Evaluation of Relationship between Health Literacy and Illness Perception in Patients with Multiple Sclerosis in Iran

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Abstract
Background: Inadequate health literacy has negative effects on physical and mental performance, medication adherence, self-care behaviors and quality of life . The impact of health literacy on different aspects of illness perception in patients with Multiple Sclerosis (MS) is not clear. Therefore, the present study aimed to determine relationship between health literacy and illness perception in patients with MS.
Methods: This was a correlational study on 100 patients with MS who had been referred to neurology clinic of Abu Ali Sina Hospital in Qazvin (Iran) in 2017-2018. The subjects were enrolled via convenience sampling. A demographic information questionnaire, the Newest Vital Sign (NVS) health literacy instrument, and the brief illness perception questionnaire (BIPQ) were used to collect data. The data were analyzed in SPSS (version 22) using descriptive statistics, the Pearson correlation coefficient, and linear regression model.
Results: Adequate health literacy level was found in 11% of patients; 26% had a possibility of limited health literacy and 63% had a high likelihood of limited health literacy. The mean illness perception score was 35.53±1.31 (moderate). There was no significant relationship between health literacy and the mean score of illness perception (r=-0.014, P=0.894). However, there was a significant relationship between perception and recognition of present illness, as a subscale of illness perception with health literacy (r=0.243, P=0.015). Variables in the multi-variate predictive model accounted for 37.6 % of the total variance in heath literacy. Duration of illness perception significantly predict health literacy (B=0.052, P=0.035). Moreover, the only predictor of illness perception in patients with MS was income level (B=87.87, P=0.05), which explained 35.7% of the illness perception changes.
Conclusion: Based on the results, illness perception is significantly associated with health literacy. Therefore, it is necessary to promote health literacy in order to improve understanding the nature and consequences of the disease and conduct further research on the relationship between health literacy and illness perception among patients with MS.

Highlights:
What is current knowledge?
Promoting illness perception can be an effective approach to improve the quality of life of patients with MS.
What is new here?
Health Literacy and Illness Perception in Patients with Multiple Sclerosis were identified. Health literacy was identified as a key factor that influences illness perception.

Introduction

Multiple sclerosis (MS) is an autoimmune and progressive disease that lead to impaired neurotransmission as well as sensory and motor function (1-2). An estimated 2.5 million people worldwide are living with MS (3). The incidence rate of MS in Iran is reported to be 5-5.89 cases per 100,000 persons (4). This debilitating disease has significant economic, social, psychological, and physical consequences (2, 5, and 6).

Chronic diseases is one of the leading causes of psychological and cognitive disorders, illness perception is influenced by several factors including individual, social and environmental factors These factors influence the patient's perception of the nature, cause, treatability, controllability, and consequences of the illness (2, 5, and 6). It is important to examine the consequences of MS, such as illness perception. Research shows that illness perception in patients with chronic illnesses, such as MS, affects disease management, treatment, follow-up, and adaptation as well as quality of life. Lack of self-perception of illness leads to social-psychological dysfunction (6-7).

Given the extent of the physical and psychological complications of MS, it is essential to improve quality of life in patients with MS (5). Providing support and promoting illness perception can be an effective approach to improve the quality of life of patients with MS. In this regard, determining illness perception among patients with MS should be considered as part of health care services. As key

personnel in healthcare services, nurses play a vital role in promoting illness perception (7).Moving towards patient-centered health care systems and active patient participation in treatment require a high level of health literacy (1,8, and 9). Health literacy is a key determinant of community health defined as the social and cognitive skills leading to the preservation and promotion of health (10-11). According to previous studies, health literacy in Iran is inadequate (1,8), which has negative effects on physical and mental functioning, medication compliance, self-care behaviors, participation in medical decision making, disease management, and quality of life (7,8,12,13). Health literacy is influenced by several factors including individual factors such as age, sex, race, and education as well as social, economic, cultural, and language factors. Despite the importance of health literacy in management of chronic diseases, a limited number of studies has been conducted to determine factors related to health literacy in different societies (1,12,and14). In Jafari's (2018) research, Correlation test showed a positive and significant relationship between caregivers' health literacy and the behavior of women with MS (P<0.001, r=0.35) (15). low health literacy has negative effects on illness perception and medication compliance (16). in Perez's (2015) research, correlation test showed a significant relationship between acculturation, health literacy and illness perception (17). There is limited evidence related to health literacy and illness perception in patients with Multiple Sclerosis Context. Moreover, the impact of health literacy on different aspects of illness perception in patients with MS is not clear (18,19). Therefore, the present study aimed to determine the relationship between health literacy and illness perception in patients with MS.

Methods

This was a correlational study performed on patients with MS who had been referred to neurology clinic of Abu Ali Sina Hospital in Qazvin (Iran) from August 2017 to March 2018.
An a priori power analysis was conducted, indicating that for a significance level of .05, and power of .95, a minimum sample size of 100 participants would be needed for the analysis in this study (17).
Inclusion criteria consisted of having MS based on medical records, age of over 18 years, no mental and psychological illness, and having minimum reading and

writing skills. Subjects who did not answer to more than 20% of questions and those unwilling to participate in the study were excluded. Data were collected using a demographic and illness characteristics questionnaire, the brief illness perception questionnaire (BIPQ), and the Newest Vital Sign (NVS) health literacy instrument. The BIPQ was developed by Broadbent et al. (2006) and measures the outcomes, duration, personal control, treatment control, nature, concerns, perception and recognition of current illness, as well as emotional response, and the cause of the disease. The questionnaire consists of nine items. The first eight items are scored 0-10, three items (2,3, and 6) are reverse-scored, and the ninth item is an open-ended question on the three major causes of the disease from the patient's perspective. In the final analysis, each subscale should be analyzed separately. The total score of illness perception is obtained by summing the scores of items one to eight (score of 0-80), and a lower score indicates stronger illness perception. Scores of 0 to 27, 28-55, and 56-80 indicate high, moderate, and low illness perceptions, respectively (17). A Cronbach's alpha coefficient of 0.8 has been reported for this questionnaire, and the test-retest reliability coefficient with a six-week interval for different questions ranged from 0.42 to 0.75 (5).

The NVS health literacy instrument was designed by Weiss et al. (2005) in the United States to assess functional health literacy, assessing reading comprehension and numeracy skills. The questionnaire includes six questions and requires three minutes to complete. Scores vary from 0 to 6, with higher scores indicating higher degrees of literacy. A score of more than 4 indicates adequate literacy, A score 2 to 3 indicates a possibility of limited health literacy, whereas a score of less than 1 indicates a high likelihood of limited health literacy. To complete this questionnaire, a standard ice cream nutritional label was given to each subject. The subject held on to the label until all questions were answered. Cronbach's alpha coefficient for this questionnaire was 0.8, indicating the appropriate internal homogeneity of the questionnaire (20).

The study was approved by the Ethics Committee of Iran University of Medical Sciences (ethical code: IUMS.REC.1395.28546), and written informed consent was taken from all participants.

Analysis of data was carried out using SPSS Statistics 22.0. Normal distribution of data was tested using the Kolmogorov-Smirnov test, and the Pearson correlation coefficient was used to investigate the correlation of health literacy with illness perception and its related factors. Two linear regression models were used to determine the predictors of health literacy and patients' illness perception, so that in the first linear regression model, patients' health literacy was predicted by age, gender, level of education, marital status, occupation, income, insurance status, duration of illness, and body mass index (BMI). Then, using the second linear regression model, patients' illness perception, as a dependent variable, was predicted by health literacy and other independent variables used in the first regression model. The statistical significance level was set at 0.05.

Results

Most of the patients were female (75%), married (70%), and university graduates (64%). The mean age of patients and duration of illness were 33.43±8.53 years and 4.3±4.48 years, respectively (Table 1). Based on the results, Adequate HL level was found in 11% of patients; 26% had intermediate HL level, and 63% had low HL level Moreover, the mean score of illness perception was 35.53±1.31.

There was a weak correlation between health literacy and the mean score of illness perception among patients with MS (r=-0/014, P=0.893). In addition, there was a significant relationship between health literacy and perception and recognition of present illness, as a subscale of illness perception (r=0.243, P=0.015) (Table 2).

Duration of illness was found as the only variable that could predict health literacy (β=0/052, P=0.035). The independent variables of the regression model completely explained 37.6% of the health literacy changes (Table 3).

When investigating predictors of illness perception, only income could significantly predict illness perception (β=1.87, P=0.05). This model predicted 35.7% of the illness perception changes (Table 4).

Discussion

This study aimed to investigate the relationship between health literacy and illness perception in patients with MS. The results showed that 63% of patients had a high likelihood of limited health literacy, as in previous studies, different results have been reported (8, 10, 12, 21, 22). The conflict may reflect that they used different measures for health literacy (the Rapid Estimate of Adult Literacy in Medicine (12), the S-TOFHLA tool (22)or due to differences in the research setting, educational systems and the duration of illness (17).

In the present study, income was found as a predictor of illness perception in patients with MS. People with higher incomes achieved a higher illness perception score. Consistent with this finding, a study by Boonsatean et al. (2016) on patients with type 2 diabetes showed that poor socioeconomic status is accompanied with lower illness perception. On the other hand, income is significantly correlated with education level so that people with higher education level have more opportunities to earn money, and Low income is accompanied with lower quality of life (23). Previous studies also reported that ethnic minorities with lower income and lower education levels often have low health literacy (16, 19, and 24). This study demonstrated that low income significantly predict illness perception. Studies on the other groups of patients showed similar

findings, chronic illness can cause several complications such as tension, fear, depressed mood, it may have negative effect on illness perception (20).

Duration of the illness was found as another predictor of health literacy in a way that patients who had the illness for a longer time had higher health literacy. This may be related to the fact that having to deal with an illness for a longer period provides the opportunity to obtain sufficient information about the disease. Contrary to this finding, Marrie et al. (2014) reported that a shorter illness duration was accompanied by an increase in health literacy score in patients with MS (19). The inconsistency of the findings on this issue could be related to differences in study environment, ethnicity, demographic characteristics, and patient's tendency to obtain quick access to information at the onset of the disease.

Our results show no association between health literacy and the mean total score of illness perception, this study demonstrated that duration of illness perception significantly associated with health literacy. Health literacy is significantly related to patients' knowledge so that higher health literacy is accompanied with increased disease awareness (25). According to the Common Sense Model, patients' illness perception is influenced by the information provided to them (26), and the relationship between health literacy and illness perception could be justified by increased awareness and recognition of the disease

. Shiyanbola et al. (2018) stated that health literacy was significantly associated with disease risk perception in patients with type 2 diabetes so that low health literacy led to increased disease risk perception and poor adherence to treatment (27).

In a study by Basharpoor et al. (2015), perception of illness duration and illness concern in cancer patients were significantly correlated with health literacy (28). A study by Federman et al. (2013) also showed that asthma patients with poor health literacy believed that their illness is present only at the time of symptoms manifestation, and did not believe that the nature of illness is chronic (22). Perez et al. (2015) reported a significant relationship between health literacy, culture, and illness perception (disease outcomes, control, symptoms, and emotions) (17). However, we found no significant relationship between health literacy and illness perception (illness duration and concern of illness). This inconsistency could be related to the differences in the study population, culture, and health literacy measurement tools.

In explaining the research findings can be stated Health literacy is the degree to which individuals have the capacity to obtain, process, and understand basic health information needed to make appropriate health decisions given the small study population and the sampling method used in the present study, it was not possible to reach a definite conclusion about causal relationship. Therefore, caution should be exercised when generalizing the results of the present study. One of the limitations of this study is the type of questionnaire used to measure health literacy because it focuses only on reading and computing skills, while these skills are only part of the health literacy skills.

Conclusion

The findings from this study indicate a substantial opportunity for improving illness perception, through improved health literacy. Health literacy appears to be the strongest identified factor that influences illness perception. To date, enhancing diabetes-related health literacy by developing readable health-care materials has been the most frequent intervention in general practice. Interventions to enhance health literacy of patients with T2DM is recommended in order to improve illness perception. It is essential to promote health literacy in order to improve understanding the nature and consequences of the disease, as well as to increase the ability to adapt to the disease.

Ethical statement

Written consent was obtained from all individuals prior to participation in the study. The study was approved by the Ethics Committee of Iran University of Medical Sciences (ethical code: IUMS.REC.1395.28546).

Conflict of interest

The authors declare that there is no conflict of interest regarding publication of this article.

Author contributions

The authors confirm contribution to the paper as follows: study conception and design: Abdollahi.F; data collection: Taher Harikandeie.S, Dehghankar. L; analysis and interpretation of results: Tayebi Myaneh.Z, Zarrabadi Pour.S; draft

manuscript preparation: Taher Harikandeie.S, Abdollahi.F. All authors reviewed the results and approved the final version of the manuscript.

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Table 1: Frequency distribution of demographic, social, and illness characteristics of patients with MS

Variables		N (%)	Variables		N (%)
Gender	Male	25 (25)	Level of education	Secondary education	4 (4)
	Female	75 (75)		High school diploma	32 (32)
Marital status	Single	26 (26)		University and higher	64 (64)
	Married	70 (70)	Age range (years)	21-30	45 (45)
	Divorced	4 (4)		31-40	36 (36)
Occupation	Employed	32 (32)		41-50	15 (15)
	Self-employed	12 (12)		51-60	4 (4)
	Homemaker	38 (38)	Illness duration (years)	<5	70 (70)
	Student	1 (1)		5-10	25 (25)
	Unemployed	10 (10)		10-15	4 (4)
	Resigned	2 (2)		>15	1 (1)
	Retired	5 (5)			
Income (million Rials)	<5	16 (16)	BMI (kg/m^2)	<18.5 (underweight)	4 (4)
	5-10	27 (27)		18.5-24.9 (normal)	63 (63)
	10-15	32 (32)		25-29.9 (overweight)	27 (27)
	15-20	5 (5)		≥30 (obese)	6 (6)
	>20	20 (20)			
Insurance status	Yes	89 (89)			
	No	11 (11)			

Table 2: The relationship between health literacy and illness perception

Relationship of health literacy variable NVS	Impact of illness perception on life	Perception of illness duration	Perception of illness control	Perception of treatment impact	Perception of illness symptoms experience in life	Perception of concern about illness	Rate of illness recognition	Perception of illness impact on emotions
P-value	0.30	0.051	0.60	0.95	0.68	0.80	0.01	0.28
r	- 0.10	- 0.06	0.052	0.00	- 0.04	0.02	0.24	- 0.10

*the Pearson correlation coefficient

Table 3: Health literacy predictors among patients with MS

	Non-standard regression coefficient	Standard error	Standard regression coefficient	P-value
Gender	- 0.091	0.206	- 0.057	0.662
Age	- 0.006	0.011	- 0.074	0.0598
Marital status	0.149	0.160	0.120	0.354
Occupation	0.004	0.051	0.009	0.944
Level of education	0.187	0.133	0.174	0.162
Income	- 0.071	0.066	- 0.136	0.284
Insurance status	- 0.430	0.251	- 0.197	0.090
Illness duration	0.052	0.024	0.256	0.035
Frequency of hospitalization and emergency visits	- 0.014	0.052	- 0.030	0.786
BMI	0.032	0.023	0.158	0.172
Illness perception	0.001	0.007	0.014	0.894

R^2=0.376, R^2adjusted=0.033, F=1.304, P-value=0.236

Table 4: Illness perception predictors among patients with MS

	Non-standard regression coefficient	Standard error	Standard regression coefficient	P-value
Gender	2.03	3.01	0.087	0.502
Age	- 0.233	0.163	- 0.200	0.157
Marital status	2.68	2.34	0.148	0.255
Occupation	0.123	0.747	0.020	0.869
Level of education	- 3.23	1.93	- 0.207	0.098
Income	1.87	0.956	0.246	0.05
Insurance status	6.14	3.68	0.194	0.098
Illness duration	0.481	0.363	0.168	0.188
Frequency of hospitalization and emergency visits	- 0.509	0.767	- 0.074	0.509
BMI	0.029	0.344	0.010	0.933
Health literacy	0.211	1.57	0.014	0.894

R^2=0.357, R^2adjusted=0.017, F=1.15, P-value=0.328