

Quality of life and its affecting factors among patients with multiple sclerosis: a cross-sectional study in northwest Iran

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Abstract

Background: Multiple Sclerosis (MS) is one of the most important diseases due to its adverse clinical, social and economic consequences for affected people.

Objectives: This study tried to assess the quality of life of the patients suffering from Multiple Sclerosis in East Azerbaijan.

Methods: This cross-sectional study used the Multiple Sclerosis Quality of Life-54 (MSQOL-54) questionnaire for interviewing 300 randomly selected MS patients in East Azarbaijan province, Iran. The independent T-test, ANOVA and Tukey post hoc test were used to examine the relationship between demographic variables and quality of life, and all analyses were performed using SPSS19.

Results: The quality of life score among the MS patients is 48.22. The "life satisfaction" is the best and "physical role limitation" is the worst quality of life aspect. There were significant relationships between marital status, education level, employment status, age of symptoms onset and years of illness with quality of life ($P < 0.05$).

Conclusion: The quality of life of the MS patients in East Azarbaijan province is lower than other parts of Iran and much lower than OECD countries.

Background

Multiple Sclerosis (MS) is a complicated chronic and inflammatory disorder of the Central Nervous System (CNS) with the main characteristic of demyelination and loss of neuronal axons which, consequently contributes to malfunction and disabilities (1–3). Epidemiological studies have shown that the prevalence of MS is about 150/100000 people (4, 5). Worldwide about 1.3 million are suffering from MS (6). MS generally affects young adults causing long-lasting disabilities during the productive age of the patients imposing many clinical and socioeconomic burdens (2, 7).

The cause of MS is still unclear and the prognosis of its improvement is very difficult. Although MS does not affect life expectancy, 50% of the cases, after 10 years of the diagnosis, face main problems of movement and need others' support (8). Most of the patients with major disabilities need informal and specialized care services by their families (9). MS leaves significant negative effects on the Quality of Life (QOL) among patients. For instance, in Switzerland it causes a loss of 0.3 in the Quality Adjusted Life Years (QALY) index of different ages and genders (10). By the QOL, we mean "patients' perception of their life conditions demonstrated according to their expectations, goals, norms and concerns" (10).

With high prevalence (9), early occurrence in productive ages (11), long term survival after the diagnosis (12) and with the destructive effects on patients and families (13) MS is one of the main challenges of public health in different societies. It is the second cause of neurodegenerative disorders in working-age among adults making 50–80% of patients to be unemployed 10 years after the disease occurrence (14).

Usually, MS is initiated with symptoms like sensory disturbances, inflammation of unilateral optic neuritis, diplopia, lhermitte, limb weakness, poor coordination and gait ataxia (15).

MS causes progressive disorder where symptoms appear gradually. About half of the patients are unable to do their home and work tasks after ten years of disease occurrence. After 15 years, half of them can not walk without help. After 25 years and half of them need to use a wheelchair (16). MS also causes a wide range of other disorders like depression, disappointment, cognitive disorders, lack of independence, pain, fatigue, anxiety, dysthymia, social problems, lack of confidence, and neuronal symptoms (17). This emphasises on proper evaluation and management of the effects on different physical, psychological, behavioural, and social features of the MS patients (18, 19). There are studies available from the OECD countries (1–11). However, there is a dearth of literatures from the low- and middle-income countries (LMICs) such as Iran (20). Therefore, the current study was conducted to assess the quality of life of the MS patients in East Azerbaijan province; Iran. Also, the association between QOL and demographic and background variables of the MS patients was explored.

Methods

Participants

The current cross-sectional study was conducted between 21st April to 28th May 2018. Three hundred patients were randomly selected from the MS patients register in East Azerbaijan province; Iran. The sample size was allocated by using Morgan table (21). Inclusion criteria was the MS patient was registered in the MS society and had received medical treatment for at least one year.

Randomization

All MS patients are registered in the MS Society of the East Azerbaijan Province. First, we have assigned numerical code to all the 1200 registered MS patients. We have determined sample size of 300 MS patients. Second, we have selected number two patient as the first selection randomly. Finally, we have selected every fourth patient starting from two (e.g. 2, 6, 10, 14....) until we arrive at 300 MS patients. If any selected MS patient was not willing to participate we have invited the next person for the study interview.

Study Tool

This study was conducted using the Multiple Sclerosis Quality of Life-54 (MSQOL-54) standardized Iranian version (20, 22). Questions on demographic and background variables of patients were added. Twelve dimensions of the questionnaire were divided into two parts of physical health (physical problems, physical role limitations, pain, health perception and sexual function) and psychological health (emotional role limitation, emotional well-being, cognitive function, social function, health distress and life satisfaction). Quality of Life scores were 0-100 where the highest number suggested the highest quality. Data were collected through interview with the MS patients.

Data analysis

Mean \pm Standard Deviation (SD) was presented. We used the t-test, ANOVA and Tukey test for assigning relations between the score of QOL and demographic variables. SPSS Software (version 19) was used. $P < 0.05$ was considered to be significant.

Ethical considerations

Principles of patients' freedom to accept or reject participation in the study or rights for withdraw from the study was assigned. Informed consent from the MS patients was obtained. Privacy and patients' personalities received full consideration and respect. Anonymity and assurance by using patients' data exclusively in the study was secured. The present study was approved by the Committee of Ethics of Tabriz University of Medical Sciences.

Results

The average age of participants was 37.15 (± 9.68). The youngest patient was 16 years old while the oldest was 68 years. Most of the patients were in their middle ages of life. About two third of patients were women. The age average of disease symptoms appearance was 27.18 (± 7.06) years and in average about 9.95 (± 7.06) years were elapsed from the first appearance of disease symptoms. Most of the patients were married, housewives, residents of Tabriz, and had diploma and lower level of education. All patients had basic Social Security Insurance. Only one third of patients had supplementary insurance (Table 1).

Table 1
Patients' characteristics

Variables	Categories	Frequency	Percentage
Age	Childhood and teenage (under 20 years)	14	4.7
	Youth (20–35 years)	128	42.6
	Middle ages (35–60)	156	52
	Elderly (60 years and more)	2	0.7
Gender	Male	96	32
	Female	204	68
The age of disease symptoms appearance	Under 20 years	67	22.3
	20–29 years	122	40.7
	30–39 years	92	30.7
	40–50 years	19	6.3
Elapsed years from the appearance of disease symptoms	Under 5 years	96	32
	6–10 years	90	30
	11–15 years	53	17.7
	More than 15 years	61	20.3
Marital status	Single	99	33
	Married	188	62.7
	Divorce	13	4.3
Educational level	Illiterate	15	5
	Diploma and lower	157	52.3
	Upper-diploma and B.Sc.	103	34.3
	M.Sc.	20	6.7
	MD and PhD	5	1.7
Job status	Employee (public or private sector)	27	9
	Self-job	10	3.3
	Student	22	7.3

Variables	Categories	Frequency	Percentage
	Housewife	152	50.7
	Retired	11	3.7
	Jobless	24	8
	Other	54	18
Having basic insurances		300	100
Basic insurance type	Tamine Ejtemaei (Social Welfare)	193	64.3
	Khadamate Darmani (Health services)	73	24.4
	Nirouhaie mosalah (Military forces)	6	2
	Komiteie emdad (Aid committee)	4	1.3
	Others (Banks, Broadcasting, ...)	24	8
Having supplementary insurance		105	35
Locality	Tabriz	254	84.7
	Other cities	46	15.3

By studying QOL among the patients in different dimensions it was revealed that they had the most problems in "physical role limitations", "emotional role limitations" and "health perception" and less problems in "life satisfaction", "pain", and "social function". Dimensions of "total physical health", "total psychological health" and "total QOL" obtained 48.27%, 47.95%, and 48.22% score respectively (Table 2).

Table 2
conditions of patients' QOL in different dimensions (%)

Quality of life dimensions	Respondents	Minimum	Maximum	Mean	St. Dev.
Physical problems	300	0	100	52.36	32.03
Physical Role Limitations	300	0	100	30	43.61
Pain	300	0	100	57.16	24.96
Sexual Function	204	0	100	48.85	34.79
Health Perceptions	299	0	100	44.50	29.60
Emotional Role Limitations	300	0	100	31.56	45.58
Emotional well-being	300	6	98	46.71	21.47
Cognitive Functioning	300	0	100	55.62	33.35
Social Function	300	8	100	56.51	20.44
Health Distress	300	0	100	45.91	30.68
Life satisfaction	300	0	100	60.93	30.89
Total physical health	300	0	98	48.27	26.28
Total psychological health	300	7	94	47.95	21.39
Total QOL	300	6	94	48.22	22.48

QOL of MS patients' in different dimensions are illustrated in Fig. 1 using Radar Chart.

In total, based on the ratings of scores of QOL, it can be seen that more than 40% of the MS patients had poor QOL. Only 30% evaluated that their QOL was at the appropriate level (Table 3).

Table 3
classification of patients based on main QOL aspects (%)

QOL	Very Bad	Bad	Middling	Good	Very Good
Physical	16.6	25.3	23.5	20.1	14.5
psychological	8.1	32.4	29.6	20.1	9.9
Total	9.7	31.9	28.5	19.1	10.8

There was a statistically significant relationship between marital status, education, job, age of diseases symptoms appearance, and disease elapsed years ($P \leq 0.05$). The type of insurance, gender, having basic and supplementary insurance and native patients did not affect the score of their QOL ($P > 0.05$). Single

people had significantly higher levels of QOL when compared to the married and especially divorced people. MS patients with primary school education had lower levels of QOL when compared to their peers with diploma and university degrees. People with post-diploma degree had better QOL than patients with high school degree of education. Patients who were university or school students had higher QOL when compared to the others. Age, was another affecting variable on QOL. Children and teens had significantly higher level of QOL when compared to other age groups. The same trend was there when we compared young patients with middle-aged. People who diagnosed their MS when they were ≤ 20 years had higher level of QOL when compared to the people who were living at their 4th decade of their lives. People with less than 5 years of post-disease diagnosis had also higher level of QOL when compared to the others (Table 4).

Table 4

the association between QOL and demographic and background variables of the MS patients

Demographic/background variables	Basic group	Compare group	Mean differences	P-value
Marriage status	Single	Married	7.20	0.045
		Divorces	22.15	0.022
Educational status	Primary education	Diploma	-23.88	0.001>
		Upper diploma	-28.81	0.001>
		B.Sc.	-18.71	0.013
		M.Sc.	-28.97	0.001>
		MD and PhD	-37.22	0.011
	Upper diploma	Illiterate	20.91	0.026
		Primary education	28.81	0.001>
Job status	Students	Public employee	22.46	0.032
		Private employee	35.36	0.001>
		Housewife	31.07	0.001>
		Retired	33.80	0.001
		Jobless	42.18	0.001>
Age	Childhood and teenage (under 20 years)	Youth (20–35 years)	20.58	0.004
		Middle ages (35–60)	29.84	0.001>
		Elderly (60 years and more)	46.34	0.023
	Middle ages (35–60)	Youth (20–35 years)	-9.25	0.002
The age of disease symptoms appearance	Under 20 years	30–39 years	11.52	0.007
Elapsed years from the	3–5 years	6–10 years	10.93	0.003

appearance of disease symptoms Demographic/background variables	Basic group	Compare group	Mean differences	P-value
		11–15 years	13.88	0.001
		More than 15 years	18.12	0.001>

Discussion

The present study was carried out to investigate QOL among MS patients in East Azerbaijan province; Iran. Our results found that dimensions of "total physical health", "total psychological health" and "total QOL" obtained 48.27, 47.95 and 48.22%, respectively. A study by Choubfroushzade et al calculated these scores to be 51.34, 45.06, and 55.96%, respectively (23). Also, the mean score of total QOL in the study by Haresabadi et al was 56.2 (20), in Masoodi et al was 44.8 (24), in Mohammad et al. 65.5 (25), in Hazrati et al was 48.5 (26) and in Marghati Khoei et al. it was calculated to be 22.7 (27). In the high-income countries such as Italy, Netherlands, Spain, France, Turkey, and the United States, the score of QOL among MS patients was reported for over 65 (28–31). It is evident that QOL among MS patients in Iran is lower than patients from America and European countries. The probable reason could be insufficient quality and ineffective quantity of healthcare services received by the Iranian MS patients and the absence of socioeconomic supports.

The current study indicates that "life satisfaction" has the highest and "Physical Role limitations" the lowest score of QOL. In the study by Haresabadi et al the lowest and highest score was respectively to "physical role limitation" and "cognitive functioning" (20). Marghati Khoei et al. also allocated the highest score to "emotional role limitations" and the lowest score to "health perceptions" and "emotional well-being" jointly (27). In the study by Sangelaji et al., the highest and lowest scores of QOL were respectively for "pain" and "physical role limitations" (32). Choubfroushzade et al. study allocated the highest and lowest QOL scores to "social function" and "physical role limitations", respectively (23). The lowest and highest scores were for "social function" and "physical role limitations" in the study by Mohammad et al. (25). In most of the studies conducted in other countries, physical problems, especially fatigue was considered to be the most disturbing negative consequences of the MS (28, 33). Comparison of present findings with other literature (especially inside the country) suggested the very fact that "physical role limitations" was the worst dimension of QOL among the MS patients in Iran, because they receive insufficient healthcare which is not enough to solve their physical problems for performing their jobs. Single MS patients had the highest level of QOL when compared to divorced and married individuals.

The current study has demonstrated a statistically significant relationship between education, age, gender and disease elapsed time with QOL scores, which is in line of the study by Choubfroushzade et al. (23) or by Pfaffenberger et al. (34)

The present study was the first evaluation of the quality of life among MS patients in the northwest of Iran that tried to investigate the relationship between a wide range of demographic and background variables and MS patients' quality of life. The limitation was the problem of interviewing the sick and home-staying MS patients due to their unwillingness to participate in the study. Based on the findings, suggestions such as promoting basic and supplementary insurance system upon United Healthcare (UHC) principles, promoting social security system, enhancing governmental and charitable support, promoting and developing social work system by considering MS patients physical capabilities, designing MS care centers for providing comprehensively and quality cares, and on-time supply of MS drugs are warranted. Similar studies in other parts of the country and in low and middle income countries are warranted to identify different dimensions of disease and to better recognize the clinical and socioeconomic consequences of the disease.

Conclusion

This investigation showed that QOL among East Azerbaijan MS patients is not at its desired level while different factors play vital role. The current results can help health policymakers to eliminate existing challenges faced by the MS patients and to provide them with more quality clinical cares and desired socioeconomic supports.

Abbreviations

MS

Multiple Sclerosis

MSQOL-54

The Multiple Sclerosis Quality of Life-54

OSCD

The Organisation for Economic Co-operation and Development

CNS

The Central Nervous System

QOL

The Quality of Life

QALY

The Quality Adjusted Life Years

LMICs

The low- and middle-income countries

UHC

United Healthcare

Declarations

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Authors' contributions

All authors contributed to the design of this paper. AK and NJ contribute to the data collection. FG, AI and KD contribute to analysis and original drafting of the manuscript. All authors critically revised the manuscript and approved the final version.

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Availability of data and materials

The datasets used and/or analyzed during the current study are available from the corresponding author on reasonable request.

Ethics approval and consent to participate

Ethical approval was obtained through the Tabriz University of Medical Sciences Ethics Committee.

Consent for publication

Not applicable.

Competing interests

The authors declare that they have no competing interests

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Figures

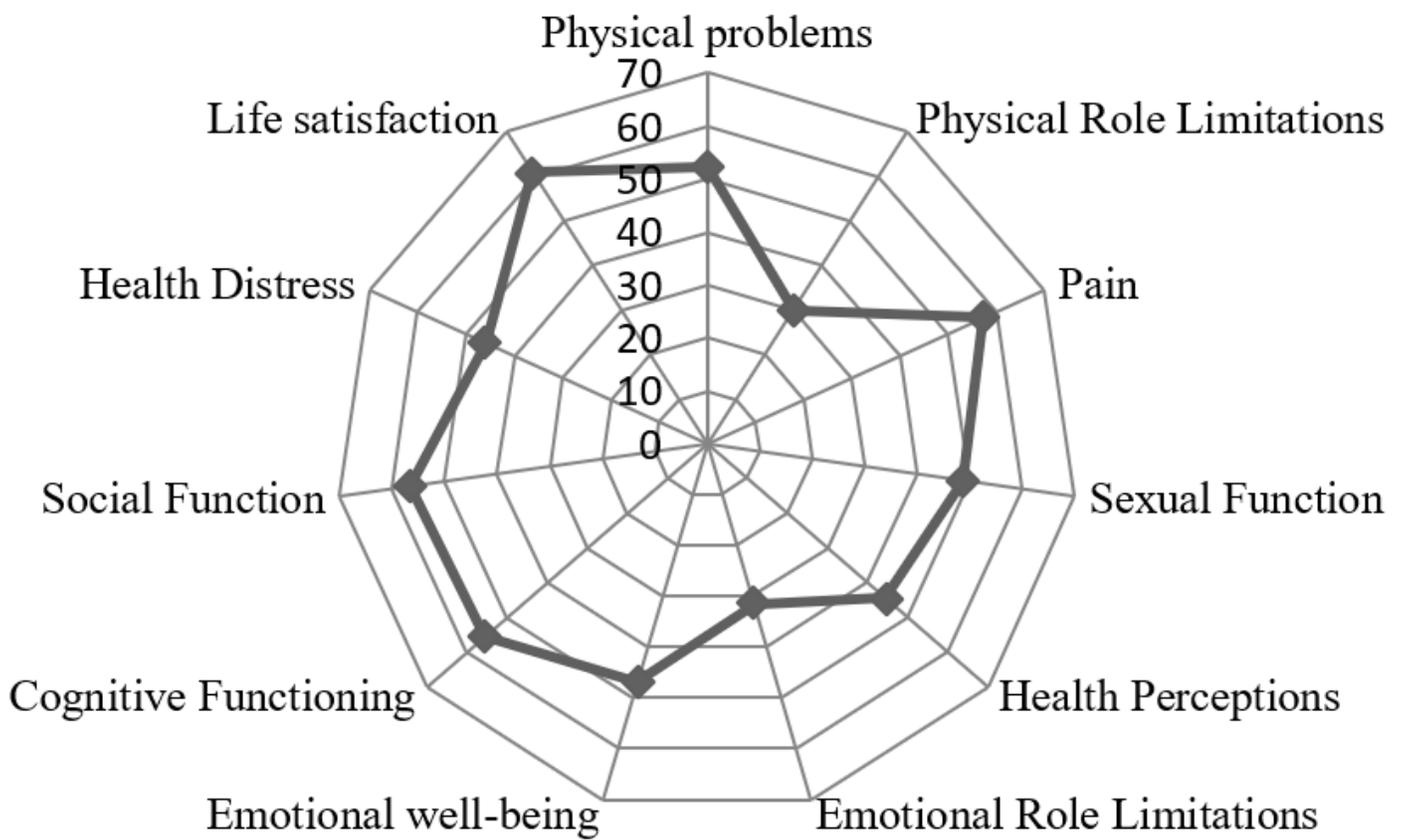


Figure 1

Comparison of MS patients' QOL in different aspects