What happens to the health-related quality of life of multiple sclerosis patients if they benefit from health literacy related to multiple sclerosis? A cross-sectional study in a developing country

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Abstract

Health literacy is an important pathway that provides insights into appraise of health information, the ability to search health information, knowledge of caring for the disease and successful practices in health conditions, and also opportunities for effective change in individual health. Health-related quality of life refers to the physical and mental health of an individual or group over time. Both heath literacy and health related quality of life are the priorities of WHO. This study aimed to determine the relationship between health literacy and health-related quality of life among multiple sclerosis (MS) patients, refered to Fars MS society, Shiraz-Iran, a developing country. This is a descriptive-correlational study. Three hundred and nine persons with MS completed two forms: the Multiple Sclerosis and Related Disorders and Multiple Sclerosis Impact Scale validated questionnaires. Health literacy was significantly related to health quality of life in MS patients. The dimensions of health literacy had a significant relationship with health quality of life, and the physical dimension was significantly correlated with health literacy. Among the demographic variables, "source of health information" was most related to heath literacy, and "age" was most related to health quality of life. Thus, holding training classes, communicating with other patients, effective communication with medical staff, using disease-related web facilities, finding correct information in the web environment, and using the facilities of hospital libraries can ensure quality of life of MS patients.

Keywords: Multiple sclerosis, health-related quality of life, health literacy, developing country

INTRODUCTION

Many patients with multiple sclerosis (MS) are facing various problems in developing countries, among them are lack of awareness about the disease and social exclusion. The prevalence of MS in Iran was initially from low risk to moderate risk, but now it is high and is rising over time. Iran had the highest prevalence of MS among the countries of the Eastern Mediterranean region (72.11/100,000). The prevalence of MS in Tehran was 79.3 cases per 100,000 people in 2006 which increased to 162.38 cases per 100,000 people in 2019.[1]

Being equipped with heath literacy (HL) is essential in today's society. HL is defined as the individual's capacity to acquire, interpret, and understand basic information about health services, and it involves applying the skills of reading, listening, analyzing, and decision-making in health related situations.[2] This skill enables people to have more control over their health status.[3] HL is an important priority of the World Health Organization. Given WHO reports, the HL index is both a critical indicator of individual health and the key to determining community health.[4] In fact, the effectiveness of health care depends on people's access to the desired level of HL.[5] Chronic diseases are more common in people with low levels of HL, and these population at risk of the diseases' adverse effects.[6] A number of chronic diseases are also closely related to patients' lifestyle, mental health and quality of life,

and if not moderated in a timely and appropriate manner, they will have negative outcomes.[7]

Life quality is a multidimensional complex construct defined by WHO as comprehending the situation people live in. This perception is formed by the individuals' goals, expectations, standards and interests.[8] In the health related context, the quality of life cannot be fully studied. Therefore, the concept of "health-related quality of life" (HQL) is used. HQL refers to perceived mental, emotional, social and physical well-being and reflects patients' mental assessment of the disease[9], and includes both mental and physical components. While the main challenge of public health in the 20th century was to increase life expectancy, the main challenge in the 21st century is to have a "better quality of life".[10] MS is a chronic disease which greatly affect quality of life.[11] Many patients with MS have problems in developing countries; lack of awareness about the disease and social exclusion are among them.[12] Iran is placed in the medium-prevalence MS region in the World Atlas of MS 2013. However, based on recent statistics, Iran's status has changed to a high-prevalence of MS.[1,13,14]

As the disability caused by MS increases, life quality satisfaction decreases.[15] On the other hand, lack of knowledge about the components of heath literacy may cause irreparable complications for these patients. Given the importance of HL and HQL on this issue[16], this study aimed to determine the relationship between HL and HQL among MS patients referred in 2019 to Fars MS society, Shiraz-Iran; a developing country. We hope that this study will help to clarify the relationship between HL and HQL of MS patients, and help health policymakers to improve the MS patients' quality of life.

METHODS

This is a descriptive-analytical and correlational study, the participant sample and population consisted of all people with MS in Fars province seen in 2019 (N=2,763). Three hundred and nine of the patients were selected based on Morgan table and the desire to participate in the study.

Patient-reported outcome measures

The participants completed the Multiple Sclerosis Helth Literacy Questionnaire (MSHLQ) and Multiple Sclerosis Impact Scale (MSIS-29) Persian version of validated questionnaires. MSHLQ was designed by Dehghani *et al.*, (2018) to evaluate levels of health literacy in MS patients. In addition to demographic information, the tool included 22 questions in 4 dimensions, including appraisal of health information (D1) (5 questions), ability to search health information (D2) (5 questions), knowledge of caring for the disease (D3) (7 questions) and successful practices in health conditions (D4) (5 questions). These questions were answered on a 5-point Likert scale (5 = Always, 4 = Most of the time, 3 = Sometimes, 2 = Seldom, 1 = Never). Therefore, in D1, D2 and D4, borderline and insufficient heath literacy scores were between 5-11, 12-18 and 19-25 respectively. In D3, adequate, borderline, and inadequate health literacy were between 26-35, 25-17, and 7-16 respectively. In general, the adequate level of heath literacy was between 110-181, the borderline level was between 52-80, and the inadequate level is between 22-51. The internal consistency of the MSHLQ was confirmed with Cronbach's alpha coefficient of 0.94%; Its reliability calculated with a correlation coefficient of 0.96% was confirmed.[17] Multiple Sclerosis Impact Scale (MSIS-29) measures life quality in MS patients. This questionnaire contained 29 questions. The first 20 questions assess the physical dimension, while the psychological dimension of quality of life was measured by the last 9 questions. The respondents identify answers on a 5-point Likert scale (1 = Not at all, 2 = A little, 3 = Moderately, 4 = Quite a bit, 5 = Extremely). Therefore, a higher score indicates patients' quality of life. The overall range of scores was from 29 to 145. In the physical dimension, the scores are between 20-100; in the psychological dimension, between 9-45. A score between 29-58 refer to high, 59-87 to moderate, and above 87 to low life quality in MS patients. The mean quality of life was 60 in the physical and 27 in the psychological dimension. Cronbach's alpha coefficients for examining the internal consistency of each of the physical and mental scales were 95% and 89%, respectively, which are acceptable.[18]

Data analysis

The two mentioned questionnaires were distributed for three months (from April to June 2019) in the MS Association of Fars Province. Descriptive and inferential statistics, including Pearson correlation coefficient and multivariate regression, were used to test the hypotheses. Data were analyzed using SPSS21 software.

Table 1: Health literacy rates in the MS patients

Variables		Dimentions	Min	Max	Mean	SD
HL	D1	Appraisal of Health information	5	24	15.8	6.49
	D2	Ability to search health information	5	23	13.89	8.26
	D3	Knowledge of caring for the disease	10	32	20.49	4.42
	D4	Successful practices in health conditions	5	24	13.44	7.01
Total (N=309)			25	103	63.64	26.19

Ethics

The study was approved by the institutional ethics committee with reference number IR.SBMU. RETECH.REC.1399.1215

RESULTS

Demographics

Sixty-eight percent of the participants were female, 75% were under-educated, 45.6% had very little knowledge of English, and 40.8% were housewives. Most of them obtained health information by asking their doctors and healthcare staff (58.3%). The participants' mean of age was 45 years. The mean of MS duration in these patients was 7.17 years.

Table 1 shows that the mean (standard deviation) of heath literacy was 63.64 (26.19) which was moderate. Among the dimensions of heath literacy, the highest score belonged to knowledge of caring for the disease (D3) with a mean (standard deviation) of 20.49 (4.42) and the lowest score belonged to successful practices in health conditions (D4) with a mean (standard deviation) of 13.44 (7.01).

Table 2 shows that 50% of women under the study had borderline health literacy and 1% had adequate health literacy. 85% of men had borderline health literacy and 6% had adequate health literacy. Generally, 36% of the participants had insufficient, 3 of participants had adequate health literacy and 61% had borderline health literacy.

Table 3 shows that the mean (standard deviation) of life quality was 85.63 (36.29), which was moderate. Also, the mean (standard deviation) of the physical and psychological dimensions were 58.54 (30.54) and 27.08 (5.15). Since lower scores indicate higher life quality, patients' life quality in the psychological dimension was higher.

Table 4 shows that 35% of the participants had low, 41% had moderate, and 24% had high quality of life.

The results of the correlation test for measuring the relationship between the dimensions of heath

Table 2: Health literacy level in MS patients based on their gender

	Inadequate health literacy		Borderline health literacy		Adequate health literacy		Total	
	Frequency	Percentage	Frequency	Percentage	Frequency	Percentage	Frequency	Percentage
Female	103	49	105	50	2	1	210	100
Male	9	9	84	85	6	6	99	100
Total	112	36	189	61	8	3	309	100

Table 3: Health quality of life rates in MS patients

Variables	Dimentions	Min	Max	Mean	SD
HQL	Physical Dimention	22	90	58.54	30.54
	Psychological Dimention	11	45	27.08	5.15
Total (N=309)		33	141	85.63	36.29

Table 4: Health quality of life level in MS patients based on their gender

	Inadequate health literacy		Borderline health literacy		Adequate health literacy		Total	
	Frequency	Percentage	Frequency	Percentage	Frequency	Percentage	Frequency	Percentage
Female	54	26	91	43	66	31	210	100
Male	54	54	36	37	9	9	99	100
Total	108	35	126	41	75	24	309	100

literacy and health-related quality of HLQ in MS patients using the Pearson correlation coefficient are shown in Table 5.

A significant relationship was found between health information evaluation, and the ability to search information and heath literacy. Also, health information evaluation was significantly correlated with the general quality of life and the physical dimensions. There was no significant correlation between health information evaluation, and knowledge of self-care against disease, effective performance in health situations and psychological dimension of the patients' quality of life (P<0.05).

There was a significant relationship between the ability to search for health information and the dimensions of heath literacy (health information evaluation, knowledge of self-care against disease, effective performance in health situation, and total heath literacy). The ability to search for health information was also significantly correlated with the total quality of life and physical dimensions. There was no significant relationship between the ability to search for health information and the psychological dimension (P<0.05).

There was a significant relationship between the knowledge of self-care against disease and the dimensions of HL (health information evaluation, effective performance in health situations, and total HL). A significant negative relationship was discovered between knowledge of self-care against disease, and quality of life and its physical

Table 5. Correlation matrix between dimensions of heath literacy and health-related life quality

	Variables		1	2	3	4	5	6	7	8
1	Appraisal of Health information	C*	1	0.307**	0.009	-0.032	0.575**	0.269**	0.302**	0.052
		P*		0.000	0.872	0.578	0.000	0.000	0.000	0.364
2.	Ability to search health information	C	0.307**	1	0.341**	0.169**	0.710**	0.168**	0.165**	0.105
		P	0.000		0.000	0.003	0.000	0.003	0.004	0.065
3.	Knowledge of caring for the disease	C	0.009	0.341**	1	0.212**	0.695**	-0.164**	-0.213**	0.053
		P	0.872	0.000		0.000	0.000	0.004	0.000	0.355
4.	Successful practices in health conditions	C	-0.032	0.169**	0.212**	1	0.441**	0.076	0.088	0.008
		P	0.578	0.003	0.000		0.000	0.181	0.123	0.886
5.	Health Literacy	C	0.575**	0.710**	0.695**	0.441**	1	0.123*	0116*	0.090
		P	0.000	0.000	0.000	0.000		0.031	0.041	0.115
6.	Health quality of life	C	0.269**	0.168**	-0.164**	0.076	0.123*	1	0.968**	0.661**
		P	0.000	0.003	0.004	0.181	0.031		0.000	0.000
7.	Physical Dimension	C	0.302**	0.165**	-0.213**	0.088	0.116*	0.968**	1	0.453**
		P	0.000	0.004	0.000	0.123	0.041	0.000		0.000
8.	Psychological Dimension	C	0.052	0.105	0.053	0.008	0.090	0.661**	0.453**	1
		P	0.364	0.065	0.355	0.886	0.115	0.000	0.000	

dimensions. Knowledge of self-care against disease was not significantly correlated with health information evaluation and its psychological dimension (P<0.05).

There was a significant relationship between effective performance and the dimensions of HL (health information evaluation, knowledge of self-care against disease, effective performance in health situations, and total heath literacy). No significant correlation was found between effective performance in health situations, and health information evaluation, total life quality, and its physical and psychological dimensions (P<0.05).

The total HL was significantly correlated with the HL (health information evaluation, the ability to search health information, knowledge of self-care against disease, effective performance in health situation) (P<0.05).

The total HL was significantly correlated with quality of life and physical and psychological dimensions (P<0.05).

The total Quality of life was significantly correlated with the HL dimensions (health information evaluation, the ability to search health information, knowledge of self-care against disease). A significant correlation was discovered between the total HL, and its physical and psychological dimensions. The total HL and effective performance in health situations were not significantly correlated (P<0.05).

There was a significant relationship between the physical dimension, and the total life quality and its psychological dimension (P<0.05).

Table 6 manifests, the multiple correlation coefficient between the demographic variables and HL is 0.64, and the value of the coefficient of determination is 0.41. This means that 41% of changes in HL scores are explained by the demographic variables. Also, since the value of F (10.256) is significant at P<0.05, the demographic variables can predict HL. The value of the regression coefficient (Beta) shows that the source of health information has the strongest relationship with health literacy. The other variables including English language familiarity, type of financial support, disease duration, number of relapses, type of medication and frequency of medication use have a significant relationship with HL.

As Table 7 manifests, the multiple correlation coefficient between the demographic variables of life quality is 0.80, and the value of the coefficient of determination is 0.64. This means that 64% of changes in HL scores are explained by the demographic variables. Also, since the value of F (26.55) is significant at P<0.05, the

demographic variables can predict quality of life. The value of the regression coefficient (Beta) shows that age has the strongest relationship with quality of life. The other variables including gender, height, marital status, education level, number of children, English language familiarity, disease duration, number of hospitalizations, type of medication, and the first symptom and the most debilitating problem of the disease have a significant relationship with quality of life.

DISCUSSION

This study revealed a significant relationship between the HL and HQL in MS patients (P<0.05). These two variables were positively and directly correlated, meaning that the increase in health literacy leads to an increase in the quality of life of MS patients. This finding is consistent with the various studies[9,19-21] that reported a positive and significant relationship between HL and HLQ. So improving HL have effect on life quality. Holding training classes, communicating with other patients, effective communication with medical staff, using disease-related web facilities, finding correct information in the web environment, and using the facilities of hospital libraries ensure the quality of life of MS patients.

Our study showed that most of the patients obtained their health information by asking physicians and health care staff. Therefore, the medical staff contributes to improving the MS patients' quality of lives by making health information available. Librarians can also improve these patients' information literacy by introducing other sources of health information through preparing brochures, manuals in libraries or making communication channels to help them find information from other resources, besides asking physicians and health care staff.

The HL of the MS patients in this study was borderline, and the lowest score belonged to the effective performance in health situations. Therefore, these patients should be educated to be able to apply the information they have about their disease in daily activities, search in reliable sources to obtain information about the disease, follow a proper diet, and manage their symptoms when the disease strikes. This enforces patients' effective performance in health situations, and in turn, rectifies their health literacy. Also, the HQL of these patients was moderate, and its psychological dimension played better than the physical dimension. This indicates that the symptoms of MS affect the patients' physical abilities and disrupt them. Teaching how to control

Table 6: Results of the multiple regression analysis of the relationship between the demographic variables and heath literacy

Test Variables	R	R²	F	significance level	Beta	T	sig	sd	B
1. Age	0.645ᵃ 0.05	0.416	10.256		-0.043	-0.493	0.623	4.373	-1.051
2. Sex					0.162	1.920	0.056	1.436	8.397
3. Weight					0.110	1.147	0.252	0.870	1.647
4. Marital status					-	-	0.194	3.633	-
5. Education level					0.098	1.301			1.132
6. Familiarity with English language					-0.087	-1.370	0.172	2.133	-2.805
7. Number of children					-0.160	-1.776	0.077	1.924	-0.789
8. Job position					0.070	0.687	0.492	1.076	1.323
9. Income					0.053	0.777	0.438	2.177	0.836
10. Financial support (insurance)					-0.035	-0.550	0.583	0.808	-1.197
11. Source of health information					-0.161	-3.032	0.003	0.947	-2.450
12. Duration of the disease					-0.401	-5.927	0.000	0.376	-5.614
13. Recurrence rate					-0.169	-2.783	0.006	2.500	-1.047
14. Number of hospitalizatiions					0.235	2.244	0.026	2.457	5.610
15. The first sign of disease					0.127	1.221	0.223	0.750	3.001
16. The most important debilitating probelm					0.074	1.374	0.170	0.775	1.031
17. Other diseases					-0.027	-0.459	0.647	4.483	-0.355
18. The first sign of disease					0.088	1.379	0.169	0.975	6.182
19. Type of medication					0.189	2.891	0.004	0.522	2.818
20. Frequency of medication					-0.237	-3.713	0.000	18.565	-1.938

symptoms helps to strengthen their physical characteristics, and ultimately, modifies their quality of life. HQL of the MS patients were significantly correlated with health information evaluation, the ability to search for information, and knowledge of self-care against disease. Training these patients about these dimensions enforces their health literacy and HLQ. Given the relationship between HL and demographic variables, it is concluded that the strongest predictor of HL is the source of health information. Therefore, patients' HL varies depending on their source of the information. Other characteristics, including the disease duration, are also related to HL. In fact, health information, and therefore, HL is stronger in those with longer disease duration. The HQL of these patients depends on their age, gender, height, weight, disease duration, and the most debilitating problem of the disease, which refers to the physical characteristics of patients and

Table 7: Results of the multiple regression analysis of the relationship between the demographic variables and the life quality

Test Variables	R	R²	F	significance level	Beta	T	sig	sd	B
1. Age	0.805ᵃ 0.05	0.648	26.550		0.312	-4.581	0.000	2.281	11.366
2. Sex					-0.162	-2.473	0.014	5.087	-12.578
3. Weight					0.266	3.583	0.000	1.670	5.985
4. Marital status					0.243	-4.168	0.000	1.012	-4.218
5. Education level					0.126	2.332	0.020	4.226	9.853
6. Familiarity with English language					-0.073	-1.481	0.140	2.381	-3.526
7. Number of children					-0.272	-3.883	0.000	2.481	-9.635
8. Job position					-0.205	-2.603	0.010	2.239	-5.828
9. Income					-0.024	-0.454	0.650	1.252	-0.569
10. Financial support (insurance)					-0.034	-0.696	0.487	2.532	-1.763
11. Source of health information					0.078	1.887	0.060	0.940	1.774
12. Duration of the disease					-0.054	-1.029	0.304	1.102	-1.134
13. Recurrence rate					0.248	5.275	0.000	0.437	2.308
14. Number of hospitalizatiions					0.149	1.836	0.067	2.908	5.340
15. The first sign of disease					0.164	2.026	0.044	2.858	5.790
16. The most important debilitating probelm					0.265	6.376	0.000	0.873	5.564
17. Other diseases					-0.155	-3.462	0.001	0.902	-3.122
18. The first sign of disease					0.061	1.239	0.261	5.215	6.464
19. Type of medication					-0.092	-1.815	0.071	1.134	-2.058
20. Frequency of medication					0.098	1.967	0.050	0.607	1.194

their disease status, which affects their quality of life. Although, the translation of MS information into local language may be a good alternative to improve patient's knowledge but, Given the effect of English language familiarity on HL, it seems that holding English language classes for MS patients can advance their HL, especially when there is no option to access information other than English language. Holding training classes, communicating with other patients, effective communication with medical staff, using disease-related web facilities, finding correct information in the web environment, and using the facilities of hospital libraries ensure the quality of life of MS patients.

In conclusion, in the current study, the HL and HQL of the MS patients was moderate, and a positive and significant relationship was observed between these two variables. These results emphasize the importance of paying attention to the HL and quality of life of these patients.

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