Published online 2018 June 9.

Research Article

Correlations Between Severity of Disease and Quality of Life in Patients with Multiple Sclerosis in Hamadan

Masoud Khodaveisi,¹ Fatemeh Ashtarani,^{2,*} and Hossein Mahjub³

¹Chronic Diseases (Home Care) Research Center, Community Health Nursing Department, Hamadan University of Medical Sciences, Hamadan, Iran
²Community Health Nursing Department, Hamadan University of Medical Sciences, Hamadan, Iran
³Department of Epidemiology and Biostatistics, School of Public Health, Hamadan University of Medical Sciences, Hamadan, Iran

^{*} Corresponding author: Fatemeh Ashtarani, MSc, Department of Nursing and Midwifery, School of Nursing and Midwifery, Hamadan University of Medical Sciences, Hamadan, Iran. Tel: +98-8138380320, E-mail: ashtarani66@yahoo.com

Received 2018 February 01; Revised 2018 May 26; Accepted 2018 May 29.

Abstract

Background: Multiple sclerosis (MS) is the most common chronic disease. Limitation in the patient's independence eventually has a negative impact on their quality of life.

Objectives: The aim of this study was to assess the association between the severity of disease and patients' quality of life in Hamadan city, western Iran.

Methods: In this cross-sectional study, 72 patients with MS were selected using simple sampling in Hamadan, during year 2015. Patients were divided to three groups based on their score of expanded disability status scale (EDSS). expanded disability status scale was classified at three levels of 0 to 3.5, 4.0 to 6.5, and 7.0 to 9.5. Data were collected using the multiple sclerosis quality of life-54 instrument (MSQOL-54). Data was analyzed with analysis of variance (ANOVA) and the SPSS 18 software.

Results: Quality of life in three groups of MS patients had a significant difference (P < 0.05). The patients achieved middle and low scores in all MSQOL-54 dimensions. The mean score of physical and mental health showed that EDSS was significantly different between the three groups (P < 0.001).

Conclusions: Patients with MS and low EDSS had higher quality of life than other EDSS levels. It is recommended for education and empowerment to be provided to people with middle and high scores in EDSS.

Keywords: Multiple Sclerosis, Quality of Life, Patients, Disability Evaluation

1. Background

Nowadays, chronic diseases have created serious problems throughout the world (1). Multiple sclerosis (MS) is the most prevalent inflammatory disease and the second most common cause of neurological disability in workingaged adults. This disease is the demyelination of the central nervous system (2, 3), which leads to inflammation and destruction of myelin, development of plaque lesions, and nervous attacks, and is characterized by progressive neuronal damage. Clinical symptoms, duration of the disease, and response to the treatment varies among patients (4, 5).

Multiple Sclerosis is approximately twice as common in females. It is typically found in young adults between 20 and 40 years of age (6), with a peak occurrence at 30 years of age, although it occasionally occurs during childhood or at older age (6, 7). About 80% of the patients with multiple sclerosis experience relapsing-remitting periods (5). Although the disease is progressive, approximately 80% of patients survive more than 35 years (8). The disease results in five to ten years of life lost (9).

Based on the report of the multiple sclerosis international federation (MSIF) in 2013, the estimated number of people with MS has increased from 2.1 million in 2008 to 2.3 million in 2013 with a ratio of 2:1, females: males. Iran has a high prevalence of MS in the Middle East with 20.01 to 60 per 100 thousand individuals; the number of MS cases in Iran is estimated at about 50,000 people (10). Female to male ratio is estimated at 3.43 in Hamadan Province, the west of Iran. As indicated by other studies (6), relapsing-remitting MS is the most common type of disease in Hamadan. About 83.14% of the patients in this province are aged 18 years or older (11).

Chronic diseases make life very difficult and patients dealing with such diseases face many challenges in reaching an acceptable level of health, and physical, mental, and social functioning (12). Today, quality of life is one of the most important issues when it comes to health care, so that

Copyright © 2018, Jundishapur Journal of Chronic Disease Care. This is an open-access article distributed under the terms of the Creative Commons Attribution-NonCommercial 4.0 International License (http://creativecommons.org/licenses/by-nc/4.0/) which permits copy and redistribute the material just in noncommercial usages, provided the original work is properly cited enhancement of individuals' health is one of the greatest health goals and is recognized as one of the most important factors affecting people's life (13).

Evidence demonstrates that improved quality of life is considerably important in treatment of a chronic disease (14). Patients with the debilitating disease of MS have several problems with disabling functional consequences for patients that lead to significant reduction in their quality of life and the ability of individuals to carry out their roles and job tasks (15). The quality of life in patients with multiple sclerosis is significantly affected compared with the general population (16). Age of onset of MS coincides with the time of important life situations, such as a marriage, job selection, and obtaining financial security. On one hand, the disease threatens the patients' ability to effectively participate in social activity and on the other hand, the unpredictable prognosis of the disease has a significant impact on the patient's quality of life and health. The patients are usually unable to find a way to solve their problems and achieve appropriate approaches to improve their quality of life and health (17).

The disability effect of MS on daily living activities, particularly in the progressive phase of the disease, is much greater than other chronic diseases. Patients with MS have less compliance with their minimum general health, wellbeing, physical activities, and limitation in their social activities. At least one-third of the patients experience a considerable reduction in their life standards when their disease is diagnosed. Over 70% of the patients are unemployed, mostly because of the recurrent attacks of the disease (18).

Given the importance of quality of life in patients with MS and the prevalence of disease in youth, which is the stage of prosperity, the present study was conducted in order to assess the association between the severity of disease and patients' quality of life in Hamadan city, the west of Iran.

2. Methods

2.1. Study Design and Population

This cross-sectional study was performed in Hamadan city, the west of Iran, during year 2015, on 72 patients with MS, who referred to the Hamadan multiple sclerosis society using simple sampling. The objectives of the study were explained for the patients and an informed consent was taken from all participants. The inclusion criteria included: a, having medically confirmed evidence of MS; b, being a member of the MS society; c, not being in the acute phase of the disease; and d, age of 20 to 40 years. In total, 600 MS patients were registered at the multiple sclerosis association, among which 40 patients had the inclusion criteria and EDSS 7-9.5 (were eligible for the study). Finally, 24 patients consented to participate in the study. For this reason, 24 cases were also selected for the other two groups of patients.

2.2. Measuring Tools

Today, Kurtzke expanded disability status scale (EDSS) is a standard scale, which is widely used for assessing the progression of MS disease (19). The EDSS can measure extend of the disability much better than other conventional methods. This measure assesses eight functional systems, including pyramidal, cerebellar, brain stem, sensory, mental, visual, bowel, and bladder functions. Each organ has different signs and symptoms. The EDSS has a range of scores between zero (normal function) and ten (death due to MS) (19-21).

A EDSS score of 0 to 3.5 indicates full mobility with mild disabilities, mostly with functional disability in at least one functional system. A score of 4.0 to 6.5 shows full mobility with severe disability and need of constant mutual assistance for walking 20 meters. A score of 7.0 to 9.5 refers to patients, who need a wheelchair, rest in bed, and are completely dependent on others. A score of 10 means death due to multiple sclerosis (22). This scale is widely used both in national and internal literatures (19-22). In this study, the patients were divided to three groups, based on the EDSS scores.

The MSQOL-54 was used as the data collection tool for assessing the patients' quality of life with a range of score between zero to 100. A higher scores represented higher quality of life. The questionnaire has 12 sections assessing physical aspects (including physical problem, physical health, energy, understanding of health, and sexual function) and psychological aspects (including the limitations related to emotional problems, vitality, mental function, social function, health deficiency, and life satisfaction). This questionnaire was first developed by Vickrey in 1995 for assessing health status of the patients with MS. The validity and reliability of the questionnaire was assessed and confirmed. Cronbach's alpha coefficient of internal consistency of the questionnaire was 0.86 (23).

2.3. Methods

After obtaining informed consent of patients to participate in the study, patients were divided to three groups based on the EDSS criteria. Then, method for completion of the questionnaire was explained to the patients. Patients in the low and moderate groups at the time of referral to the MS association received quality of life questionnaires, yet for the third group, the researcher completed the questionnaire by visiting the patient's home.

2.4. Data Analyses

All the statistical analyses were performed at the 0.05 confidence level, using the statistical package for the social sciences (SPSS Inc, Chicago, IL, USA) (version 18). The comparison of the mean differences between the three groups of patients were investigated using analysis of variance (ANOVA).

2.5. Ethical Considerations

All patients participated voluntarily in the study and signed an informed consent. The entire study process was approved by the research ethics committee of the Hamadan University of Medical Sciences (approval no: 920127220).

3. Results

Seventy-two individuals participated in the study, including 30 males and 42 females. The patients were divided to three groups of 24 based on the EDSS score, including group 1 with a score of 0 to 3.5 and a mean age of 33.25 ± 6.9 years, group 2 with a score of 4.0 to 6.5 and mean age of 32.25 ± 7.6 years, and group 3 with a score of 7.0 to 9.5 and mean age of 36.17 ± 6.8 years.

Table 1 shows the distribution of the physical health status in patients with MS, according to EDSS levels. The mean score of EDSS for group 1 was 52.93 ± 23.53 , for group 2 was 38.97 ± 9.97 , and for group 3 was 8.39 ± 4.93 . According to these results, there was a statistically significant difference between the three groups (P < 0.001).

Table 2 indicates the distribution of the mental health status in patients with MS according to the EDSS level. The mean score of EDSS for the three groups was 50.85 \pm 19.11, 33.46 \pm 9.00, and 12.32 \pm 4.70 respectively. Accordingly, there was a statistically significant difference between the mean score of the three groups (P < 0.001).

Table 3 indicates the comparison of quality of life dimensions in patients with MS by EDSS levels. The main study variables, including the means, standard deviations, and differences measured between the three levels of EDSS, are given in Table 3. The subgroup of patients with ESDD of 0 to 3.5 had a significantly higher score in all dimensions of quality of life than those with EDSS of 4 to 9.5

4. Discussion

The aim of this study was to evaluate the association between the three levels of EDSS and patients' quality of life in a group of patients with MS. The patients generally achieved middle and low scores in all MSQOL-54 dimensions. The results are similar to earlier studies reporting that quality of life (QoL) was poor in patients with MS (24-26). Very low scores were found in the dimensions of general health, role of physical functioning, and physical functioning in the MSQOL-54.

McCabe and McKern conducted a study entitled "quality of life in patients with multiple sclerosis and comparison with the general population" and enrolled 381 patients with MS (144 males and 237 females) and 291 subjects from the general population (101 males and 190 females). They filled out an MSQOL-54 questionnaire for all participants and showed the level of quality of life was lower in patients with MS compared to the general population (26).

Taraghy et al. performed a study on 101 patients with MS in Mazandaran Province, the north of Iran, using the SF-36 questionnaire. They concluded that the patients' quality of life was moderate in all indexes. This can be due to mild illness of the enrolled patients, younger age at the onset of the disease, and short duration of the disease (27).

Zwibel conducted a study entitled "Health and quality of life in patients with relapsing multiple sclerosis" and indicated that some characteristics of the disease was harmful for quality of life. For example, decline in ability to walk properly has an impact on physical functions. Furthermore, depression is common among the patients and may affect many of the psychosocial functions of the patients in the family. Fatigue is also a common symptom that is experienced by the majority of patients and limits physical function. The authors concluded that the selection of proper treatment for each patient depends on his or her quality of life (28).

Marrie et al. assessed quality of life in 859 patients with MS in Manitoba. They showed that anxiety and depression, which were a result of MS, had a negative effect on the patients' quality of life and reduced it (24).

Szilasiova et al. assessed quality of life in patients with MS in Slovakia. They concluded that disability, fatigue, and depression were associated with physical health while anxiety, discomfort, and periods of illness were associated with mental health. They also reported that the quality of life in patients with MS was low (29).

Ghanbari et al. in their research assessed perspectives and experiences regarding leisure of people with multiple sclerosis in Ahvaz; they reach the conclusion that clinicians must consider the importance of leisure participation, which has effects on quality of life, and consider leisure in evaluations and interventions for people with MS. In this study, leisure participation was one of the sections of the questionnaire, which was important in quality of life of MS patient (30).

Limitations of the present study included having no

Table 1. The Distribution of the Physical Health Status in Patients with Multiple Sclerosis Using the Kurtzke Expanded Disability Status Scale (EDSS)								
EDSS (Score)	No.	Min	Мах	Mean \pm SD	P Value			
Group 1 (0.0 - 3.5)	24	47.79	92.24	71.83 ± 19.02				
Group 2 (4.0 - 6.5)	24	43.88	83.32	62.74 ± 12.03	0.001			
Group 3 (7.0 - 9.5)	24	23.26	44.19	31.99 ± 6.54				

Table 2. The Distribution of the Metal Health Status in Patients with Multiple Sclerosis Using the Kurtzke Expanded Disability Status Scale (EDSS)								
EDSS (Score)	No.	Min	Max	Mean \pm SD	P Value			
Group 1 (0.0 - 3.5)	24	46.04	85.35	64.34 ± 16.93				
Group 2 (4.0 - 6.5)	24	40.76	73.42	58.21 ± 9.92	0.001			
Group 3 (7.0 - 9.5)	24	28.37	48.07	38.48 ± 7.18				

Table 3. Comparison of Quality of Life Dimensions Distribution in Patients with MS According to EDSS Scores^a

Variable	Total Sample (N = 72)	EDSS, 0 - 3.5 (N = 24)	EDSS, 4 - 6.5 (N = 24)	EDSS, 7 - 9.5 (N = 24)	P Value ^b
Physical health	25.41 ± 3.85	41.25 ± 4.26	33.33 ± 6.55	1.66 ± 1.12	**
Role limitations due to physical problems	17.36 ± 4.54	39.58 ± 9.46	12.50 ± 5.75	0.00	***
Role limitations due to emotional problems	13.88 ± 4.27	36.11 ± 9.58	5.55 ± 3.74	0.00	***
Pain	35.60 ± 4.49	51.38 ± 6.55	48.75 ± 5.56	6.66 ± 2.15	*
Emotional well-being	41.55 ± 4.20	65.33 ± 4.54	44.00 ± 4.99	15.33 ± 2.94	***
Energy	37.44 ± 3.80	57.00 ± 5.89	40.66 ± 3.93	14.66 ± 2.22	**
Health Perceptions	34.58 ± 4.69	54.58 ± 8.82	42.08 ± 4.12	7.08 ± 2.34	***
Social function	40.50 ± 5.42	63.88 ± 8.96	50.00 ± 5.61	7.63 ± 3.62	***
Cognitive function	45.55 ± 26.74	60.41 ± 7.94	56.25 ± 5.07	20.00 ± 3.31	**
Health distress	37.53 ± 4.99	58.75 ± 9.39	43.85 ± 5.29	10.00 ± 2.82	***
Sexual function	60.32 ± 6.82	76.04 ± 7.29	77.79 ± 5.12	27.37 ± 10.24	*
Change in health	28.47 ± 4.99	47.91 ± 9.95	33.33 ± 6.40	4.16 ± 2.80	***
Satisfaction with sexual function	48.80 ± 6.09	68.75 ± 7.83	54.16 ± 4.16	21.42 ± 8.50	**
Overall quality of life	26.33 ± 1.71	33.07 ± 3.43	26.61 ± 2.26	19.31 ± 1.65	***

^aValues are expressed as mean \pm SD.

^bStatistical significant value; *P < 0.05; **P < 0.01; ***P < 0.001.

matched control group and evaluation of variables in a short time.

Future studies are recommended to undertake training programs in communities and modify quality of life to maintain and enhance MS patient's quality of life, specially in patients with EDSS ≥ 4 .

4.1. Conclusions

In conclusion, the current assessed the quality of life among patients with MS at different levels of EDSS. The researchers indicated that the quality of life was low in all three groups yet the severity of disability was greater in group 3 compared the group 1 and 2. However, improving the quality of life in patients with MS may reduce their physical and mental stress.

Acknowledgments

The authors would like to appreciate the vicechancellor of research and technology of Hamadan University of Medical Sciences for approval and financial support of this work. In addition, the authors thank the patients, who referred to the multiple sclerosis association, for their sincere collaboration with this study.

Footnote

Conflict of Interest: The authors declare that they had no conflicts of interest.

References

- Zangeneh Pour Zadeh A, Javadnoori M, Abedi P, Saki Malehi A. Investigating the relationship between family caregiving and chronic diseases among sandwich generation females. J Chronic Dis Care. 2016;5(4). doi: 10.17795/jjcdc-36549.
- Andalib S, Talebi M, Sakhinia E, Farhoudi M, Sadeghi-Bazargani H, Motavallian A, et al. Multiple sclerosis and mitochondrial gene variations: a review. *J Neurol Sci.* 2013;330(1-2):10–5. doi: 10.1016/j.jns.2013.04.018. [PubMed: 23669867].
- Ahmadi Z, Sadeghi T. Application of the Betty Neuman systems model in the nursing care of patients/clients with multiple sclerosis. *Mult Scler J Exp Transl Clin*. 2017;3(3):2.0552173177268E+15. doi: 10.1177/2055217317726798. [PubMed: 28839950]. [PubMed Central: PMC5565031].
- Rammohan K, Giovannoni G, Comi G, Cook S, Rieckmann P, Soelberg Sorensen P, et al. Cladribine tablets for relapsing-remitting multiple sclerosis: Efficacy across patient subgroups from the phase III CLARITY study. *Mult Scler Relat Disord*. 2012;1(1):49–54. doi: 10.1016/j.msard.2011.08.006. [PubMed: 25876451].
- Soundy A, Benson J, Dawes H, Smith B, Collett J, Meaney A. Understanding hope in patients with Multiple Sclerosis. *Physiotherapy*. 2012;**98**(4):344–50. doi: 10.1016/j.physio.2011.05.003. [PubMed: 23122442].
- Milo R, Kahana E. Multiple sclerosis: geoepidemiology, genetics and the environment. *Autoimmun Rev.* 2010;9(5):A387–94. doi: 10.1016/j.autrev.2009.11.010. [PubMed: 19932200].
- Roudbari SA, Ansar MM, Yousefzad A. Smoking as a risk factor for development of Secondary Progressive Multiple Sclerosis: A study in IRAN, Guilan. *J Neurol Sci.* 2013;330(1-2):52–5. doi: 10.1016/ji.jns.2013.04.003. [PubMed: 23628463].
- Dalgas U, Stenager E. Exercise and disease progression in multiple sclerosis: can exercise slow down the progression of multiple sclerosis? *Ther Adv Neurol Disord*. 2012;5(2):81–95. doi: 10.1177/1756285611430719. [PubMed: 22435073]. [PubMed Central: PMC3302199].
- Ragonese P, Aridon P, Salemi G, D'Amelio M, Savettieri G. Mortality in multiple sclerosis: a review. *Eur J Neurol.* 2008;15(2):123–7. doi: 10.1111/j.1468-1331.2007.02019.x. [PubMed: 18217882].
- 10. Thompson A, Baneke P. *Mapping multiple sclerosis around he world*. Multiple Sclerosis International Federation; 2013.
- 11. Mazaheri S, Fazlian M, Hossein Zadeh A. [Clinical and epidemiological features of early and adult onset multiple sclerosis in Hamedan, Iran, 2004–2005]. *Yafteh*. 2008;9(4):39–44. Persian.
- 12. Nikmanesh Z, Azaraein S. The role of religious coping in perception of suffering among patients undergoing dialysis. *Jundishapur J Chronic Dis Care*. 2016;**6**(2). doi: 10.17795/jjcdc.40063.
- Zahmatkeshan N, Akaberian S, Yazdanpanah S, Khoramroodi R, Gharibi T, Jamand T. [Assessing quality of Life and related factors in Bushehr, s elders-1387-8]. J Fasa Univ Med Sci. 2012;2(1):53–8. Persian.
- Barez S, Miladinia M, Mosavinouri E. A comparison of quality of life between adolescences with beta thalassemia major and their healthy peers. *Jundishapur J Chronic Dis Care*. 2016:1195–204. doi: 10.22038/ijp.2016.6228.
- Toosy A, Ciccarelli O, Thompson A. Symptomatic treatment and management of multiple sclerosis. *Handb Clin Neurol*. 2014;**122**:513–62. doi: 10.1016/B978-0-444-52001-2.00023-6. [PubMed: 24507534].

- Chen K, Fan Y, Hu R, Yang T, Li K. Impact of depression, fatigue and disability on quality of life in Chinese patients with multiple sclerosis. *Stress Health*. 2013;**29**(2):108–12. doi: 10.1002/smi.2432. [PubMed: 22566371].
- Allahbakhshian M, Jaffarpour M, Parvizy S, Haghani H. [A Survey on relationship between spiritual wellbeing and quality of life in multiple sclerosis patients]. J Univ Med Sci Zahedan. 2010;12(2):29–33. Persian.
- Mitchell ÅJ, Benito-Leon J, Gonzalez JM, Rivera-Navarro J. Quality of life and its assessment in multiple sclerosis: integrating physical and psychological components of wellbeing. *Lancet Neurol.* 2005;4(9):556– 66. doi: 10.1016/S1474-4422(05)70166-6. [PubMed: 16109362].
- Orme M, Kerrigan J, Tyas D, Russell N, Nixon R. The effect of disease, functional status, and relapses on the utility of people with multiple sclerosis in the UK. *Value Health*. 2007;**10**(1):54–60. doi: 10.1111/j.1524-4733.2006.00144.x. [PubMed: 17261116].
- Tyas D, Kerrigan J, Russell N, Nixon R. The distribution of the cost of multiple sclerosis in the UK: how do costs vary by illness severity? *Value Health.* 2007;10(5):386–9. doi: 10.1111/j.1524-4733.2007.00192.x. [PubMed: 17888103].
- Kargarfard M, Eetemadifar M, Mehrabi M, Maghzi AH, Hayatbakhsh MR. Fatigue, depression, and health-related quality of life in patients with multiple sclerosis in Isfahan, Iran. *Eur J Neurol.* 2012;**19**(3):431–7. doi: 10.1111/j.1468-1331.2011.03535.x. [PubMed: 21967324].
- 22. Mazdeh M. [Comparing the efficacy of Avonex, Rebif and Betaferon in motor disability (Expanded Disability Status Scale) and relapsing rate of multiple sclerosis patients]. *Med Sci J.* 2007;**17**(3):139–46. Persian.
- Pfaffenberger N, Pfeiffer KP, Deibl M, Hofer S, Gunther V, Ulmer H. Association of factors influencing health-related quality of life in MS. Acta Neurol Scand. 2006;114(2):102–8. doi: 10.1111/j.1600-0404.2006.00659.x. [PubMed: 16867032].
- Marrie RA, Patten SB, Berrigan LI, Tremlett H, Wolfson C, Warren S, et al. Diagnoses of Depression and Anxiety Versus Current Symptoms and Quality of Life in Multiple Sclerosis. *Int J MS Care*. 2018;20(2):76– 84. doi: 10.7224/1537-2073.2016-110. [PubMed: 29670493].
- Ysrraelit MC, Fiol MP, Gaitan MI, Correale J. Quality of Life Assessment in Multiple Sclerosis: Different Perception between Patients and Neurologists. *Front Neurol.* 2017;8:729. doi: 10.3389/fneur.2017.00729. [PubMed: 29375468]. [PubMed Central: PMC5769192].
- McCabe MP, McKern S. Quality of life and multiple sclerosis: Comparison between people with multiple sclerosis and people from the general population. J Clin Psychol Med Settings. 2002;9(4):287–95. doi: 10.1023/a:1020734901150.
- 27. Taraghi Z, Ilali E, Abedini M, Zarvani A, Khoshnama I, Mohammadpour RA. [Quality of life among multiple sclerosis patients]. *Iran J Nurse*. 2007;**20**(50):51–9. Persian.
- Zwibel H. Health and quality of life in patients with relapsing multiple sclerosis: making the intangible tangible. J Neurol Sci. 2009;287 Suppl 1:S11–6. doi: 10.1016/S0022-510X(09)71295-X. [PubMed: 20106342].
- Szilasiova J, Krokavcova M, Gdovinova Z, Rosenberger J, Van Dijk JP. Quality of life in patients with multiple sclerosis in Eastern Slovakia. *Disabil Rehabil*. 2011;**33**(17-18):1587-93. doi: 10.3109/09638288.2010.540292. [PubMed: 21174630].
- Ghanbari S, Shayanpour R. Perspective and experiences of iranian people with multiple sclerosis regarding leisure: A qualitative study. *Jundishapur J Chronic Dis Care*. 2015;4(4). doi: 10.17795/jjcdc-29776.