Research Paper Quality of Life and Its Relative 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 critical diseases due to its adverse clinical, social, and economic consequences for affected people. This study aims to assess the quality of life (QoL) of patients with MS in East Azerbaijan, Iran.

Methods: This cross-sectional study was conducted using the multiple sclerosis quality of life-54 (MSQoL-54) questionnaires to interview 300 randomly selected MS patients in East Azarbaijan Province, Iran. The independent t-test, analysis of variance (ANOVA), and Tukey post hoc test were used to examine the relationship between demographic variables, and QoL, and all analyses were performed using SPSS software, version 19.

Results: The QoL score in MS patients is 48.22 ± 22.48 . The "life satisfaction" is the best and "physical role limitation" is the worst QoL aspect. Significant relationships were observed between marital status, education level, employment status, age of symptoms onset, and years of illness with QoL (P<0.05).

Conclusion: The QoL of the MS patients in East Azarbaijan Province is lower than in other parts of Iran and much lower than in Organization for Economic Co-operation and Development (OECD) countries.

Keywords: Public health, Multiple sclerosis, Quality of life (QoL)

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1. Introduction

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chronic and inflammatory disorder of the central nervous system (CNS) with the main characteristic of demyelination and loss of neuronal axons, resulting in malfunction and disabilities [1, 2].

ultiple sclerosis (MS) is a complicated

Epidemiological studies have shown that the prevalence of MS is about 150 100 000 people [3]. MS generally affects young adults causing long-lasting disabilities during the productive age of the patients and imposing many clinical and socioeconomic burdens [4].

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 [5]. Most patients with major disabilities need informal and specialized care services from their families [5]. MS has 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 [6]. By the QoL, we mean "patients' perception of their life conditions demonstrated according to their expectations, goals, norms, and concerns" [7].

With high prevalence, early occurrence in productive ages, long-term survival after the diagnosis, and destructive effects on patients and families, MS is one of the main challenges of public health in different societies [8, 9]. It is the second cause of neurodegenerative disorders in working-age among adults making 50% to 80% of patients to be unemployed 10 years after the disease occurrence. MS usually begins with symptoms, such as sensory disturbances, inflammation of unilateral optic neuritis, diplopia, lhermitte, limb weakness, poor coordination, and gait ataxia [10, 11].

MS causes progressive disorder whose 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 cannot walk without help. After 25 years and half of them need to use a wheelchair [12]. MS also causes a wide range of other disorders, such as depression, disappointment, cognitive disorders, lack of independence, pain, fatigue, anxiety, dysthymia, social problems, lack of confidence, and neuronal symptoms [13]. This emphasizes proper evaluation and management of the effects on different physical, psychological, behavioural, and social features of MS patients [14]. Studies are available from the Organization for Economic Co-operation and Development (OECD) countries [15]. However, there is a dearth of literature from the low- and middle-income countries (LMICs), such as Iran [16].

Objectives

Therefore, the current study was conducted to assess the QoL of MS patients in East Azerbaijan Province, Iran. Also, the relationship between QoL and demographic and background variables of the MS patients was explored.

2. Methods

Participants

The current cross-sectional study was conducted between April 21 and May 28, 2018. Three hundred patients were randomly selected from the MS patients register in East Azerbaijan Province, Iran. The sample size was allocated using the Morgan table [15]. The inclusion criteria were that the MS patient was registered in the MS society and had received medical treatment for at least one year. The exclusion criteria of the patients from the study included their suffering from skeletal-muscular diseases.

Selection

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

Study tool

This study was conducted using the Multiple Sclerosis Quality of Life-54 (MSQoL-54) Iranian standard version [11]. Questions on the 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). QoL scores were 0-100 with the highest number indicating the highest quality. Data were collected via interview with the MS patients. Data analysis

Mean±SD was presented. We used the t-test, analysis of variance (ANOVA), and Tukey test to assign the relationships between the score of QoL and demographic variables. SPSS software, version 19 was used. P<0.05 was considered to be significant.

3. Results

Most of the patients were middle-aged and about two third of them were women. Most patients were 20-40 years old, married, housewives, urban, and residents of Tabriz City, Iran, and had diploma and lower levels of education. All patients had basic social security insurance and one-third of them had supplementary insurance (Table 1).

By studying QoL among the patients in different dimensions, it was revealed that they had the most problems with "physical role limitations", "emotional role limitations" and "health perception" and fewer problems with "life satisfaction", "pain", and "social function". Dimensions of "total physical health", "total psychological health" and "total QoL" obtained $48.27\pm$ 26.28, 47.95±21.39, and 48.22 ± 22.48 score, respectively (Table 2).

Figure 1 illustrates QoL of MS patients in different dimensions using bar chart. Based on the ratings of scores of QoL, more than 40% of the MS patients had poor QoL. Only 30% evaluated that their QoL was at the appropriate level (Table 3).

A statistically significant relationship was observed between marital status, education, job, age of disease symptoms appearance, and disease elapsed years (P<0.05). The type of insurance, gender, basic and supplementary insurance, and urban or native patients did not affect the score of their QoL (P>0.05). Single people had significantly higher levels of QoL compared to married and especially divorced people. MS patients with primary school education had lower levels of QoL compared to their peers with diploma and university degrees. People with post-diploma degree had better QoL than patients with high school degrees of education. Patients who were university or school students had higher QoL compared to the others. Age was another affecting variable on QoL. Children and teens had significantly higher levels of QoL compared to other age groups. The same trend was present when we compared young patients with middle-aged patients. People who diagnosed their MS when they were <20 years had higher level of QoL compared to the people who were living in the fourth decade of their lives. People with less than 5 years of post-disease diagnosis had also higher levels of QoL compared to the others (Table 4).

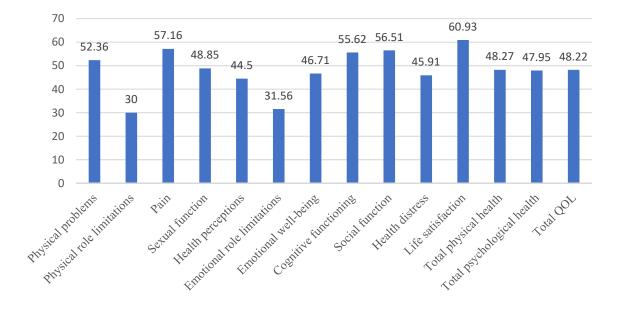


Figure 1. Comparison of multiple sclerosis (MS) patients' quality of life (QoL) in different aspects

Table 1. Patients' characteristics

Variables	Categories	No. (%)	
Age (y)	Childhood and teenage (>20)	14(4.7)	
	Youth (20-35)	128(42.6)	
	Middle ages (35-60)	156(52.0)	
	Elderly (60 and <60)	2(0.7)	
Gender	Male	96(32.0)	
	Female	204(68.0)	
	>20	67(22.3)	
The age of disease symptoms	20-29	122(40.7)	
appearance	30-39	92(30.7)	
	40-50	19(6.3)	
	<5	96(32.0)	
Elapsed years from the	6-10	90(30.0)	
appearance of disease symptoms	11-15	53(17.7)	
	<15	61(20.3)	
	Single	99(33.0)	
Marital status	Married	188(62.7)	
	Divorce	13(4.3)	
	Illiterate	15(5.0)	
	Diploma and lower	157(52.3)	
Educational level	Upper-diploma and BSc	103(34.3)	
	MSc	20(6.7)	
	MD and PhD	5(1.7)	
	Employee (public or private sector)	27(9.0)	
	Self-job	10(3.3)	
	Student	22(7.3)	
lob status	Housewife	152(50.7)	
Job status	Retired	11(3.7)	
	Jobless	24(8.0)	
	Other	54(18.0)	
	Having basic insurances	300(100)	

Variables	Categories	No. (%)
Decisionaria func	Tamine Ejtemaei (social welfare)	193(64.3)
	Khadamate Darmani (health services)	73(24.4)
	Nirouhaie mosalah (military forces)	6(2.0)
Basic insurance type	Komiteie emdad (aid committee)	4(1.3)
	Others (banks, broadcasting,)	24(8.0)
	Having supplementary insurance	105(35.0)
Le cellte :	Tabriz	254(84.7)
Locality	Other cities	46(15.3)
Cattlemant	Urban	237(79.0)
Settlement	Rural	63(21.0)

Abbreviations: MD: doctor of medicine; PhD: doctor of philosophy; MSc: master of science; BSc: bachelor of science

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Table 2. Conditions of patients' quality of life in different dimensions (%)

QoL Dimensions	Mean±SD
Physical problems	52.36±32.03
Physical role limitations	30.0±43.61
Pain	57.16±24.96
Sexual function	48.85±34.79
Health perceptions	44.50±29.60
Emotional role limitations	31.56±45.58
Emotional well-being	46.71±21.47
Cognitive functioning	55.62±33.35
Social function	56.51±20.44
Health distress	45.91±30.68
Life satisfaction	60.93±30.89
Total physical health	48.27±26.28
Total psychological health	47.95±21.39
Total QoL	48.22±22.48
Abbreviations: QoL: quality of life	URA .

Gharibi F, et al. Quality of Life in Patients With Multiple Sclerosis. JRH. 2023; 13(4):263-272

 Table 3. Classification of patients based on main quality of life aspects as frequency (%)

QoL Levels (Cut-off Points) QoL Dimension	Very Bad (Lower Than 20)	Bad (20-40)	Middling (41-60)	Good (61-80)	Very Good (Higher Than 80)
Physical	50(16.6)	76(25.3)	71(23.5)	60(20.1)	43(14.5)
psychological	24(8.1)	97(32.4)	89(29.6)	60(20.1)	30(9.9)
Total	30(9.7)	96(31.9)	85(28.5)	57(19.1)	32(10.8)

Abbreviations: QoL: quality of life

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Table 4. The Association between quality of life (QoL) and demographic and background variables of the multiple sclerosis (MS) patients

Demographic/Background Variables	Basic	Compare	Mean Differences	Р
Marriage status	Single	Married	7.20	0.045
		Divorces	22.15	0.022
	Primary education	Diploma	-23.88	<0.001
		Upper diploma	-28.81	<0.001
		BSc	-18.71	0.013
Educational status		MSc	-28.97	<0.001
		MD and PhD	-37.22	0.011
	Upper diploma	Illiterate	20.91	0.026
		Primary education	28.81	<0.001
		Guidance education	13.90	0.031
	Students	Public employee	22.46	0.032
		Private employee	35.36	<0.001
Job status		Housewife	31.07	<0.001
		Retired	33.80	0.001
		Jobless	42.18	<0.001
	Childhood and teenage (>20 y)	Youth (20-35 y)	20.58	0.004
		Middle ages (35-60)	29.84	<0.001
Age		Elderly (60 y and more)	46.34	0.023
	Middle ages (35-60)	Youth (20-35 y)	-9.25	0.002
The age of disease symptoms appear- ance	>20 y	30-39 y	11.52	0.007
		6-10 у	10.93	0.003
Elapsed years from the appearance of disease symptoms	3-5 y	11-15 у	13.88	0.001
		More than 15 y	18.12	<0.001

Abbreviations: MD: doctor of medicine; PhD: doctor of philosophy; MSc: master of science; BSc: bachelor of science

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4. Discussion

The present study was conducted to investigate QoL in MS patients in East Azerbaijan Province. The results showed that dimensions of "total physical health", "total psychological health" and "total QoL" obtained 48.27%, 47.95%, and 48.22%, respectively. A study conducted by Choobforouszade et al calculated these scores to be 51.34%, 45.06%, and 55.96%, respectively [17]. Also, the mean score of total QoL was 56.2 in the study conducted by Haresabadi et al [16], it was 44.8 in Masoodi et al's study [18], it was 65.5 in Mohammad et al.'s study [19], it was 48.5 in Hazrati et al's study [20], and it was calculated to be 22.7 in Marghati Khoei et al.'s study [21]. In high-income countries, such as Italy, Netherlands, Spain, France, Turkey, and the United States, the score of QoL among MS patients was reported to be more than 65 [22]. QoL among MS patients in Iran is lower than patients from America and European countries. The probable reason can be insufficient quality and ineffective quantity of healthcare services received by the Iranian MS patients and the absence of socioeconomic support.

The current study indicates that "life satisfaction" has the highest and "physical role limitations" has the lowest score of QoL. In the study conducted by Haresabadi et al, the lowest and highest score was respectively related to "physical role limitation" and "cognitive functioning" [16]. 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 [21]. In the study conducted by Sangelaji et al., the highest and lowest scores of QoL were respectively related to "pain" and "physical role limitations" [23]. Choobforouszade et al.'s study allocated the highest and lowest QoL scores to "social function" and "physical role limitations", respectively [17]. The lowest and highest scores were related to "social function" and "physical role limitations" in the study conducted by Mohammad et al. [19]. In most studies conducted in other countries, physical problems, especially fatigue was considered the most disturbing negative consequences of MS [22]. Comparison of present findings with other literature (especially inside the country) suggested 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 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 consistent with the study conducted by Choobforouszade et al. [17] or by Pfaffenberger et al. [24].

The present study was the first evaluation of the QoL 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' QoL. 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 results, suggestions, such as promoting a basic and supplementary insurance system upon United Healthcare (UHC) principles, promoting social security system, enhancing governmental and charitable support, and 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.

5. Conclusion

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

Ethical Considerations

Compliance with ethical guidelines

This study was conducted after approving by the Ethics Committee and receiving an ethical code from Tabriz University of Medical Science (Code: IR.TBZMED. REC.1396.101).

Funding

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Study design: Farid Gharibi, Ali Imani, Koustuv Dalal; Data collection: Farid Gharibi, Mehdi Haghi, Ali Khezri, Nasrin Joudyian, Masoumeh Ebrahimi Tavani; Data analysis: Farid Gharibi, Koustuv Dalal, Mehdi Haghi, Masoumeh Ebrahimi Tavani; Drafting of the manuscript: Farid Gharibi, Ali Imani, Ali Khezri, Nasrin Joudyian; Critical appraisal: Koustuv Dalal, Mehdi Haghi, Masoumeh Ebrahimi Tavani.

Conflict of interest

The authors declared no conflict of interest.

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