Use of complementary and alternative medicine among people with multiple sclerosis in Eastern Turkey

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Abstract

*Objective:*The purpose of this study was to examine the use of complementary and alternative medicine (CAM) in patients with multiple sclerosis (MS) living in eastern Turkey as well as the factors affecting the use of CAM modalities. *Methods:*This is a descriptive and cross-sectional study. Data were obtained from 130 patients with MS at the neurology clinics of Ataturk University. *Results:* Out of all patients surveyed, 61.5% reported use of at least one form of CAM. The most common three modalities used by these patients were herbs taken orally, relaxation therapies and prayer, with rates of 55.5%, 26.3% and 18.8%, respectively.Massage and relaxation therapies were perceived as very effective by more than half of study participants.It was determined that variables such as education level, residential area and duration of disease affected the use of CAM (P < .05).
Conclusions: CAM therapy is widely used by patients with MS in eastern Turkey.

INTRODUCTION

Multiple Sclerosis (MS) is a relapsing or progressive neurological disease with an unknown etiology and only partially effective treatment.[1] In industrialised countries, prevalence rates vary between 15–145 per 100,000.[2] It is estimated that the prevalence of MS in Turkey is about 30–40 in 100,000, and the total number of MS patients is 35,000.[3] People with MS may experience a variety of symptoms, including paraesthesia, ataxia, spasticity, paralysis, fatigue, pain, visual disorders, lack of coordination, tremors, bowel problems, bladder and sexual dysfunction and visual disorders.[4] Currently, there is no cure for MS. However, treatments to slow the progress of the disease and control MS symptoms are available.[5,6] Conventional MS treatments are limited, and many have significant adverse effects[7], prompting the increased use of complementary and alternative medicine (CAM) among MS patients.[8-11]

According to the National Center for Complementary and Alternative Medicine (NCCIH), "complementary" generally refers to using a nonmainstream approach together with conventional medicine, while "alternative" refers to using a nonmainstream approach in place of conventional medicine.[12] The two major categories of CAM include natural products (such as herbs, botanicals and probiotics) and mind and body interventions (such as massage therapy, meditation, relaxation techniques, exercises and traditional Chinese medicine).[12]

The use of CAM treatments has been increasing among people with MS during the last 15 years.[13] The literature reports the prevalence of CAM therapy use in MS varies from 33% to 80%.[8–11,14,15] The largest study was conducted in the U.S. by Nayak *et al*. (n = 3140),[9] which found that 64.9% of individuals with MS used at least one CAM. Other smaller studies conducted in Italy[10], Australia[14] and Spain[15] reported that 35.7%, 67.4% and 40.9% of MS respondents used at least one CAM, respectively. An unknown number of patients with MS in Turkey are using CAM products or practices. There have been different studies on the use of CAM in eastern Turkey. These studies report frequent use of CAM among adult (70%)[16], older adult female (48.3%)[17] and cancer patients (41.1%).[18]

The CAM methods used might vary according to geographical area and culture. For example, the rate of the use of prayer to improve MS symptoms in the U.S. is consistently reported to be much higher than in the Europe.[9] Traditional Chinese medicine consists of herbal medicines and other forms of treatment, including acupuncture, massage (Tuina), exercise (qigong) and dietary therapy.[12] CAM practices have been widespread in Anatolia for centuries and remain so in modern times. This CAM practices cover a wide spectrum ranging from herbal prescriptions to

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religious practices.[19] The six most used CAM therapies in MS include reflexology, massage, yoga, relaxation, meditation, aromatherapy, and acupuncture.[20]

Patient characteristics that are predictive of CAM use in MS are reported to be similar to those reported in the general population and include female gender, high education, high income, long MS duration and low self-assessed state of health.[9,11,21–24] However, these results are not entirely consistent in terms of age, MS duration and self-assessed state of health.

Health care professionals need to know about the use of CAM by patients with MS so that they can determine whether patients are using CAM therapies that may interact negatively with mainstream treatments. Of significant concern is the safety of CAM methods and practices. Because many patients with MS are using CAM therapies, health care professionals must be knowledgeable about their use. However, the frequency and patterns of the use of CAM therapies by patients with MS in eastern Turkey is largely unknown.

The aims of this study were (a) to determine the prevalence of CAM use among patients with MS, (b) to determine the types of CAM used, (c) to describe sociodemographic and medical factors associated with the use of CAM (d) and to assess the perceived effectiveness of CAM in eastern Turkey.

METHODS

This cross-sectional and descriptive study was performed on patients with MS who were admitted to the neurology clinics of Ataturk University Hospital in the city of Erzurum in Turkey between October, 2013 and June, 2014. The research sample comprised patients with MS meeting the research inclusion criteria selected through convenience sampling technique and 140 of them were contacted but only 130 of them responded to the questionnaire. Ten MS patients did not participate because they were busy or unwilling.

Inclusion criteria were as follows: (a) being followed at a neurology outpatient unit with an MS diagnosis, (b) aged 18 years or older, (c) able to speak, understand and communicate verbally in Turkish, (d) having been diagnosed with MS at least six months previously and (e) volunteering to participate in the research. The patients with MS were selected according to the Poser criteria or the McDonald diagnostic criteria.[25,26]

Questionnaire

A semi-structured questionnaire was developed to collect sociodemographic variables, disease variables and aspects of the use of CAM. The questionnaire was developed by the researchers after a review of related literature.[9,11,22,24] Face validity for the questionnaire was determined by researchers and was pilot tested with ten MS patients to estimate the time needed for administration and to test for clarity and logical flow. No changes were needed after pilot testing.

The questionnaire was divided into three sections, the first of which was related to the patients' sociodemographic characteristics, such as age, sex, education, marital status and income level. Participants' income level was described as income > expenditure, income = expenditure or income < expenditure using the subject's self-report.

The second section of the questionnaire covered disease related characteristics, such as type of MS, duration of illness and classification on the Expanded Disability Status Scale (EDSS). MS type and EDSS information were derived from patients' records and medical files.

The third section of the questionnaire asked patients whether or not they used any form of CAM. Patients were asked whether they had ever used or were using any of the following CAM therapies: acupuncture, aromatherapy, herbal medicine, nutritional supplements, exercise, relaxation therapies (including relaxation, hypnosis, meditation, yoga and biofeedback), imagery, massage therapy, prayer, homoeopathy, energy healing (including reiki) or other CAM methods mentioned by the participants. Classification of the CAM categories was based on the CAM classification of the NCCIH.[16] After the participants were asked to describe the types of CAM they used, other questions regarding reasons for use, how the CAM was used, sources of information about CAM, anticipated benefits, CAM user satisfaction and communication about CAM use with physicians or nurses were also asked.

Expanded Disability Status Scale (EDSS)

The EDSS is the standard measure of disease progression and the degree of neurological impairment in clinical practice and clinical trials. The EDSS divides functioning into eight functional systems: pyramidal, cerebellar, brainstem, cerebral, bowel and bladder, sensory, visual and other; impairment in each system is

graded and then summed across the eight systems. The EDSS measures the extent of neurological deficit, with higher scores indicating a greater deficit. Scores for the total scale can range from zero (no neurological abnormality) to 10 (death from MS). It describes the progression of MS and changes in the performance of the primary motor functions. The EDSS score preferentially reflects the function of the lower extremities. According to this scale, a person with a score of four or less has no difficulties in walking, whereas patients with a higher score (4.5–6.5) are limited in their ability to walk or may be unable to walk (> 7.0).[27]

This study was approved by the Ethical Board of Ataturk University. Patients were verbally informed and their consent was obtained. The individuals who participated in the research were informed that they could withdraw from the study any time they wished. Individuals to be included in the research were assured of the confidentially of their personal information, and the confidentially principle was observed.

The researchers visited the Neurology Policlinic for five working days every week. The questionnaire and EDSS were explained to the participants, who then read it and marked their answers. All participants were also assured that their answers with regard to CAM use would not affect their future care and would not be used for purposes other than scientific research. The questionnaire took approximately 15 minutes to complete and could be understood by patients with minimal reading ability. Patients completed the questionnaire in a isolated, quiet room of the Neurology Policlinic to ensure that they correctly understood items in the questionnaire. All of the patients found the questionnaire understandable and easy to complete.

Questionnaire responses were analysed using the Statistical Package for the Social Sciences (SPSS), version 18.0. Frequency, percentage and other descriptive statistics were used to describe and summaries data. Chi-square tests and Student's t test were used to examine relationships between participants' demographics/health-related factors and use of CAM. P < 0.05 was accepted as the level of prespecified statistical significance.

RESULTS

When we compared socio-demographic and clinical characteristics of CAM users and non-CAM users, there were no significant differences between the two groups in terms of age, gender, marital status, occupation, income level, type of MS or severity of MS. There were significant differences between users and non-users of CAM in terms of education level (P = 0.043), residential area (P = 0.026) and duration of disease (P = 0.002) (Table 1).

Data on CAM usage are shown in Table 2. In this study, the prevalence of CAM use was 61.5% (n= 80). The patients using CAM reported that they had most frequently heard about CAM from family members (31.3%, n = 25), media or internet reports (28.8%, n = 23), friends (22.5%, n = 18) and health professionals (17.5%, n = 14). Out of all patients, 56.3% stated that they did not inform their nurse or physician about their use of CAM.

Of the 80 (61.5%) patients who reported use of at least one form of CAM, most of the CAM users were using herbs. Of the 80 CAM users, 44 (55.0%) used herbal therapies, 21 (26.3%) used relaxation therapies, 15 (18.8%) used praying, 11 (13.8%) used massage therapies and nutritional supplements (fish oil or honey), 8(10.0%) used exercises and 6(7.5%) used spa treatments. More than half of the CAM users (55.0%) were using herbal therapies. Almost all the herbs (96.3%) were taken orally (only 3patients [3.7%] used herbs externally, as a pomade) (Table 3).

Perceived benefits of CAM usage are also shown (Table 3). This table demonstrates that massage had the highest rates of perceived efficacy (63.6%, n = 7; vs. 9.1%, n = 1), followed by relaxation therapies (52.4%, n = 11; vs. 9.5%, n = 2) and praying (40.0%, n = 6). In this study, 66.7% of patients using thermal springs reported them to be ineffective.

Among the patients using herbs, 27.3% used St. John's wort, 22.7% used ginseng, 20.5% used bee pollen, 18.2% used capparisspinoza and evening primrose, 13.6% used wheat, 11.4% used stinging nettle, 9.1% used black cummin and soybean, 6.8% used French lavender and 4.5% used echinacea and horsetail (Table 4).

As reported in Figure 1, the most common benefits that CAM users experienced were reduced fatigue (75%), improved sleep (58%) and improved in decreased function (44%), reduced depression (30%), pain reduction (28%), improved memory (23%) and healing of infections (15%).

Patients gave the following main reasons for using CAM: it improves quality of life (70%), it fits my lifestyle (40%), it is easier to access than traditional medicine (26.3%), it is less expensive (22.5%) and other (3.8%). Other reasons for using CAM included curiosity and to treat incurable disease (Figure 2).

Table 1: Demographic and disease-related characteristics of users and non-users of CAM therapy (N=130)

Characteristics	CAM Users n (%) n= 80	Non-users n (%) n= 50	p (t- or X^2-test)
Demographic factors			
Age (mean ± SD)	(36.40±10.25)	(35.84 ±13.77)	t= 0.297 P=0.767
Gender			
Female	57 (71.3)	36 (72.0)	X^2= 0.009
Male	23 (28.7)	14 (28.0)	P=0.927
Marital status			
Married	52 (65.0)	36 (72.0)	X^2= 0.689
Unmarried	28 (35.0)	14 (28.0)	P=0.406
Education level			
Primary school	42 (52.5)	36 (72.0)	X^2= 6.311
Secondary school	24 (30.0)	6 (12.0)	**P= 0.043**
High school/University	14 (17.5)	8 (16.0)	
Residential area			
City center	54 (67.5)	22 (44.0)	
Town	15 (18.8)	14 (28.0)	X^2= 7.336
Village	11 (13.7)	14 (28.0)	**P=0.026**
Occupation			
Unemployed	56 (70.0)	38 (76.0)	X^2= 0.553
Occupied	24 (30.0)	12 (24.0)	P=0.457
İncome level			
Income > expenditure	13 (16.3)	8 (16.0)	X^2= 0.020
Income = expenditure	36 (45.0)	22 (44.0)	P=0.990
Income < expenditure	31 (38.8)	20 (40.0)	
Health-related factors			
Type of MS			
Relapsing—remitting	57 (71.3)	36 (72.0)	X^2= 1.118
Primary progressive	6 (7.5)	6 (12.0)	P=0.572
Secondary progressive	17 (21.3)	8 (16.0)	
Duration of disease			
< 2 years	10 (12.5)	19 (38.0)	
3–7 years	32 (40.0)	20 (40.0)	X^2= 14.618
8–12 years	25 (31.3)	6 (12.0)	**P=0.002**
> 12 years	13 (16.2)	5 (10.0)	
Severity of MS (EDSS)			
None/mild (0-3)	33 (41.2)	28 (56.0)	
Moderate (3-5)	31 (38.8)	11 (22.0)	X^2 = 4.158
Severe (>5)	16 (20.0)	11 (22.0)	P=0.125

CAM, complementary and alternative medicine.

Table 2: CAM therapies used by patients with MS

Variable	Percent (n)
Patients using CAM	61.5 (80)
Patients non-using CAM	38.5 (50)
Source of information about CAM	**Percent (n)***
Family members	31.3 (25)
Media or Internet	28.8 (23)
Friends	22.5 (18)
Health professionals	17.5 (14)
Discussed with nurse/physician	**Percent (n)***
Yes	43.8 (35)
No	56.3 (45)

CAM, complementary and alternative medicine.
*Percentage was taken based on total number of 80.

DISCUSSION

The use of CAM has become increasingly popular, particularly among MS patients[9], and the methods used might vary according to geographical areas and culture.[28] A high rate of CAM use (61.5%) was found in this study population, endorsing a similar trend of CAM use throughout the world,[8,9,14] as well as in Turkey.[16-18] The popularity of CAM highlighted by recent studies indicates a patient preference for holistic approaches over traditional health care. Also, this finding can be attributed to the dominance of CAM practices and to "the traditional society" structure in Anatolia.

We found significant differences in terms of level of education, place of residence and duration of disease between CAM users and non-users. The findings of this study showed that the rate

Table 3: Types and CAM used, perception of CAM benefit

Types of CAM	Use of this type of CAM Percent (n)*	Perception of CAM Benefit		
		Very Effective Percent (n)**	Somewhat effective Percent (n)**	Ineffective Percent (n)**
Plant/herbal supplements	55.0 (44)	27.3 (12)	50.0 (22)	22.7 (10)
Relaxation therapies	26.3 (21)	52.4 (11)	38.1 (8)	9.5 (2)
Prayer / spiritual practice (Resorting to a hodja, wearing an amulet, praying, etc)	18.8 (15)	40.0 (6)	60.0 (9)	-
Massage	13.8 (11)	63.6 (7)	27.3 (3)	9.1 (1)
Nutritional Supplements (Fish oil, honey)	13.8 (11)	-	63.6 (7)	36.4 (4)
Exercises	10.0 (8)	37.5 (3)	37.5 (3)	25.0 (2)
Spa (Thermal water, baths)	7.5 (6)	-	33.3 (2)	66.7 (4)

CAM, complementary and alternative medicine.
Percentage is calculated based on total number of 80. *More than one answer. **Percentage is based on total number using the particular therapy
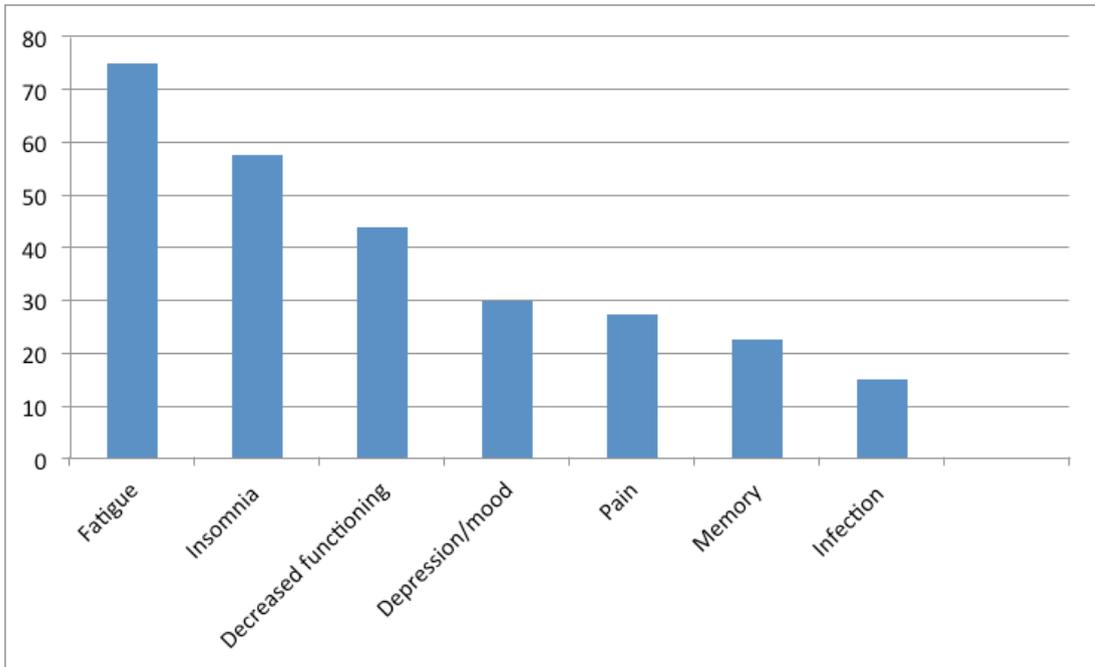
Figüre 1: Symptom relieffor using CAM interventions in MS (n = 80).
        Percentages add up to more than 100% because more than one target symptom could be chosen.

of CAM use was higher in MS patients with less education. However, contrary to our observations, some studies have found higher education to be associated with CAM usage.[9,14] Future studies are needed to clarify this discrepancy.

Respondents' places of residence were found to influence the use of CAM. Patients living in city centre areas were more likely than those living in rural areas to use CAM. This result is supported by the findings of Barnes *et al*.[29], Ock*et al*.[30] and Fox *et al*.[31]

In the present study, there was a significant relationship between duration of disease and CAM use. The results are consistent with the previously reported association between CAM use and long MS duration among people with MS.[8,9,24,32] As a result, it is not surprising that patients are more likely to have learned about CAM through the
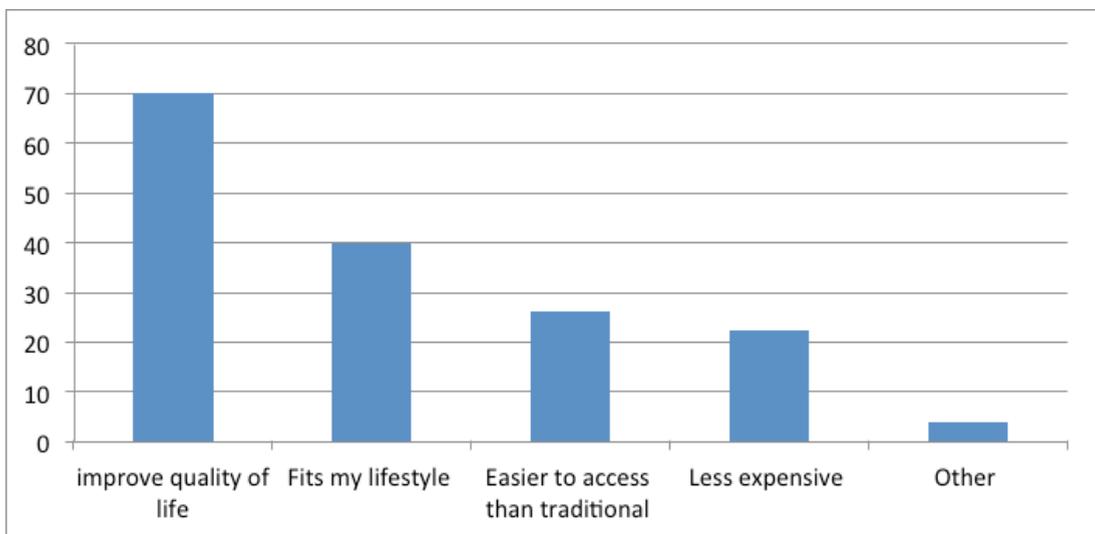

Figüre 2: Reasons for using CAM interventions in MS (n = 80).
        Percentages add up to more than 100% because more than one target symptom could be chosen.

prolonged process of MS treatment.

The literature suggests that there may be a typical profile of CAM user, with middle-aged, high income and female patients being commonly reported.[33,34] However, in the present study, when comparing CAM users and non-users, there were no statistically significant differences in terms of age, gender, marital status, occupation, income level, type of MS or severity of MS. In contrast to the findings of Sastre-Garriga et al.[15], we did not find any relationship between higher EDSS scores and the use of CAM. This conflicting evidence might be due to differences in the beliefs, values and cultural features of the communities included in the studies.

The most frequent sources of information about CAM (family members and media or the internet) are similar to those reported by Leong et al.[14] and Page et al.[35] We found that only 43.8% of patients using CAM had informed their health care professionals. Only 15.3% in Nayak's study[9] indicated that their physician recommended CAM treatment. There are other studies in which the majority of respondents have been found not to have informed their physican about their use of CAM.[36,37] It is probable that patients do not reveal CAM use to conventional health professionals because of fear of negative feedback.

Herbal therapy, relaxation therapy, praying, massage and exercise were the five most commonly used CAM modalities, with prevalences ranging from 10.0%–55%. The CAM method most commonly used by patients with MS was herbal therapy. This finding was consistent with those of other studies.[9,38,39] According to the results of this study, a high rate of herbal medicine use may be due to several factors. First, there is a rich variety of herbs and plants in Turkey. Therefore, it is easy to obtain them. Second, a common belief among patients is that natural products are safe because of their 'naturalness'.

The herbal supplement most commonly used by MS patients in our study was St. John's wort (27.3%), followed by ginseng and bee pollen. St. John's wort was also used frequently in other studies.[14,40] St. John's wort is frequently used in potentially dangerous combinations. Potential herbal supplement interactions with commonly used prescription drugs in MS have also been identified. Health professionals should be aware of these common interactions and warn patients appropriately.[41]

The second most common CAM method was relaxation therapy. Our population had a high rate of relaxation therapy usage, similar to that reported by Apel et al.[8] and Kochs et al.[42] Application of relaxation techniques has recently become an integral part of the care of individuals with chronic disease due to its benefits, such as reducing anxiety and stress, distracting attention away from pain, relieving muscle strain and contractions, facilitating sleep and reducing sensitivity to fatigue and pain.[43]

That the third most common CAM method is prayer is not surprising in Turkey, where an estimated 99% of people are Muslims. Our population had a high usage of prayer similar to that reported by Nayak et al.[9] CAM therapies might be attractive for patients because they are perceived as more congruent with patients' spiritual values and beliefs regarding the nature of health and illness.[44] The effects of prayer might have simply taken place at the psychological or emotional levels by reducing stress, a factor known to exacerbate MS symptoms. Therefore, health professionals should avoid categorical rejection of this modality of CAM treatment.

In this study, massage (about 64%) and relaxation exercises (about 52%) were considered more effective than other CAM therapies. Massage appears to be a promising treatment for MS in terms of improving psychological wellbeing.[45] Page et al.[35] reported that 72% of their respondents perceived positive effects from CAM, whereas 5% reported experiencing negative effects from CAM. The most often cited beneficial therapies were massage therapy and acupuncture. Reflexology may also be of benefit in treating physical symptoms of MS.[46] Studies available in the literature report a high prevalence of fatigue and sleep problems among patients with MS and the benefits of relaxation, such as facilitating sleep[47,48] and reducing fatigue.[20,47]

The most common benefits that CAM users experienced were reduced fatigue, improved sleep and functions, reduction of depression and pain, improved memory and healing of infections. These findings are similar to those found in earlier studies.[9,22] For example, pain reduction, greater relaxation (addressing the symptoms of stress) and reduction of fatigue were the most frequently listed benefits experienced in the U.S. study of Nayak et al.[9]

The most common reason that patients gave for using CAM is that it improves quality of life. It was found that 70% of the respondents stated that their life quality was improved by alternative therapies. These findings are similar to those found in earlier studies.[46,49,50]

The second most common reason for the

use of CAM was congruence with the patient's lifestyle. This result is in accordance with the results of previous research.[51] A recent study that compared several potential explanations of CAM use, including dissatisfaction with the effectiveness of traditional medicine and philosophical congruence, found that values and attitudes were much stronger predictors of CAM use than dissatisfaction.[52]

The study limitations were firstly side effects experienced by the patients, for whom CAM was used, were no examined in this study. Statistical interpretation of the results was difficult due to the small sample. In addition, although the results may be generalised to the sample group in this study, the sample in this study reflects only one area of Turkey. Therefore, the findings cannot be generalised to all MS patients in Turkey. Future studies should include larger samples from different regions in Turkey.

In conclusion, many patients with MS in eastern Turkey use CAM therapies.Most patients with MS commonly used CAM therapy among them is herbal medicine. Usage of these interventions was higher in those with primary education, living in the city centre and longer duration of MS. Family members, media, friends and health professionals are significant sources of information about CAM. Healthcare providers should routinely ask their patients about CAM use and discuss the positive and negative results of CAM use with them. Also, because of the high prevalence of the use of CAM therapies among patients with MS, healthcare providers dealing with MS treatment should increase their knowledge about these therapies. Informing the patients is an essential intervention to prevent adverse effects and negative outcomes that can result from the use of CAM modalities.

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DISCLOSURE

Conflict of interest: None

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