# The relationship between the use of complementary and alternative medicine methods and health literacy in female patients with fibromyalgia

Fibromiyaljili kadın hastalarda tamamlayıcı ve alternatif tıp yöntemlerinin kullanımı ile sağlık okuryazarlığı arasındaki ilişki

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### ÖZET

AMAÇ: Fibromiyaljili birçok hasta, geleneksel tedaviye ek olarak tamamlayıcı ve alternatif tedavilerden (TAT) yararlanmaktadır. Sağlık okuryazarlığı (SOY), sağlık bilgilerini arama, anlama ve uygulama becerisini ifade eder. Bu çalışmanın amacı fibromiyaljili kadın hastalarda TAT kullanımı ile SOY arasındaki ilişkiyi araştırmaktır.

GEREÇ VE YÖNTEM: FMS tanısı almış 160 hastaya, TAT tercihlerini de değerlendiren açık uçlu anket uygulandı ve verileri kesitsel analitik tasarımda değerlendirildi. Hastalara ağrı için, görsel analog skala (VAS), fibromiyalji etki anketi (FIQ) ve SOY Anketi (HLS-EU-Q47) uygulandı. Hastalar 2 gruba ayrıldı (TAT kullanan (Grup 1); TAT kullanmayan (Grup 2)).

BULGULAR: Anket sonuçlarına göre SOY puanı 30.94 ± 8.40 olup problemli-sınırlı düzeydeydi. Her iki grup arasında demografik, klinik parametreler, SOY ve alt indeksleri açısından anlamlı fark yoktu (p> 0.05). En sık kullanılan TAT yöntemlerine göre yapılan değerlendirme sonuçları SOY genel puanı ve alt ölçek puanlarına göre ilgili TAT yöntemini kullananlar ile kullanmayanlar arasında fark olmadığını göstermiştir. En çok tercih edilen TAT yöntemleri sırasıyla dua (%37,9), ıslak kupa (%21,8), bitkisel tedavi (%16,30), kuru kupa (%12,9) ve termal banyo idi (%11,40).

SONUÇ: Çalışmamızın sonuçları FMS'li kadınlarda TAT kullanımının yaygın olduğunu ve spiritüel yöntemlerin önde gelen yöntemler olduğunu göstermiştir. Ayrıca, TAT kullanan ve kullanmayanlarda hastalık şiddeti ve sağlık okuryazarlığı düzeyleri benzerdi.

Anahtar Kelimeler: fibromiyalji, sağlık okuryazarlığı, tamamlayıcı ve alternatif tıp, spiritüel yöntemler, bitkisel tedavi, hacamat

#### **ABSTRACT**

OBJECTIVE: Many patients with fibromyalgia benefit from complementary and alternative therapies (CAM) in addition to traditional therapy. Health literacy (HL) refers to the ability to seek, understand and apply health information. The aim of this study is to investigate the relationship between CAM use and HL in female patients with fibromyalgia.

MATERIALS AND METHODS: An open-ended questionnaire, which also evaluates CAM preferences, was applied to 160 patients with FMS, and their data were evaluated in a cross-sectional analytical design. Visual analogue scale (VAS) for pain, fibromyalgia impact questionnaire (FIQ) and HL Questionnaire (HLS-EU-Q47) were applied. The patients were divided into two groups (using CAM (Group 1); not using CAM (Group 2)).

RESULTS: According to the results of the questionnaire, the HL score was  $30.94 \pm 8.40$  (problematic-limited level). There was no significant difference between the two groups in terms of demographic, clinical parameters, HL and sub-indices (p> 0.05). The results of the evaluations made according to the most commonly used CAM methods showed that there is no difference between those who use the relevant CAM method and those who do not, according to the HL general score and subscale scores. The most preferred CAM methods were prayer (37.9%), wet cupping (21.8%), herbal therapy (16.30%), dry cupping (12.9%) and thermal bath (11.40%), respectively.

CONCLUSION: The results of our study showed that the use of CAM is common among women with FMS, and spiritual methods are the leading methods. In addition, disease severity and health literacy levels were similar in CAM users and non-users.

Keywords: fibromyalqia, health literacy, complementary and alternative medicine, spiritual methods, herbal therapy, cupping

#### INTRODUCTION

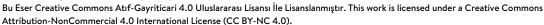
Fibromyalgia Syndrome (FMS) is a chronic systemic disease characterized by widespread pain and tender points,

accompanied by a multitude of symptoms such as fatigue, sleep disturbance, depression, and anxiety. Fibromyalgia, also defined as central sensitization syndrome

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characterized by allodynia and hyperalgesia, is usually accompanied by psychogenic or psychosomatic findings that worsen the quality of life of the affected individuals. (1). The prevalence of FMS, the majority of whom female, in the general population is 1-11%. Patients with FMS have lower mechanical and thermal pain thresholds (2). Although the exact pathophysiology of fibromyalgia is still unknown, abnormalities in both neuroendocrine and stress responses blamed for it (3). According to EULAR recommendations, the ideal multimodal treatment approach should start with а combination pharmacological and non-pharmacological treatments and patient education (4,5).

Complementary and alternative medicine (CAM) includes a variety of medical applications and products that are not currently considered part of traditional medicine (6). The rate of CAM use in the general population ranges from 9% to 65%. CAM users are more often women and suffer from chronic illnesses (7). In addition, patients with pain-related or mobility-limiting conditions are more likely to seek CAM. Therefore, it is not surprising that CAM is widely used in rheumatic diseases (8). Many patients with fibromyalgia benefit from complementary and alternative therapies in addition to traditional therapy. Studies have shown that FMS patients use at least one CAM therapy consisting of heat treatments, thermal baths, homoeopathy, dietary supplements and vitamins, acupuncture and meditative exercises such as yoga or tai chi. (9,10). For FMS, numerous studies have been published with conflicting results on the effects of complementary and alternative therapies (11). Half of CAM users with rheumatic diseases do not inform their doctors. The most common reasons expressed by the patients were not being asked, forgetting to tell the physician and rarely fear of disapproval (8,12).

Health literacy (HL) refers to the ability to seek, understand and apply health information when making decisions about one's own health (13). Studies have shown that HL is a better indicator of health status than education, employment, socioeconomic status, race, or gender (7). Studies show that individuals with low HL levels have less knowledge of their health status, available treatments and the skills required to negotiate within the health system (14). It has been reported that there is a relationship between low HL levels and poor treatment outcomes, such as non-adherence to drug use, high admission to emergency rooms, less ability to interpret labels and health

messages, reduced health status and increased mortality in the elderly (15). Access to the appropriate sources of information and the ability to evaluate the information gained to make safe and appropriate decisions are essential components of health literacy (16,17).

It is important to understand the use of CAM and HL patterns (7,18). We thought that HL might affect the use of CAM and the preferred CAM method. However, we did not find any study investigating the relationship between CAM use and HL in fibromyalgia patients in our literature review. The aim of this study was to investigate the relationship between CAM use and HL in female patients with fibromyalgia.

#### **MATERIAL & METHODS**

The prospective cross-sectional study included 160 literate female patients between the ages of 18-60 who were diagnosed with FMS according to the 2016 ACR diagnostic criteria (19). Patients who did not want to participate in the questionnaire or who were illiterate were excluded from the study. The study was planned in accordance with the rules in the Helsinki declaration, and the approval of the local ethics committee was obtained (2011-KAEK-25 2018 / 04-09). Before the study, detailed information was given to the patients, and their written informed consent was obtained.

The research tool was a questionnaire and was administered in face-to-face interviews in polyclinics. The questionnaire was developed according to research questions and relevant literature. The questionnaire included demographic and socioeconomic information of the patients, clinical status related to FMS, CAM preferences, attitudes towards CAM and HL questions. Prayers for health reasons include: Praying for your own health; someone else praying for your health; joining a prayer group or chain of blessings; participating in a healing ritual or order for one's health (20).

Sensitivity in FMS patients was evaluated by applying 4 kg / cm<sup>2</sup> of pressure on 19 specific body points. The pain intensity of the patients was evaluated using a visual analogue scale (VAS), and functional status was evaluated using the FMS Impact Questionnaire (FIQ).

FIQ is a valid and reliable method that evaluates the effect of the disease on daily life in FMS patients. This scale measures ten different characteristics: physical function, feeling unwell, not going to work, difficulty at work, pain, fatigue, morning fatigue, stiffness, anxiety, and depression. The maximum score for the FIQ is 100. A higher score indicates higher disease severity. In the severity analysis, a total FIQ score of 0- <39 represents low effect, ≥39 <59 moderate effects, and ≥59-100 represents severe effect (21).

Health literacy was evaluated with the Turkish version of the HLS-EU-Q47. The 47 items were graded on a 4-point scale: 1 = very difficult, 2 = difficult, 3 = easy, 4 = very easy. Questions that were not answered were not graded. The survey questions were subdivided as follows: healthcare questions 1-16, disease prevention questions 17-31 and health promotion questions 32-47. At the end of the study, it was accepted that 0-25 was inadequate,> 25-33 problematic - limited, > 33-42 sufficient and > 42-50 excellent. Formula Index = (M-1) \* (50 / 3), where the index was specific index calculated, M was the mean of all participating items for each individual, 1 was the minimal possible value of the mean, 3 was the range of the mean, and 50 was the chosen maximum value of the new metric (22)

The patients were divided into two groups as using CAM (Group 1) and not using CAM (Group 2).

#### Statistical analysis

The compliance of continuous variables to normal distribution was examined using the Shapiro Wilk test. Continuous variables are expressed as "mean ± standard deviation (minimum: maximum)" if the data conform to a normal distribution and "median (minimum: maximum)" if it does not conform to normal distribution. Categorical variables were reported as n (%). Mann Whitney U test and independent samples t-test were used in continuous comparisons between CAM groups; the chi-square test was used for comparisons involving categorical variables. The internal consistency of the health literacy scale was examined with reliability analysis, and the Cronbach alpha coefficient was calculated. SPSS (IBM Corp. Released 2012. IBM SPSS Statistics for Windows, Version 21.0. Armonk, NY: IBM Corp.) program was used for statistical analysis and p < 0.05 was considered statistically significant.

#### **RESULTS**

Since eight patients gave inadequate answers to the questionnaire questions, the study was completed with a

total of 152 female FMS patients (Figure 1). The mean age of the patients was  $36.89 \pm 8.99$  (19-58), and BMI was 26.11 (16.49-44.64) kg / m². 62.70% of the patients had less than high school education. 62.70% (n=95) did not have an income of their own. The demographic and socioeconomic data of the patients are shown in Table 1.

Figure 1. Flow diagram

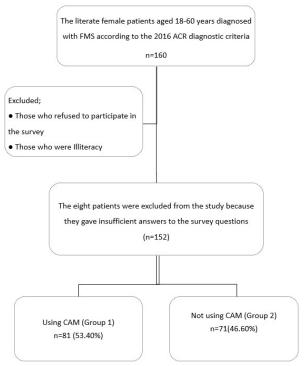


Table 1. General characteristics of the participants

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Age (year	)	36.89±8.99 (19:58)	
Body Mass Index (kg/m²)		26.11(16.49:44.64)	
Education	Status		
	Primary school	95(62.70%)	
	High school	28(18.30%)	
	Univesity	29(19%)	
Working		42(27.20%)	
Occupatio	on		
	Professional	68(45%)	
	Not have a profession	84(55%)	
Income st	atus		
	No Income	86(57.20%)	
	Minimum wage and below	40(26.30%)	
	Above the minimum wage	26(16.50%)	
Smoking			
	Current smoker	43(27.80%)	
	Ex smoker	15(10.30%)	
	Never smoker	94(61.90%)	
Pain Duration (Months)		18(3:72)	
Pain (VAS	5)	7(1:10)	
FIQ		63.23(10.01:94.26)	

Data are given as mean ± standard deviation (minimum: maximum), median (minimum: maximum) and n (%). BMI: Body mass index; CAM: Complementary and Alternative

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Medicine; VAS: Visual Analogue Scale; FIQ: Fibromyalgia Impact Ouestionnaire.

In the clinical evaluation of patients with FMS, the median duration of pain was 18 months (3-72 months), and the pain severity was VAS median 7 (1-10) and FIQ median 63.23 (10.01-94.26) (Table 1). 52.9% (n = 81) of the patients used a CAM method. The most preferred CAM methods were praying 37.9% (n=57), wet cupping 21.8% (n=33), herbal therapy 16.30% (n=24), dry cupping 12.9% (n=19) and thermal baths 11.40% (n=17). 53.40% (n=81) of the patients believed in CAM. 56.8% (n=46) of the patients stated that they benefited a little from the CAM method they used, while 35.8% (n=29) stated that they did not benefit at all (Table 2).

Table 2. CAM use and related issues

Believing	in CAM	
	I believe	81(53.40%)
	I don't believe	71(46.60%)
CAM use		81(53.40%)
	Prayer	57(37.90%)
	Wet cupping	33(21.80%)
	Dry cupping	19(12.90%)
	Leech	3(2.40%)
	Chiropractic	5(3.20%)
	Herbal therapy	24(16.30%)
	Thermal baths	17(11.40%)
	Ozone therapy	2(1.60%)
	Dry needling	5(3.30%)
	Acupuncture	3(2.40%)
	Pilates	6(4%)
	Yoga	2(1.60%)
	Hypnosis	1(0.80%)
	Apitherapy	1(0.80%)
	Exercise	8 (4.90%)
CAM's Eff	ect	
	No	29(35.80%)
	Some	46(56.80%)
	Quite	4(4.90%)
	Very	2(2.50%)
Directed t	o CAM	
	Self	39(48.60%)
	Family	13(15.70%)
	Social environment	22(27.10%)
	Internet	2(2.90%)
	Doctor	5(5.70%)

Data are given as n (%)

The average health literacy score determined according to the results of the HLS-EU-Q47 questionnaire was at a problematic-limited level with  $30.94 \pm 8.40$  (Table 3).

There was no significant difference between FMS patients using CAM and FMS patients not using CAM in terms of demographics, clinical parameters, or HL and its sub-indexes (p> 0.05) (Table 4). The results of the evaluation made according to the most commonly used CAM methods showed that there was no significant difference between those who used the relevant CAM method and those who did not, according to HL (Table 5).

#### **DISCUSSION**

The results of this study showed that more than half of female patients with FMS used at least one CAM method to cope with pain, and there was no difference in disease severity and HL between those using CAM and those who did not. Praying was the first among the preferred methods.

The etiology of FMS is still unknown, so treatment focuses mainly on pain management and modulation of fatigue. The lack of a known clear cure for FMS has led many patients to turn to CAM therapies in their search for pain relief (23). It has been reported that patients with FMS use 2.5 times more CAM than controls without FMS (24). In the literature, the prevalence of using CAM for FMS varies between 24% and 92.6% (25,26). According to our results, the rate of using CAM was 52.9%.

Making informed decisions about CAM use requires a somewhat complex level of health literacy. Studies have shown that education is positively associated with HL (27). HL skills are associated with health-seeking behaviors, and it has been suggested that adequate health literacy can predict overall CAM use (28,29). Charoencheewakul et al. showed that patients with adequate to excellent HL levels are more likely to use CAM (30). Conversely, another study showed that high CAM use was associated with lower health literacy (7). Our results showed no significant difference in HL between CAM users and those who did not use CAM among female FMS patients. HL level was problematic - limited in both groups. Studies show that patients with low HL levels have less information about their health status, current treatments and the skills required to negotiate within the health system (14). Low HF levels have also been associated with worse treatment outcomes (15). Studies have shown that the relationship between HL and CAM use varies significantly according to race (29).

As an interesting conclusion to be drawn from our survey, we can say that the most preferred method is to pray for health. Other preferred CAM methods were wet cupping, herbal therapy, dry cupping, and thermal baths. Wall et al. reported that the most common CAM methods used by

FMS patients were exercise (92.2%), chiropractic therapy (48.1%), lifestyle and diet (45.8%), relaxation therapy (44.9%), and diet and herbal supplements (36.5%). Participants in this study were well educated, and the majority made their choice of CAM with the doctor's advice (26). In studies, higher educational attainment was associated with increased CAM use (31). In addition, studies have shown that health literacy status differs according to CAM usage category.

Table 3: Health literacy distribution among participants

Health literacy and sub-indexes	Health care index (Q1-16)	Disease prevention index (Q17-31)	Health promotion index (Q32-47)	General health literacy index (Q1– 47)
Cronbach $\alpha$	0.933	0.929	0.934	0.971
Inadequate (0–25)	15.00%	27.50%	35.90%	23.50%
Problematic-limited (>25-33)	34.00%	38.60%	30.10%	41.80%
Sufficient (> 33-42)	34.60%	20.30%	22.90%	24.20%
Excellent (> 42-50)	16.40%	13.70%	11.10%	10.50%
Average (0:50)	33.37±8.73	30.09±9.87	29.32±9.33	30.94±8.40

Table 4. Comparison of CAM users and non-users in terms of clinical data and health literacy

	CAM users (n=81)	CAM non-users (n=71)	p-value
Age (year)	37.33±8.63(19:58)	36.40±9.41(19:57)	0.529a
BMI (kg/m2)	27.18±5.43 (16.53:44.64)	27.15±5.71 (16.49:44.06)	0.972a
Education Status			
Primary school	50(61.70%)	46(63.90%)	
High school	19(23.50%)	9(12.50%)	0.130b
University	12(14.80%)	16(23.60%)	
Working Status			
Working	19(22.50%)	23(32.40%)	0.172b
Not working	62(77.50%)	48(67.60%)	
Occupation			
Professional	33(41.70%)	35(48.10%)	0.520b
Not have a profession	48(58.30%)	36(51.90%)	
Income status			
Low	46(56.50%)	40(57.80%)	
Moderate	23(29%)	17(23.40%)	0.683b
High	12(14.50%)	14(18.80%)	
Smoking			
Current smoker	28(34.30%)	15(20.30%)	
Ex smoker	8(10.40%)	7(10.20%)	0.197b
Never smoker	45(55.30%)	49(69.50%)	
Pain Duration (Months)	18(3:72)	18(3:60)	0.283c
Pain (VAS)	8(1:10)	7(1:10)	0.085c
FIQ score	63.73(16.11:94.26)	60.08(10.01:90.47)	0.113c
Health literacy			
Health care	32.29(0:50)	34.93(14.58:50)	0.225c
Disease prevention	28.89(4.76:50)	29.45(4.44:50)	0.426c
Health promotion	27.08(14.58:50)	28.51(12.50:50)	0.452c
General	29.35(7.25:50)	30.50(14.54:48.94)	0.342c

Data are given as mean ± standard deviation, Median (minimum: maximum) and n%. a: Independent samples t-test, b: Chi-Square Test, c: Mann Whitney U test

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Table 5. CAM methods and Health Literacy

	Health care	Disease prevention	Health promotion	General
Prayer				
Yes	34.38 (0:50)	30.06±11.72 (4.76:50)	27.08 (12.50:50)	29.71 (14.54:48.89)
No	31.25 (14.58:50)	29.14±8.75 (4.44:50)	28.13 (14.58:50)	31.56 (7.25:50)
p-value	0.104c	0.643a	0.686c	0.429c
Wet cupping				
Yes	34.38 (14.58:50)	29.82±8.57 (13.33:50)	28.13 (16.67:50)	30.84±7.11 (15.96:50)
No	33.33 (0:50)	29.39±10.34 (4.44:50)	27.08 (12.50:50)	30.35±8.78 (7.25:49.65)
p-value	0.737c	0.845a	0.671c	0.933a
Dry cupping				
Yes	32.81 (16.67:47.92)	31.53±10.45 (13.33:47.78)	30.21 (17.71:50)	31.36 (15.96:45.74)
No	33.33 (0:50)	29.18±9.88 (4.44:50)	27.08 (12.50:50)	29.71 (7.25:50)
p-value	0.864c	0.382a	0.072c	0.314c
Cupping				
Yes	32.81 (14.58:50)	29.73±9.01 (13.33:50)	28.13 (16.67:50)	31.01 (15.96:50)
No	33.33 (0:50)	29.38±10.38 (4.44:50)	27.08 (12.50:50)	29.71 (7.25:49.65)
p-value	0.929c	0.919a	0.183c	0.544c
Herbal therapy				
Yes	32.81 (16.67:47.78)	27.45±8.93 (13.33:50)	25 (15.56:50)	29.04±7.01 (15.96:47.52)
No	33.33 (0:50)	29.80±10.14 (4.44:50)	27.78 (12.50:50)	30.64±8.66 (7.25:50)
p-value	0.597c	0.235a	0.494c	0.440a
Thermal Baths				
Yes	33.33 (0:50)	30.71±10.62 (13.33:50)	29.69 (15.63:50)	31.13±9.13 (17.38:50)
No	29.17 (21.11:50)	29.34±9.94 (4.44:50)	27.08 (12.50:50)	30.37±8.40 (7.25:69.65)
p-value	0.238c	0.763a	0.332c	0.753a

Data are given as mean ± st.dev. and median (minimum: maximum). a: Independent samples t-test, c: Mann Whitney U test

Specifically, adequate health literacy was associated with vitamin use, while poor health literacy was associated with meditation use (29). In contrast, our study population exhibited a low socioeconomic and low educational level as well as a problematic-limited health literacy level. In addition, they made the choice of CAM according to their own decisions. Considering that praying is also a form of meditation, it can be said that our results also support Bains' results. One study reported that 35% of the U.S. population used self-prayer as a treatment option, although only 7% of the U.S. population reported mental recovery (32). This systematic review of 23 trials and 2774 patients showed statistically significant treatment effects of prayer and distance healing in 13 patients (57%), no effect in 9 patients (39%), and negative effects in 1 patient (4%) (33). It has been suggested that complex social or health belief factors play a role in behavior related to CAM use (7). According to our results, only 35.80% of the patients using CAM reported that they did not benefit from the CAM method they used at all. Apart from that, the participants generally benefited from the CAM method they used. No one reported any damage. These findings were consistent with the literature (7). In addition, studies have reported that those who use alternative treatment methods have a

longer disease duration, higher disease burden and higher socioeconomic status (34). Our results did not differ significantly between the patients using CAM and those who did not use CAM in terms of symptom duration, pain level and disease severity. Socioeconomic status was similar in both groups and was low.

Although the strength of our study is that it is the first study investigating the relationship between CAM use and HL in patients with fibromyalgia, this study has some limitations. This study was conducted in a single center tertiary hospital. Prospective population-based studies can be recommended because patients visiting hospitals may have different levels of HL and CAM usage compared with those who do not visit hospitals.

## CONCLUSION

The results of our study showed that the use of CAM was common among women with FMS, and spiritual methods were the leading methods. In addition, disease severity and health literacy levels were similar in both groups when CAM users were compared with those who did not use CAM.

Patients with FMS tend to use CAM for treatment. Studies on CAM options are also increasing day by day (2). Making informed decisions about the use of CAM will ensure that the path to the treatment goal is correct and shorter. For this reason, we believe that possible mechanisms for the relationship between HL and CAM among patients with FMS should be investigated, as well as the factors affecting the

choice of CAM, and HL should be further developed.

Etik: Bu çalışmanın etik kurulu alınmıştır (2011-KAEK-25 2018 / 04-09).

Ethics committee approval had been taken (2011-KAEK-25 2018/04-09).

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Author contribution status; The concept of the study; İAK, MKA, HD, DAT design; İAK, MKA, HD, DAT literature review; İAK, MKA, HD, DAT collecting and processing data; İAK, MKA, HD, DAT statistics; İAK, MKA, HD, DAT writing phase; İAK, MKA, HD, DAT

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