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QUALITY OF LIFE AMONG MULTIPLE SCLEROSIS PATIENTS

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ABSTRACT

Background: Multiple sclerosis (MS) is a frequent chronic neurological disease with an increasing burden worldwide and in Arab regions. Its impacts on the physical and psychological well-being could deteriorate the life quality of the patient. The aim of our study was to assess the quality of life of patients with MS in Saudi Arabia.

Methods:A cross sectional study was conducted using an online questionnaire during a period of two months. A simple random sample of 400 patients with Multiple sclerosis was included in the study.

Results : The mean duration of the disease in our sample was 7.32 ± 5.26. The majority (45.8% participants) rated their health condition as 'good' while 7.0% had rated as 'poor health'. On a scale of 0 to 31 the average score for life quality recorded in our sample was 17.06 ± 5.89, 31% of the interviewed had a good quality of life. There was a significant association between quality of life score and age, education level and occupation. Sex, region, marital status and years of illness were not statistically significant factors for the change in the quality of life score according to this study

ConclusionThe management of patients with MS should take in consideration the evaluation of the harmful impact of the disease on the quality of the daily life of the patient in order to adapt the treatment and improve the coping ability of the patient.

KEYWORDS :

Introduction

Multiple sclerosis (MS) is the most prevalent demyelinating disease Worldwide (1). Along with increasing incidence its burden is becoming more and more important (2). The highest prevalence is recorded in North America and Europe over $100/10^5$ (3), the Arabian Gulf Region is located in a low-risk zone with a prevalence ranging between 31 and 55 per 10^5 individuals, in 2008, the prevalence of MS in Saudi Arabia 40 per 10^5 (4).

MS is an inflammatory disease of the Central Nervous System. Neurons are composed of a cell body and an extension, the axon, surrounded by a protective sheath, the myelin. In MS, the myelin is the target of the disease process. Indeed, there is an inflammatory reaction that will degrade this myelin sheath. This is called demyelination. It causes disturbances in the transmission of information developed by the brain: it is no longer transmitted to different parts of the body, causing the symptoms observed in the disease. At the same time, this demyelination will lead to axon pain because it is no longer protected. It's neurodegeneration. Most of the time, the inflammation disappears and repair mechanisms are put in place. These allow the synthesis of a new myelin sheath. This is called remyelination. (1,5–7).

The symptoms of Multiple sclerosis depend on the areas of the central nervous system that have been affected. Multiple sclerosis

has no typical progression, and each patient has a distinct set of symptoms that can vary from one period to another and whose severity and duration may also change. The most commonly affected systems are vision, coordination, physical strength, sensation, word articulation, bladder control, sexuality, and cognitive function (1,6). Unfortunately, during the course of the disease or during major inflammatory attacks, the repair mechanisms are insufficient, leading to persistent symptoms and the installation of a disability. Despite the progress of research on multiple sclerosis, there is no cure to date, however, a multidisciplinary management of MS could improves daily life people with multiple sclerosis (8). As it is defined by the WHO, the quality of life represents the individual's perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns, It is a broad ranging concept affected in a complex way by the person's physical health, psychological state, level of independence, social relationships, personal beliefs and their relationship to salient features of their environment (9). Many tools have been developed by researchers to assess the quality of life of a patient (10). The aim of this study was to assess the quality of life of patients with MS in Saudi Arabia.

Methods

We conducted a cross sectional study during a period of two

months. A simple random sample of 400 patients with Multiple sclerosis was included in the study. The sample size was computed using the following formula

$$SS = \frac{Z^2 * (p) * (1-p)}{c^2}$$

Where Z is 1.96 for 95% confidence level, p is the prevalence of MS in Saudi Arabia (40/10[5]), c is the precision: 0.05. Using those values we obtain 277 for an expected response rate of 70% the final sample size should be 400 persons.

Data were collected using an online questionnaire composed of 5 sections demographics, general health, physical health, social health and psychiatric health

Statistic analysis

Categorical variables were presented as frequency and percentages and mean ± SD values were presented for continuous variables. Quality of life score was calculated by assigning positive points to the positive answers and zero points to the negative answers. One-way ANOVA test was done to compare the mean quality score of different demographic characteristic.

There was no missing data for this study. The analysis was performed in 95% confidence interval using Statistical Package for Social Science (SPSS), version 20 (IBM, Armonk, NY, USA).

Results

Total 400 multiple sclerosis patients were included in this study done on Department of Medicine, Taif University, Kingdom of Saudi Arabia. More than two thirds (70.3%) of the study population was female. Most of the respondents (78.0%) were aged between 20 to 40 years. The highest number of the participants was from the central region (36.0%) and the smallest number of respondents was from North region (5.5%). More than half of the respondents (61.0%) had college-level educational qualification. Others had below secondary (7.5%), secondary (27.0%) and postgraduate level (4.5%) education. The proportion of married respondents was 52.0%. Their mean duration of illness was 7.32 ± 5.26 years. (Table 1)

45.8% participants rated their health condition as 'good' while 7.0% had rated as 'poor health'. The majority (58.5%) were somewhat active during the day. 34.8% suffered from difficulty to run while 8.8% respondents had difficulty to move feet. In most of the cases (63.5%) multiple sclerosis did not make the patients so debilitated that they cannot practice their daily activity. But, 22.8% patients could not practice their favorite hobby due to the sufferings. 11.3% patients were unable to leave their home, 29.3% showed underperformance in work and 25.0% left the job due to being incapacitated by the disease. 22.0% respondents asked help from someone for performing their daily task, 35.8% practiced sport, 69.5% received support from parents or friends, and 32.0% had issues with social situations and 45.0% suffered from relationship difficulties. Little less than half (47.3%) patients considered themselves as an active personality in the community whereas 51.5 had their social status affected by the disease. Only 6.0% felt delighted about their life but the mainstream (45.5%) felt a mixture of satisfaction and dissatisfaction. (Table 2)

The highest possible quality of life score was 31 if someone could give the optimum answer for each question. But in this study, the maximum score was 30 and the minimum noted score was 1 while the mean ± SD was 17.06 ± 5.89. We have considered a score of > 20 to be of good quality of life, which was obtained by 124 (31.0%) patients. Others had an average quality of life (score 10 to 20, 57.5%) and poor quality of life (score < 10, 11.5%). (Table 3)

One-way ANOVA test showed there was a significant difference in the mean quality of life score for different age groups (F: 8.850, p: <.001). The highest mean was obtained for <20-year-old respondents (20.76 ± 2.68) and the lowest mean was noted for 40+ year old patients (14.90 ± 6.07). There were significant differences in quality of life score for different educational levels (F: 7.218, p: <.001), and occupations (F: 10.139, p: <.001). Sex, region, marital status and years of illness were not statistically significant factors for the change in the quality of life score according to this study (Table 4).

Table 1: Demographic characteristics of all respondents (n = 400)

Variables	N	%
Age		
< 20 years	17	4.3
20 to 40 years	312	78.0
> 40 years	71	17.8
Sex		
Male	119	29.8
Female	281	70.3
Region		
North	22	5.5
East	108	27.3
South	33	8.3
Central	144	36.0
West	92	23.0
Education		
Below secondary	30	7.5
Secondary	108	27.0
College	244	61.0
Postgraduate	18	4.5
Occupation		
Student	55	13.8
Employed	161	40.3
Unemployed	184	46.0
Marital status		.
Married	208	52.0
Unmarried	192	48.0
Years of Illness (Mean ± SD)	7.32 ± 5.26	

Table 2: Answers to the quality of life related questions (n = 400)

Questions and answers	N	%
In general, how do you rate your health?	77	19.3
Excellent	183	45.8
Good	112	28.0
Fine	28	7.0
Poor		
Evaluate your activity during the day	57	14.3
Active	234	58.5
Somewhat active	109	27.3
Sedentary		
Do you suffer from one of the following	139	34.8
situations?	89	22.3
Difficulty to run	35	8.8
Difficulty to walking	137	34.3
Difficulty to moving the feet		
Did not suffer from any of these		
Has the disease prevented you from practicing	33	8.3
daily activities such as dressing clothes,	254	63.5
watching television?	113	28.3
Yes		
No		
Sometimes		
Has the disease prevented you from practicing	91	22.8
your favorite hobby?	166	41.5
Yes	143	35.8
No		
Sometimes		

Have you been prevented from leaving your home? Yes No Sometimes	45 212 143	11.3 53.0 35.8
Does your work performance (school level) affect your illness? Yes No Sometimes	117 137 146	29.3 34.3 36.5
Did you leave your job (study) because of illness? Yes No	100 300	25.0 75.0
Do you ask for help from someone in performing your daily tasks? Yes No Sometimes	88 149 163	22.0 37.3 40.8
Do you practice sport? Yes No	143 257	35.8 64.3
Do you receive support from parents or friends? Yes No	278 122	69.5 30.5
Social withdrawal "Apologies for events and communication" with those around Yes No To a certain extent	128 97 175	32.0 24.3 43.8
Has the disease affected your relationship with your family? Yes No	180 220	45.0 55.0
How do you evaluate your use of social networking programs? Very active Medium Do not use it	178 209 13	44.5 52.3 3.3
From your point of view, do you consider yourself an active personality in the community? Yes No	189 211	47.3 52.7
Has the disease affected your social status? Yes No	206 194	51.5 48.5
What is the best description of how you feel about your life in general? Very bad Not pleased Not satisfied A mixture of satisfaction and dissatisfaction Satisfied often Pleased Delighted	6 16 15 182 118 39 24	1.5 4.0 3.8 45.5 29.5 9.8 6.0
Do you receive one of the following treatment methods (Multiple response) Bee stings Vitamin D Traditional remedies Physical therapy None of the above	6 225 20 75 130	1.5 56.3 5.0 18.8 32.5

Table 3: Mean, SD, SE, Min and Max values of quality of life score (n = 400)

	Scores
Mean	17.06
Standard Deviation	5.89
Standard error	0.29

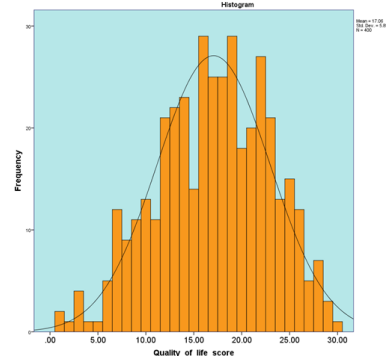| Minimum	1.00
Maximum	30.00
Score category >20 10 to 20 < 10	124 (31.0%) 230 (57.5%) 46 (11.5%)

Figure 1: Histogram of quality of life score

Table 4: One-way ANOVA test to compare the mean quality score of different demographic characteristic (n = 400)

	Mean score	SD	F	95% CI	p-value
Age					
< 20 years	20.76	± 2.68	8.850	22.14-19.39	<.001
20 to 40 years	17.35	± 5.82		18.00-16.70	
>40 years	14.90	± 6.07		16.34-16.48	
Sex	17.55	± 6.27		18.69-16.41	
Male	16.86	± 5.72	1.143	17.53-16.48	.286
Female					
Region					
North	17.45	± 5.80		20.03-14.88	
East	17.06	± 5.92		18.19-15.94	
South	16.00	± 6.25	0.419	18.21-13.79	.795
Central	17.38	± 5.75		18.32-16.43	
West	16.86	± 6.03		18.11-15.61	
Education					
Below secondary	13.03	± 5.33		15.02-11.04	
Secondary	16.38	± 6.09	7.218	17.54-15.22	<.001
College	17.70	± 5.66		18.42-16.99	
Postgraduate	19.17	± 5.71		22.01-16.48	
Occupation					
Student	17.71	± 4.95		19.05-16.37	
Employed	18.42	± 5.81	10.13 9	19.33-17.52	<.001
Unemployed	15.68	± 5.94		16.54-14.82	
Marital status					
Married	16.66	± 5.97		17.47-15.85	
Unmarried	17.49	± 5.79	1.994	18.32-16.67	.159
Years of illness	17.06	± 5.89	1.365	17.64-16.48	.068

Discussion

The majority of the patients suffering from MS included in our study rated their health condition as good. On a scale of 0 to 31 the average score for life quality recorded in our sample was 17.06 ± 5.89, 31% of the interviewed had a good quality of life. There was a significant association between quality of life score and age, education level and occupation. In another Saudi study, conducted by Algahtani et al, the average score of life quality on the EuroQol Visual Analog Scale (a scale from 0 to 100) was 73.87±23.41 (11).

The demyelination process impair the transmission of the nervous

signal which is responsible of the fatigue, a major complain of MS patients and more common than motor deficits, spasticity and sphincter disorders (12). The fatigue in MS patients is a physical and cognitive fatigue which hinders the degree of participation of the patient in social life and therefore can trigger anxiety or depression, in our study 51 % responded that the disease affected their social status. Numerous papers reported the association between physical impairment and depression and anxiety and their role in the determinism of the patient life quality (13–16).

The assessment of the quality of life of an individual suffering from a chronic disease is an important step in the management process of the disease; this evaluation will reveal the unseen impact of the disease progression as well as the possible side effects of the different therapies on daily life activities. The practitioner point of view alone is not sufficient for such assessment, in fact studies evinced of the existence of a discrepancy between the physician evaluation of the quality of his patient life and the evaluation by the patient himself (17–19).

In a study conducted by Ysrraelit et al there was a significant difference between the response of MS patient and the neurologists the level importance physical limitation emotional limitation and vitality (20). In our study around 56% of the patients had physical activities difficulties in running and walking, the level of life quality was associated with education level and occupation which is consistence with the findings of other authors (15)

The mean disease duration among our sample was 7.32 ± 5.26; we couldn't highlight a significant association between the years of illness and life quality score however other papers, with approximately the same the average disease duration, asserted that patient life quality deteriorates with the disease duration (11). Severity of the disease was showed to be correlated to social well-being of the MS patients (21,22) and according to literature, the psychosocial dimension is one of the major factors that influence the life quality of MS patients, according to our data around 70% of the participants received support from parents or friends. A large Australian study that included 1848 MS patients found that self efficacy and social support and the psychosocial well-being of MS patients (21). Studies showed that any form of support enhanced coping abilities among MS patients and therefore influence positively their quality of life (23,24).

Conclusion

Given the different harmful effects that MS can cause, it is not surprising that quality of life is affected. The impact of the disease on quality of life is well documented. Various factors explain this decrease in quality of life, including sensitive, motor and depressive symptoms, but also cognitive status. Obviously, multiple sclerosis has a major impact on patients' autonomy, their professional capacities, their place in the socio-family environment, in particular their relationship with their relatives, and especially the spouse. The assessment of the life quality of the patient aims to improve the quality of care and the adequacy of therapeutic management of the disease and the demand for care and consequently improve the well-being of MS patients. Hence, the quality of life assessment should included as a routine management tool of MS patients.

References

1. Love S. Demyelinating diseases. 2006;59(11):1151–1159.
2. Kobelt G, Eriksson J, Phillips G, Berg J. The burden of multiple sclerosis 2015: Methods of data collection, assessment and analysis of costs, quality of life and symptoms. Mult Scler Houndmills Basingstoke Engl. 2017 Aug;23(2_suppl):4–16.
3. Leray E, Moreau T, Fromont A, Edan G. Epidemiology of multiple sclerosis. Rev Neurol (Paris). 2016 Jan;172(1):3–13.
4. Bohlega S, Inshasi J, Al Tahan AR, Madani AB, Qahtani H, Rieckmann P. Multiple sclerosis in the Arabian Gulf countries: a consensus statement. J Neurol. 2013;260(12):2959–63.
5. Loma I, Heyman R. Multiple Sclerosis: Pathogenesis and Treatment. Curr Neuropharmacol. 2011 Sep;9(3):409–16.
6. Goldenberg MM. Multiple Sclerosis Review. Pharm Ther. 2012 Mar;37(3):175–84.
7. Karussis D. The diagnosis of multiple sclerosis and the various related demyelinating syndromes: a critical review. J Autoimmun. 2014 Mar;48–49:134–42.
8. Perrin Ross A. Management of multiple sclerosis. Am J Manag Care. 2013 Nov;19(16 Suppl):s301-306.
9. ABUSE POS. PROGRAMME ON MENTAL HEALTH. 1997.
10. Technology I of M (US) C on HC, Mosteller F, Falotico-Taylor J. Assessing Quality of Life: Measures and Utility [Internet]. National Academies Press (US); 1989 [cited 2018 Apr 23]. Available from: https://www.ncbi.nlm.nih.gov/books/NBK235120/
11. Algahtani HA, Shirah BH, Alzahrani FA, Abobaker HA, Alghanaim NA, Manlangit JS. Quality of life among multiple sclerosis patients in Saudi Arabia. Neurosci Riyadh Saudi Arab. 2017 Oct;22(4):261–6.
12. Lisak D. Overview of symptomatic management of multiple sclerosis. J Neurosci Nurs J Am Assoc Neurosci Nurses. 2001 Oct;33(5):224–30.
13. Salehpoor G, Rezaei S, Hosseininezhad M. Quality of life in multiple sclerosis (MS) and role of fatigue, depression, anxiety, and stress: A bicenter study from north of Iran. Iran J Nurs Midwifery Res. 2014;19(6):593–9.
14. Amato MP, Ponziani G, Rossi F, Liedl CL, Stefanile C, Rossi L. Quality of life in multiple sclerosis: the impact of depression, fatigue and disability. Mult Scler Houndmills Basingstoke Engl. 2001 Oct;7(5):340–4.
15. Göksel Karatepe A, Kaya T, Günaydn R, Demirhan A, Ce P, Gedizlioğlu M. Quality of life in patients with multiple sclerosis: the impact of depression, fatigue, and disability. Int J Rehabil Res Int Z Rehabil Rev Int Rech Readaptation. 2011 Dec;34(4):290–8.
16. Janardhan V, Bakshi R. Quality of life in patients with multiple sclerosis: the impact of fatigue and depression. J Neurol Sci. 2002 Dec 15;205(1):51–8.
17. Grande GE, Barclay SI, Todd CJ. Difficulty of symptom control and general practitioners' knowledge of patients' symptoms. Palliat Med. 1997 Sep;11(5):399–406.
18. Undén A-L, Elofsson S. Health from the patient's point of view. How does it relate to the physician's judgement? Fam Pract. 2001 Apr 1;18(2):174–80.
19. Ewing G, Rogers M, Barclay S, McCabe J, Martin A, Campbell M, et al. Palliative care in primary care: a study to determine whether patients and professionals agree on symptoms. Br J Gen Pract J R Coll Gen Pract. 2006 Jan;56(522):27–34.
20. Ysrraelit MC, Fiol MP, Gaitán MI, Correale J. Quality of Life Assessment in Multiple Sclerosis: Different Perception between Patients and Neurologists. Front Neurol [Internet]. 2018 Jan 11;8. Available from: https://www.ncbi.nlm.nih.gov /pmc/art icles/PM C5769192/
21. Wollin JA, Fulcher G, McDonald E, Spencer N, Mortlock MY, Bourne M, et al. Psychosocial factors that influence quality of life and potential for self-management in multiple sclerosis. Int J MS Care. 2010;12(3):133–141.
22. Holland BE. Factors Affecting Quality Of Life In Persons With Multiple Sclerosis. 2014;
23. Rommer PS, Sühnel A, König N, Zettl U-K. Coping with multiple sclerosis-the role of social support. Acta Neurol Scand. 2017 Jul;136(1):11–6.
24. Jaracz K, Pawlak M, Górna K, Kołcz B, Wołoszyn D, Kozubski W. Quality of life and social support in patients with multiple sclerosis. Neurol Neurochir Pol. 2010 Aug;44(4):358–65.