ORIGINAL ARTICLE

Evaluation of the health literacy level of female fibromyalgia patients and relationship between health literacy level and disease activity

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ABSTRACT

Objectives: This study aims to evaluate the health literacy in women with fibromyalgia (FM) and relationship between health literacy and disease activity.

Patients and methods: This cross-sectional study included a total of 32 female patients (mean age: 46.2±8.8 years; range, 28 to 62 years) with FM according to the 2016 American College of Rheumatology classification criteria and 27 healthy female controls (mean age: 41.7±12.6 years; range, 24 to 65 years) between May 2020 and July 2020. Demographic and clinical characteristics were recorded. Health literacy levels of the participants were assessed with the Turkish version of European Health Literacy Scale (EHLS-TR), disease activity by Fibromyalgia Impact Questionnaire (FIQ), and pain level with the Numerical Rating Scale (NRS).

Results: Age, education, marital status, and residential area were similar between the groups. There was a significant difference in the job and income level between the groups (p=0.004 and p<0.001, respectively). The EHLS-TR scores were significantly lower, in FM group compared to the control group (p=0.006, p<0.001, and p<0.001, respectively). There was a negative correlation between the EHLS-TR scores and age in the FM group (r=-0.499, p<0.001). A positive significant correlation was found between education status, income level, and EHLS-TR scores in the FM group (r=0.416, p<0.05 and r=0.316, p<0.05, respectively).

Conclusion: Our study results suggest that healthy literacy level is lower in patients with FM compared to healthy controls. In addition, healthy literacy is associated with age, education status, and income level in this patient population.

Keywords: Disease activity, fibromyalgia, health literacy.

Health literacy is defined by World Health Organization (WHO) as individuals' health-related information defined as cognitive and social skills in which the individuals have the ability to reach, understand, and use information.[1] Health literacy, has been increasingly included in the international literature with understanding the physicians' recommendations, using the medicines and medical devices correctly, and knowing where to go when one needs medical assistance.[2] Insufficient level of health literacy in the society affects the diagnosis and treatments adversely, causes an increase in hospitalizations and improper use of the emergency services, bringing an additional burden on the health system.[3,4] Having a sufficient level of health literacy not only improves one's own health by changing his/her personal lifestyle, but also allows one to reach the level of knowledge, skills and self-confidence required to improve the public health.

According to Schillinger,[5] individuals with a low level of health literacy experience more problems in managing chronic diseases, visit more frequently the clinics, and have poorer clinical responses.

Fibromyalgia (FM) is one of the well-known chronic diseases. It is a disease characterized by widespread pain, fatigue, and memory and sleep disorders and is encountered in 2 to 8% of the population.[6] Treatment includes medical therapy, as well as multimodal treatment approaches such as aerobic, resistance and flexibility exercises, cognitive behavioral therapy, acupuncture, and massage therapy.[7] There are no studies in the literature evaluating health literacy in patients with FM. However, there are some studies in the literature evaluating health literacy in patients with rheumatoid arthritis. A study showed that patients with rheumatoid arthritis had a low health literacy level in the southwestern Ontario.[8] Studies of patients with rheumatoid arthritis have shown that low levels of health literacy have a weak, but consistent effects on the most outcome measures.[9,10] Patients with rheumatoid arthritis who had a lower health literacy level found the Patient Global Assessment-Visual Analog Scale (PGA-VAS) confusingly.[10] Therefore, these patients may misrepresent their disease activities with scales such as VAS, when the researchers evaluate disease activity, due to the health literacy level.

Improving health literacy in patients with FM enables patients to obtain information from the right sources, and to access and evaluate the correct information. In addition, they can evaluate different treatment options and decide on the treatment options that suit them, increase their compliance with treatment, and increase the chance of success in the treatment. In the present study, we aimed to evaluate the health literacy in women with FM and relationship between the health literacy and disease activity.

PATIENTS AND METHODS

This cross-sectional study included a total of 32 female patients (mean age: 46.2±8.8 years; range, 28 to 62 years) with FM according to the 2016 American College of Rheumatology (ACR) classification criteria and 27 healthy female controls (mean age: 41.7±12.6 years; range, 24 to 65 years) who were admitted to the outpatient clinic for health check-up including vitamin D and B12 measurements and osteoporosis screening between May 2020 and July 2020. Those with concomitant rheumatic disease; neurological disease; history of other systemic diseases such as hypothyroidism/hyperthyroidism, diabetes mellitus; previous history of overt trauma; and previous orthopedic surgery were excluded. Demographic and clinical characteristics were recorded. The health literacy levels of the participants were assessed with the Turkish version of European Health Literacy Scale (EHLS-TR), disease activity with the FM Impact Questionnaire (FIQ), and pain level with the Numerical Rating Scale (NRS). A written informed consent was obtained from each participant. The study protocol was approved by the Hitit University Clinical Research Ethics Committee (Date: 05.05.2020/No. 204). The study was conducted in accordance with the principles of the Declaration of Helsinki.

The EHLS-TR evaluates the health literacy level of participants over the age of 15 years. The scale contains 47 items. The total score that can be obtained from the scale is between 47 and 88. For ease of calculation, total score is standardized with the help of the following index formula with a score ranging between 0 and 50: Index=(arithmetic mean -1) $\times$ 50/3 [0-25 point: insufficient health literacy level, 25-33 point: limited health literacy level, 33-42: sufficient health literacy level, 42-50: excellent health literacy level].[11]

The validity and reliability of the FIQ for the Turkish population were assessed by Sarmer et al.[12] This scale is composed of 10 items. It measures physical functioning, well-being, missed work days, difficulty in work, pain, fatigue, morning tiredness, stiffness, anxiety, and depression. Evaluation was performed over a total of 100 points, including 10 points for each subheading. Low scores indicate a low severity of the disease, while high scores indicate a greater severity of the disease.[13]

The NRS is a subjective measurement in which patients rate their pain on an 11-point

numerical scale. It is composed of 0 (no pain) to 10 (worst pain).[14]

Statistical analysis

Statistical analysis was performed using the SPSS for Windows version 15.0 software (SPSS Inc., Chicago, IL, USA). The variables were investigated using visual and analytical methods to determine whether or not they are normally distributed. Continuous variables were expressed in mean ± standard deviation (SD) or median (min-max), while categorical variables were expressed in number and percentage. The Student's t-test was used to compare age, NRS, FIQ, and EHLS-TR scores. The Chi-square test and Fisher exact test were used to compare nominal values. The Pearson correlation coefficient was used to evaluate the linear relationship between the predictive variables. A p value of <0.05 was considered statistically significant.

RESULTS

Age, education, marital status, and residential area were similar between the groups (Table 1). Of the FM group, 25 (78.1%) were housewives, five (15.6%) were civil servant, and two (6.3%) were workers. Of the control group, 12 (44.4%) were housewives and 15 (55.6%) were civil servants, indicating a significant difference between the groups (p=0.004). In the FM group, there were 14 (43.8%) patients with 0 TL income level, 11 (34.4%) patients with <2,020.00 TL income level, and seven (21.9%) patients with >2,020.00 TL income level. In the control group, there were three (11.1%) participants with 0 TL income level, two (7.4%) participants with <2,020.00 TL income level, and 22 (81.5%) participants with >2,020.00 TL income level (Table 1). The participants in the control group had a significant higher income level compared to FM patients (p<0.001) (Table 1). The use of

Table 1. Demographic characteristics of FM group and control group

	FM group (n=32)			Control group (n=27)			
	n	%	Mean±SD	n	%	Mean±SD	p
Age (year)			46.2±8.8			41.7±12.6	0.121
Job							0.004
Housewife	25	78.1		12	44.4		
Civil servant	5	15.6		15	55.6		
Worker	2	6.3		0	0		
Education							0.132
Illiterate	2	6.3		0	0		
Primary school	20	62.5		11	40.7		
Secondary school	3	9.4		5	18.5		
High school or higher	7	21.9		11	40.7		
Marital status							0.066
Married	30	93.8		20	74.1		
Single	2	6.3		7	25.9		
Income level							<0.001
0 TL	14	43.8		3	11.1		
<2,020.00 TL	11	34.4		2	7.4		
>2,020.00 TL	7	21.9		22	81.5		
Computer (present)	19	59.4		17	63		0.778
Smart phone (present)	29	90.6		25	92.6		0.787
Internet (present)	22	68.8		21	77.8		0.547
Residential area							0.583
Village	2	6.3		3	11.1		
District	1	3.1		2	7.4		
City	29	90.6		22	81.5		

FM: Fibromyalgia; SD: Standard deviation; p<0.05.

Table 2. Turkish version of EHLS-TR, FIQ, and NRS scores of FM group and control group

	FM group (n=32)			Control group (n=27)			
	n	%	Mean±SD	n	%	Mean±SD	p
EHLS-TR (score)			29.9±13.4			38.5±8.1	0.006
EHLS-TR							0.076
Insufficient	10	31.3		2	7.4		
Limited	7	21.9		4	14.8		
Sufficient	7	21.9		11	40.7		
Excellent	8	25		10	37		
FIQ (score)			70.8±16.5			-	
NRS (score)			7.5±1.6			-	

EHLS-TR: Turkish version of European Health Literacy Scale; FIQ: Fibromyalgia Impact Questionnaire; NRS: Numerical Rating Scale; SD: Standard deviation; FM: Fibromyalgia; p<0.05.

computer, internet, and smart phone was similar between the groups (Table 1).

The EHLS-TR significantly decreased in the FM group, compared to the control group. There was no significant difference between the two groups in EHLS-TR classification (Table 2). In the FM group, the mean disease duration was 50±47.1 (range, 1 to 180) months. In the FM group, 11 patients used pregabalin and 15 patients used duloxetine. There was no significant difference in the EHLS-TR, FIQ, and NRS scores between the patients using pregabalin and those using duloxetine (Table 3).

There was a negative correlation between the EHLS-TR scores and age in the FM group. A positive correlation was found between the education status, income level, and EHLS-TR scores in the FM group (Table 4).

DISCUSSION

Fibromyalgia is a chronic illness with physical and cognitive-emotional symptoms. Patients with FM report poorer mental and physical health-related quality of life.[15] Health-related quality of life depends on some factors such as environmental factors (engagement with health-care providers and systems), attitudinal influences (beliefs and values pertaining to wellness), health behaviors and treatment engagement.[15,16] In FM patients, maladaptive health beliefs and unsafe attitudes about physician-level and systemic-level healthcare provision are negatively related to both treatment adherence and physical and mental health-related quality of life.[16] Previous studies have shown that information about one's condition is important in acceptance, embracing, or coming to terms with pain.[17] This is associated with less

Table 3. EHLS-TR, FIQ and NRS scores of patients using pregabalin or duloxetine in FM patients

	Patients using pregabalin (n=11)	Patients using duloxetine (n=15)	
	Mean±SD	Mean±SD	p
EHLS-TR (score)	33.9±14.4	28.6±11.9	0.316
FIQ (score)	68.7±15.1	71.8±17.3	0.642
NRS (score)	7.5±1.4	7.5±2.1	0.916

EHLS-TR: Turkish version of European Health Literacy Scale; FIQ: Fibromyalgia Impact Questionnaire; NRS: Numerical Rating Scale; SD: Standard deviation; FM: Fibromyalgia; p<0.05.

Table 4. Correlation between EHLS-TR score and age, FIQ, NRS, disease duration, education status, and income level in FM group

	EHLS-TR	EHLS-TR
	r	p
Age	**-0.499**	**0.004**
FIQ	-0.050	0.787
NRS	-0.077	0.674
Disease duration	0.021	0.907
Education	**0.416**	**0.018**
Income level	**0.361**	**0.042**

EHLS-TR: Turkish version of European Health Literacy Scale; FIQ: Fibromyalgia Impact Questionnaire; NRS: Numerical Rating Scale; FM: Fibromyalgia.

pain, disability, symptoms, and mood disturbance with better general health and functioning.[18,19] The insufficient level of health literacy of patients with FM can lead to difficulty in accessing the right information form the right sources and, thus, increased pain and disability. In our study, we found that health literacy level decreased in patients with FM. Disease activity was higher in patients with FM. Low health literacy level may have contributed to high disease activity. In this study, we determined the health literacy level of patients with FM. As a matter of fact, providing education to improve the health literacy of patients with FM may be effective in decreasing the disease activity.

Among the FM patients, the number of housewives was higher and the income level was lower. Therefore, the high number of housewives and low income levels may have contributed to the difficulty in accessing information, probably due to low health literacy. We also found that health literacy level was correlated with education level and income level in FM patients. However, we were unable to find show any correlation between disease duration and health literacy level. According to a prospective study examining the effect of the relationship between sociodemographic variables and healthy literacy on the change in health literacy for 10 years, the determinants of the change were age, race, education level, cognitive functionality, and income level.[20] According to the WHO health literacy report, individuals with a low education level have often a limited health literacy level.[21] However, we could not comment on whether the drugs used by patients with FM had an effect on the level of health literacy, since there was no significant difference in the health literacy level between the patients using pregabalin and duloxetine.

Randomly selected 4,929 participants were included in the Turkey Health Literacy Level Survey and 64.6% of the participants were found to have an insufficient or limited health literacy level.[22] In our study, 53.2% of FM patients and 22.2% of healthy controls had insufficient or limited health literacy levels. Compared to this cohort, patients with FM had a higher health literacy level. However, in this study, the participants were randomly selected. Both healthy participants and patients with various diseases and comorbidities were most probably included in this study. Therefore, there is a need for further studies evaluating the health literacy level of completely healthy participants in Turkey.

In FM patients, self-management has been increasingly recommended.[23] This study showed that the level of health literacy should be improved to achieve success in self-management. The increased health literacy level can be effective in improving self-management in FM. Thus, physiatrists should be aware of the low health literacy levels in patients with FM.

This is the first study evaluating the health literacy level in patients with FM. Therefore, it would contribute to the literature in determining and improving the level of health literacy in patients with FM. However, the cross-sectional design and method of selecting healthy controls can be deemed as the main limitations of our study, since the healthy controls were selected from the participants admitted for health check-up, which may have led to potential bias or not. We recommend further well-designed studies in larger samples to draw a firm conclusion on this subject.

In conclusion, healthy literacy level is lower in patients with FM than healthy individuals. In FM patients, low healthy literacy level is also associated with advanced age, lower income level, and lower education status.

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