The results of this study indicate a strong link between disability and the physical and mental health of patients with multiple sclerosis, which causes a deterioration in their quality of life. The involvement of psychological support is essential.

Key words: multiple sclerosis, neurocognitive, quality of life, state of disability, EDSS

SUMMARY

INTRODUCTION

Multiple sclerosis (MS) is a syndrome that affects a person's central nervous system (CNS). Due to its neurodegenerative and demyelinating nature of nerve fibers, MS appears the most in people aged 20 to 40, with a female predominance (Browne & al., 2014). As the most exhausting chronic disease of the CNS (J. Opara & al., 2012), it is characterized by the appearance of demyelination plaques disseminated over time and space. This gives rise to symptoms such as coordination and balance disorders, sensory disturbances, visual disturbances and pain which affect the quality of life (QoL) (Tan & al., 2010). MS is considered the second most disabling chronic disease of the central nervous system after stroke and Parkinson's disease (Kargarfard & al., 2012; J. Opara & al., 2012).

In this regard, the QoL is the principal point of this disease. Because of its personal and multidimensional character (Isaksson & al., 2005), it allows to define the appropriate tools to assess various aspects of a given situation, which are often not taken into account by medical standards (Ruet & al., 2013). Its meaning mainly depends on the theoretical point of view and the context in which it's used. Some tools focus on current abilities and limitations because of the impact of illness, while others focus on subjective feelings of health. Multiple Studies on MS patients have shown that malaise is not a simple manifestation of an impairment or handicap (Healy & al., 2021). The ineffective treatment and poorly understood etiologies of MS provide compelling evidence of the negative impact of this disease on patients' QoL (Rezapour & al., 2017). For objective monitoring of disease progression, the focus should be on motor functions and gait (Nortvedt & al., 2007). The concept of health-related QoL specifically assesses the impact of illness on self-image, health status and life satisfaction. The QoL of MS patients is often measured using the QOL questionnaire which is considered the most common standardized and disease-specific tool; its purpose is to assess the QoL of MS patients (Bandari and al., 2010; Isaksson and al., 2005; J. A. Opara and al., 2010). Therefore, this study aims to assess physical disability in patients with MS and its impact on QoL; ultimately, the goal is to facilitate the treatment of patients with this pathology

MATERIALS AND METHODS

Study population and procedure

Our study, of a prospective-descriptive nature, is carried out within the neurology and neurogenetics department (B) of the specialty hospital of Ibn Sina University, Hospital Center in Rabat; it focused on 75 patients aged between 18 to 89 suffering from multiple sclerosis.

After explaining to them the exact meaning of each item and establishing inclusion and exclusion criteria's, we filled out the questionnaire after the explanation of the used terms in our dialect (Darija/Arabic), they were given a questionnaire to complete during the consultation (case of hospitalized patients). In order to

avoid visual, motor or cognitive difficulties making self-assessment difficult, this operation took place in a quiet place or at home.

Data collection

a. Self-Questions: The exploitation sheet allowed us to collect socio-demographic information such as age, sex, and marital status, as well as the state of the clinical form of the disease[relapsing-remitting (RRMS), secondary progressive (SPMS) or primary progressive (PPMS)].

b. Scale Expanded Disability Status Scale (EDSS): we used the EDSS scale according to Kurtzke (John F. Kurtzke, 1983), which make it possible to define the degree of disability of a patient. This score is reassessed every six months. A positive evolution means a deterioration of the handicap, while a negative evolution corresponds to an improvement of it. Such a conclusion is based on the one hand on the neurological examination to assess the various functions (motricity, sensitivity, vision, balance, movement control, etc.) and on the other hand on the degree of essentially motor autonomy. The rating of the disability is carried out on a scale ranging from 0 (normal neurological examination) to 10 (death related to MS)(Meyer-Moock and al., 2014). The established score determines the level of disability according to 3 levels: a first level (EDSS \leq 3.5) which considers the deficiencies provided by the clinical examination; a second level (EDSS from 4 to 7.0) characterized by a limitation to various degrees of walking; and a third level (EDSS \leq 7.0) during which walking becomes impossible.

C. Multiple Sclerosis Quality of Life Scale-59 (SEP-59): We used the SEP-59 Multiple Sclerosis quality of life self-questionnaire proposed by Vernay and al.(Vernay and al., 2000). This self-questionnaire has been used and validated by specialists for the measurement and evaluation of QOL in patients with MS. The French version of 59 items differs slightly from the North American version Multiple Sclerosis quality of Life-54 (MSQoL-54) proposed by Vickrey and al. (Vickrey and al., 1995) and which contains 54 items (Vernay & al., 2000; Vickrey & al., 1995). SEP-59 includes items from SF-36 (Short Form) and MSQOL-54(Gerbaud and al., 2006; Ruet and al., 2013).Regarding the dimensions of MS-59, the distribution of scores for the different dimensions is very wide, with scores between 0 "which represents the worst possible QoL" and 100 "which represents the best QoL". The average score for an axis is defined as the sum of the scores assigned to each item divided by the number of items (Vernay and al., 2000).

Statistical analysis

In the statistical analysis, patient characteristics are expressed as a effective (n) and a percentage (%) for qualitative variables and as an average \pm standard deviation (SD) for quantitative variables. The Pearson (r) rank correlation coefficient was used to verify the relationship between scales and the statistically significant between to variable. p-value <0.05 is considered statistically significant. The data was analyzed with Excel and the leader in software for statistical analysis in Excel Since Premium free version 22 (XLSTAT) software.

RESULTS

Descriptive analysis

Our work concerns a group of 75 patients, of which 22.7% (n=17) are male and 77.3% (n=58) female. The sex ratio is 3.4 times of women against a single man, confirming the predominance of female patients. The average age of patients is 38.29 ± 13.310 years, with age extremes varying between 18 and 89 years. It should be noted that the majority of patients included, ie 56% (n=42) are married against 38.66% (n=29) single and 5.33% (n=4) in divorce.

Furthermore, the mean EDSS score is 4.067 ± 1.829 ; in more detail, we noted that 34.7% (n=26) of patients had a slight disability (EDSS ≤ 3.5), 45.3% (n=34) would suffer from a moderate disability (EDSS, 4 to 6.5) and 20 % (n=15) are affected by severe disability (EDSS ≥ 7). The clinical forms of our population are divided into three forms, including the RR form which represents 49 cases, i.e. 65.3%, the SP form which consists of 22 cases (29.3%) and finally the PP form which represents only 4 cases (5.3%) (Table 1).

The average scores of the multiple sclerosis QoL subscales (SEP-59) can be assessed according to several criteria: cognitive function ($54 \pm 27,571$), sleep ($53,627 \pm 24,834$) and social support (52.4 ± 32.969) obtained the highest scores. On the other hand, some dimensions are moderately low such as pain (41.307 ± 20.919), physical function (37.4 ± 23.298), social function (37.035 ± 17.098), health perception (30.39 ± 15.296), sexual function (27.553 ± 24.086) and sexual satisfaction (26 ± 22.676). Finally, the dimensions with incredibly low scores include distress (24.933 ± 19.251), emotional well-being (20.747 ± 15.86), overall quality of life (19.285 ± 15.241), energy (18.067 ± 14.952), role limitation – physical ($17 \pm 24,021$) and mental ($13,327 \pm 22,588$) health (see Table 2).

Table1. Socio-demographic and Clinical data of Multiples Sclerosis patients

Characteristic		Effectif (n)	(%)	Mean	SD
Gender	Female	58	77.3		
	Male	17	17		
Age (years)				38.29	13.310
Marital status	Single	29	38.667		
	Separated	4	5.33		
	Married	42	56		
EDSS				4.067	1.829
	$\leq 3,5$	26	34.7		
	Between 4 and 6.5	34	45.3		
	≥ 7	15	20.0		
Clinical course	RR	49	65.3		
	SP	22	29.3		
	PP	4	5.3		

EDSS, Expanded Disability Status Scale.

Table 2. SEP-59 Assessment of QOL. Results are expressed as mean score (SD)

Scale SEP-59	Mean	SD
Physical health	37.4	23.298
Role Limitation - physical health	17	24.021
Role Limitation - mental health	13.327	22.588
Pain	41.307	20.919
Emotional well-being	20.747	15.86
Energy	18.067	14.952
Health Perception	30.39	15.296
Social function	37.035	17.098
Cognitive function	54	27.571
Healthdistress	24.933	19.251
Sleep	53.627	24.834
Sexual function	27.553	24.086
Sexual satisfaction	26	22.676
Social support	52.4	32.969
Overall quality of life	19.285	15.241

Table 3. Correlation between EDSS and dimensions of SEP-59 Quality of Life

Scale	Correlation Coefficient (r)	p-Value
Physical function	-0.699	<0.0001
Role-limitations- physical	-0.311	0.007
Role-limitations- mental	-0.185	0.112
Pain	-0.471	<0.0001
Emotional well-being	-0.399	0.000
Energy	-0.321	0.005
Health perceptions	-0.454	<0.0001
Social function	-0.584	<0.0001
Cognitive function	-0.270	0.019
Health distress	-0.437	<0.0001
Sleep	-0.028	0.813
Sexual function	0.235	0.042
Sexual satisfaction	-0.156	0.180
Social support	0.310	0.007
Overall quality of life	-0.362	0.001

Statistically significant at p-value <0.05

Correlative Analysis

The factors that were analysed are: EDSS and QoL SEP-59 dimensions. The results of the bivariate analysis show that the dimensions of QoL SEP-59 are influenced by the state of the disability.

It is recognized that patients with MS experience difficulties in their daily activities; this is confirmed by our EDSS results (see Table 3 below) which demonstrate a negatively significant correlation with most of the dimensions of QoL such as: Physical function ($r=-0.699$; $p<0.0001$), role limitation – physical ($r=-0.311$; $p<0.007$), pain ($r=-0.471$; $p<0.0001$), emotional well-being ($r=-0.399$; $p<0.000$), energy ($r=-0.321$; $p<0.005$), health perception ($r=-0.454$; $p<0.0001$), social function ($r=-0.584$; $p<0.0001$), cognitive function ($r=-0.270$; $p<0.019$), distress ($r=-0.437$; $p<0.0001$) and overall quality of life ($r=-0.362$; $p<0.001$); and on the other hand, a significantly positive correlation with social support and sexual function ($r=0.310$; $p<0.007$), ($r=0.235$; $p<0.042$) respectively.

We have thus observed that the patients included in our study experience multiple limitations due to MS, which makes their mobility and autonomy extremely reduced. From this fact, we can with certainty conclude that the QoL depends on different criteria such as the physical, psychological state and somatic sensations (Table 3).

DISCUSSION

This work allowed us to assess physical disability in patients with MS and their impact on QoL. The goal is to provide accurate information to facilitate the treatment of patients with this pathology.

It is well known that the disease of multiple sclerosis is chronic, since it permanently affects the QoL as well as motor and non-motor disorders. SEP-59 is used in our study to assess the impact of this disease on the QoL of patients.

To be able to provide an answer to the effects of MS on the restriction in terms of mobility, we scrutinized the socio-demographic and clinical criteria. In this regard, it is important to underline the female predominance for a sex ratio of 3.4, with the current average age of 38.29 ± 13.310 . Among them 42 cases (56%) are married, and the clinical form RR is the most represented with 49 cases (65.3%). These results correspond to those obtained in other studies (Alharbi & al., 2022; Alshubaili & al., 2008; El Alaoui Taoussi & al., 2012; Moore & al., 2004; Tepavcevic & al., 2008). Comparing to other places, we have also noticed that affected patients are relatively younger and economically active (Browne & al., 2014); they tend to have an earlier age of disease onset (Al-Din & al., 1990; Alshubaili & al., 2005). This same category manifests a more moderate severity of the disease but loses more and more autonomy. In addition, the average EDSS score is 4.067 ± 1.829 with a moderate physical disability of 45.3% (n=34 cases); it is a profile that permanently resorts to the use of the cane; to compensate for their weakness, in addition to the cane, they lean on the walls or their companions with each movement and especially during long distances.

These results are also found elsewhere; in a study of 109 patients with MS, the mean EDSS was 4.2 ± 1.7 (Tepavcevic & al., 2008). On the other hand, that devoted to Kuwait for a group of 170 patients, it is 2.7 (SD 1.8) with a percentage of 82.2% having a slight disability (Alshubaili & al., 2008); a mild form of disability has also been observed (Moore & al., 2004). While it is true that the EDSS varies from one study to another, the finding is the same: the patients have a certain degree of physical disability and show a need for assistance to move around.

Furthermore, the analysis of the different aspects of the QoL for SEP-59 showed the alteration in the QoL of the patients. However, other studies have reported results that compare to mean scores (David Ruban et al., 2021; Miller & Dishon, 2005; Visser et al., 2021). This is the case of our sample whose average score for the dimensions of QoL of SEP-59 is lower. Similar to the work of Moore and al. the average score fluctuates between 3 and 6 (Moore & al., 2004).

Judith Bijoux, Leista and Thomas P. Leistb, in turn, conducted a study on patients with low physical disability and others with high disability. From their study, they identified the results of a significant alteration in QOL in subjects with a high physical disability score (EDSS > 4) (Bijoux Leist & Leist, 2022). Such a score means that the physical disability influences the patients' QOL, even socio-professional activities may be slightly restricted (Brochet & al., 2007). Amato and al. showed that limitations in work and social activities are correlated with the degree of cognitive decline, regardless of the degree of physical disability (Amato et al., 2001).

From our end, we have observed that patients with multiple sclerosis experience different handicap situations depending on the case. Nevertheless, as is the case for more than half of the sample, they need help to get around, either with a cane, in a wheelchair, or with an attendant. These negative effects have been demonstrated in several studies (Janardhan & Rohit Bakshi, 2000; Moore & al., 2004; Pekmezovic & al., 2007).

In this regard, a study is done by Estiasari and al. demonstrated that the majority of QoLcompositions were negatively correlated with EDSS, with the exception of sexual functioning and sexual satisfaction compositions (Estiasari & al., 2019). This is the orientation of our research, and more precisely the level of these two dimensions (sexual function and sexual satisfaction). Many studies point out that a significant proportion of the data related to sexual function and satisfaction suffers from flaws and does not seem plausible (Freeman & al., 2001; Idiman & al., 2006; Kargarfard & al., 2012; Pekmezovic & al., 2007; Solari & al., 1999). This can be explained by the fact that it is too personal or too sensitive a subject to talk about (Idiman & al., 2006) or because it is linked to taboo social and cultural characteristics (Solari & al., 1999). To be more explicit, this lack of information may also be related to the patient's degree of inability to talk about it (Freeman & al., 2001) or to the influence of cultural traditions in this regard (Pekmezovic & al., 2007). Moreover, a significant positive correlation was obtained between physical disability and sexual function. Yet no significant correlation was found between disability and satisfaction. Gerbaud and al. note that none of the items appeared bothersome for the patients, except those related to sexual function and sexual gratification (Gerbaud & al., 2006; Vernay & al., 2000).

Along with, affected patients do not engage in physical activity or sports. The sedentary lifestyle adds to the person's disability situation to generate a negative impact on the patient's QoL. As part of their treatment, such a lifestyle should be abandoned to improve their QoL. In a study by Kerdoncuff and al. it has, in fact, been demonstrated that patients who practiced regular physical and sporting activity had a better QoL compared to sedentary patients (Kerdoncuff & al., 2006).

Other than one of the other criteria to consider is mental health. Rothwell and al. pointed out that practitioners have paid attention primarily to the physical aspects of the disease. However, mental health plays an important role in determining the QoL. On the other hand, the EDSS cannot provide reliable information on aspects of mental health (Rothwell & al., 1997).

To be more implicit previous studies have shown that MS patients not only have a lower QoL than the general population, but also suffer from other chronic diseases (Fernández-Muñoz & al., 2015; Lerdal & al., 2009). MS-related disability, ineffective treatments and unknown causes provide compelling evidence on the adverse effects of this disease on patients' QOL (Afsaneh Akhane & al., 2015). Finally, there is the issue of family support. Patients show a certain degree of satisfaction with support from those around them. If the Moroccan culture lends itself well to it, this support must be maintained and encouraged for these patients. We have seen through this work that more than half of our population needs help getting around and feeling sociable. This becomes a major social necessity, especially when we know that MS patients have a lower QoL than those suffering from other chronic diseases (Fernández-Muñoz & al., 2015). As MS progresses, patients encounter new manifestations of the disease, with more limitations in daily activities and work capacity. And as the disability of patients increases with significant physical disabilities, they become dependent on their families. The ineffective treatment and poorly understood etiologies of MS provide compelling evidence of the negative impact of this disease on patients' QoL (Rezapour & al., 2017).

CONCLUSION

To summarize, the application of the SEP-59 version to the study of quality of life has proven to be easy to use and relatively well accepted by patients and of good psychometric qualities. In addition to this advantage, it has proven a certain reliability and an ability to provide satisfactory answers; the only shortcoming, which concerns a significant number, is related to the sensitivity of the responses to questions relating to factors related to sexual function and satisfaction. When discussing the quality of life of patients with MS disease, it turned out that it is highly dependent on the extent of this disease, with its progressive and irreversible course, and its various symptomatology's, such as motor and non-motor disorders, cognitive disorders. To mitigate the effects, the strategy of neurocognitive diagnosis and remediation aims to maintain an improvement in the functioning of sick people. This improvement should not focus only on the physical aspects (motor) but also on the non-motor aspects of the patient. (Neurocognitive, sensory, mood, social, etc.) It was found that few studies have been devoted to the evaluation of non-physical factors that negatively influence the patient's quality of life. In view of all this observation, it is urgent to develop the necessary and appropriate tools to improve the living conditions of these people, in order to reduce the impact of MS on their daily lives and that of their loved ones.

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