Is non-traditional therapy for multiple sclerosis overwhelming in Saudi Arabia

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ABSTRACT

الأهداف: وصف مدى انتشار والمعرفة ومواقف استخدام الطب البديل والتكميلي (CAM) ونسبة من يلتمس المشورة من طبيبه حول استخدام CAM.

الطريقة: أجريت هذه الدراسة المقطعية المستعرضة في عيادة مرض التصلب العصبي المتعدد (MS) في مستشفى الملك فهد بجامعة الخبر، المملكة العربية السعودية خلال الفترة من يناير إلى يونيو 2017م. أكمل 133 مريض المسح.

النتائج: بلغ متوسط عمر المرضى 5.2±32.3 عام و84 (63.2 %) إناث. أفاد حوالي %83.5 من المرضى استخدام CAM. من بين جميع أنواع CAM المبلغ عنها، كانت الفيتامينات هي الشكل الأكثر انتشارًا، تليها الحجامة، والصلاة الخاصة والتأمل. غالبية المرضى (62%) حصلوا على معرفة بCAM من خلال وسائل التواصل الاجتماعي. لم يكشف عدد كبير من المرضى (%75.6) عن استخدام الطب البديل والتكميلي. كان هناك اتجاه لاستخدام CAM أكثر في المرضى المتعلمين تعليماً عالياً، وكبار السن، والنساء. كان السبب المنطقي الأكثر شيوعًا لاستخدام CAM هو التحسن العام في الحالة الصحية.

الخاتمة: إن استخدام الطب البديل والتكميلي بين المرضى السعوديين المصابين بمرض التصلب العصبي المتعدد منتشر للغاية، دون الكشف عن استخدامه للأطباء. ينبغي أن تؤخذ هذه العوامل في الاعتبار في استشارة الطبيب والمريض لتجنب الأحداث السلبية.

Objectives: To describe the prevalence, knowledge and attitudes about complementary and alternative medicine (CAM) use and the proportion that seek advice from their physician about CAM use.

Methods: This cross-sectional observational study was performed in multiple sclerosis (MS) clinic of King Fahd Hospital of Universityin Alkhobar, Kingdom of

Saudi Arabia from January-June 2017. A total of 133 patients have completed the survey.

Results: The mean age of patients was 32.3±7.6 years and 84 (63.2 %) were female. Approximately 83.5% of the patients reported the use of CAM. Among all the reported forms of CAM, vitamins were the most prevalent form, followed by cupping, special prayers and meditation. The majority of patients (62%) obtained knowledge of CAM through social media. A significant number of patients (75.6%) did not disclose the use of CAM to their physician. There was a trend for using CAM more in highly educated, older age, and female patients. The most commonly reported rationale to use CAM was overall improvement in health status.

Conclusion: The use of CAM among Saudi patients with MS is highly prevalent, without disclosure of its use to physicians. These factors should be taken into account in the doctor-patient consultation to avoid adverse events.

> Neurosciences 2019; Vol. 24 (3): 192-198 doi: 10.17712/nsj.2019.3.20180010

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Received 29th September 2018. Accepted 6th March 2019.

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ultiple sclerosis (MS) is a chronic neurological Madisorder, typified by a relapsing and progressive course of symptoms, resulting in long-term severe



disability. Multiple sclerosis was thought to be uncommon in Kingdom of Saudi Arabia, but the prevalence of MS is increasing in the Gulf region, particularly in Kingdom of Saudi Arabia, and the latest prevalence estimates are 40/100,000 in 2008.^{1,2} These increasing numbers of MS patients represent a challenge to provide treatment, health promotion, employment, and rehabilitation for severely disabled patients.³ The etiology of MS is still unknown. Multiple sclerosis patients face many challenges in their daily routine life, like other patients suffering from chronic diseases. Treatment for MS is not curative, though many disease modifying drugs (DMDs) are available with United States of America's Food and Drug Administration (FDA) approval; the available treatment options for MS often have several adverse side effects and a very high cost. Therefore, MS patients turn to CAM with the hope to cure their MS, minimizing the relapses and treating their symptoms, even though the efficacy may not be established. Complementary and alternative medicine is defined as "a group of diverse medical and health-care systems, practices and products that are not presently considered to be part of conventional modern medicine".1

There is a worldwide interest in CAM. Its use ranges from 9-70% of the total population, despite insufficient scientific evidence for its use.⁴ Complementary and alternative medicine is popular among patients as well as healthy individuals.⁴ There are variations in CAM practices between countries, which depend on their traditions and the prevalence of diseases. Also, the methods that are used in different studies differ.^{4,5}

Patients suffering from MS are significant users of CAM. The prevalence of CAM use among MS patients has been reported in several studies, with a wide range of prevalence between 33-70%. Knowledge about CAM practices and the prevalence in MS patients in Arab countries is limited. To document the influence of psychosocial, religious and cultural factors on health beliefs and behaviors in Kingdom of Saudi Arabia, having a religious background, studying CAM is of utmost importance. Health care facilities are free for the nationals in Kingdom of Saudi Arabia and provided by The Ministry of Health, but the ministry does not cover CAM. However, a center for CAM was established by a ministerial decree (No. 236) on 10/8/1429 H (12/8/2008 G). This center, being a reference center for

Disclosure. Authors have no conflict of interests, and the work was not supported or funded by any drug company.

CAM and related issues, has the objectives to monitor the CAM practices among different health care services and to regulate them using evidence-based support. In a 2015 publication, Kingdom of Saudi Arabia was ranked very high in scientific research related to CAM among all Arab countries. This highlights the importance of CAM-related research in Kingdom of Saudi Arabia to document how their different psychosocial, cultural and religious background can influence the use of CAM and to see the effects on their health beliefs and attitudes.

We aimed to determine the prevalence of CAM use among MS patients in Kingdom of Saudi Arabia, as well as to document their knowledge and behaviors concerning CAM, the used types and the reasons behind them and the frequency of the patients disclosing the use of CAM to their physician. We also wanted to determine any association of demographic characteristics, health behaviors and health status with CAM use and disclosure.

Methods. This was a cross-sectional hospital-based, observational study conducted in the MS clinic of King Fahd Hospital, Imam Abdul Rahman bin Faisal University in Kingdom of Saudi Arabia. Patients with a confirmed diagnosis of MS were consecutively selected in MS clinic during their scheduled follow-up to participate in the study, after signing an informed consent and completing all the questions in the survey. They were also asked about the details of the active treatment for MS. Inclusion criteria was the following: all the patients with a confirmed diagnosis of MS, both male and female, age ≥14 years, were included in the study. 11 Exclusion criteria was the following: any patient aged <14 years or with any other chronic neurologic disease was excluded. The study was approved by the Imam Abdulrahman Bin Faisal University Institution Review Board, Kingdom of Saudi Arabia. The questionnaire was validated by content validation; in which other coauthors have discussed the questions asked to the patients and it was concluded that the questionnaire is well understood and easy to administer to patients. The participants were consecutively selected in MS clinic during their scheduled follow-up. A physician asked these questions to the patients who accepted to participate. The patients who found to have exclusion criteria were not included in the study. The main outcome measures were: patterns of CAM use; patient's knowledge and attitude about CAM use; and their willingness to disclose use of CAM to their physicians in order to avoid any harmful effects from any CAM.

We divided the questionnaire into 3 categories: demographic data (age, gender, marital status, education

level and job status); specific characteristics of the patient's disease; and details about the DMDs therapies used (mind body medicine); dietary interventions including vitamins and minerals; special dietary patterns (namely, goat milk, salt-free, fat-free diets); and special religious tasks, like cupping (Hejama), prayers or Quran recitation for at least 6 consecutive months. Calculated sample size was 109 cases (but we included 133 cases).

Data collection was started. The collected data was inserted into Excel, transferred into Statistical Package for Social Science (SPSS) and then cleaned for errors and analyzed by using the SPSS version 20 (IBM Corp., Armonk, NY, USA). Descriptive statistics were performed in the form of frequency tables, means and standard deviations. All categorical variables are presented as frequencies and percentages. Quantitative variables are presented as average and standard deviation. Chi-square test for nonmetric associations was used to check the association between CAM use and gender, age groups, educational level, disease duration and extended disability status scale (EDSS). Association between disclosure of CAM and gender, age groups, marital status and EDSS was also checked by chi-square test. Association was considered significant if the *p*<0.05.

Results. A total of 133 out of 162 patients completed the survey; 49 (36.8%) were male and 84 (63.2%) were female. Age ranged from 18-56, with a mean age of 32.3±7.6 years; most of the patients were over 30 (61.7%). The majority were Saudi national (88%) and 46.6% were married. Commonly used medicines were Interferon Beta 1a, which was used as subcutaneous injections. The patients' educational levels varied from illiterate (n=5, 3.8%) to higher education degrees (n=93, 69.9%). Demographic characteristics are presented in Table 1. Out of 133 patients who completed the survey; 111 (83.5%) patients used at least one type of CAM in the past 6 months. Table 2 shows the frequency and percentage of CAM users with and without conventional treatment. The most common methods of CAM use are presented in Table 3. Among all the reported forms of CAM, vitamins were the most prevalent form (n=25, 22.5%), followed by cupping/Hejama in 23 patients (20.7%), recitation of Holy Quran/special prayers in 18 patients (16.2%), meditation in 14 (12.6%), special dietary patterns in 8 (7.2%), bee venom in 7 (6.3%) and going to a religious scholar in 6 patients (5.4%). The least commonly used methods were yoga, acupuncture, sound therapy and reflexology.

The relapsing form of MS (RMS) was the most prevalent type of MS (82%) among the patients

Table 1 - Clinical and demographic characteristics of cases with MS (N=133).

Characteristics	n (%)		
Gender			
Male	49 (36.8)		
Female	84 (63.2)		
Age (years) Mean±SD	32.3±7.6 (18-56)		
<30	51 (38.3)		
≥30	82 (61.7)		
Marital status			
Married	62 (46.6)		
Unmarried	71 (53.4)		
Educational level			
No education	5 (3.8)		
Elementary	2 (1.5)		
Middle	5 (3.8)		
High	28 (21)		
Graduate	93 (69.9)		
Occupation			
Job	71 (53.4)		
Business	1 (0.8)		
Household	18 (13.5)		
Student	17 (12.8)		
Jobless	25 (18.8)		
Diagnosis			
RRMS	110 (82.7)		
PPMS	16 (12)		
SPMS	3 (2.3)		
CIS	1 (0.8)		
Disease duration			
>10 years	62 (45.9)		
5-10 years	45 (33.8)		
<5 years	25 (18.8)		
EDSS			
<2.5	51 (38.3)		
2.5-4.5	68 (51.1)		
>4.510	14 (10.5)		

MS - multiple sclerosis, SD - standard deviation, RRMS - Relapsing remitting multiple Sclerosis, PPMS - Primary progressive multiple sclerosis, SPMS - Secondary progressive multiple sclerosis, CIS - clinically isolated syndrome, EDSS - extended disability status scale

Table 2 - The CAM use with and without conventional treatment.

Variables	n (%)
CAM used only	18 (20)
CAM use with conventional treatments	81.98 (91)
Total	100 (111)
CAM - complementary and alter	native medicine

surveyed. Social media was found to be the major source of information (62%), while friends/family members (18.9%), other physicians (15%) and television/radio (3.6%) were less common sources of information. Regarding the perception assessment, 43.2% felt they participated in their disease management, some had inspiration from successful stories (22.5%), some

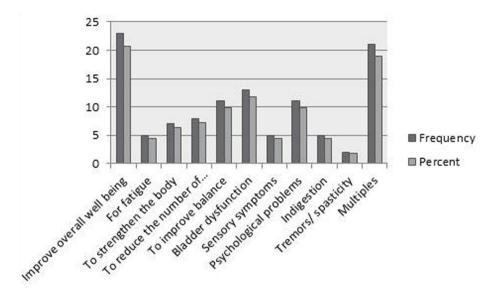


Figure 1 - Specific symptoms to be addressed by complementary and alternative medicine (CAM).

thought that conventional treatment was not effective in controlling their disease (12.6%), while approximately 12.6% of patients just got recommendations for CAM from non-physicians. The main reasons to use CAM, as presented in Figure 1, were to improve overall health (20.7%), followed by treatment for bladder dysfunction (11.7%) and improving balance and for psychological problems (9.9% each). Other less common symptoms addressed by CAM were fatigue, indigestion, sensory symptoms, tremors and spasticity. Complementary and alternative medicine was also used to reduce the number of relapses (7.2%). Nineteen percent of the patients were using CAM for more than one symptom. As presented in Table 4, the prevalence of CAM use did not differ between different genders (p=0.67), age groups (p=0.87), educational levels (p=0.75), disease duration (p=0.30), or their disability status (p=0.31). Motivations for the use of CAM differed, and approximately 43% of patients felt that active participation in disease management while using CAM was important, while some used it based on inspiration from successful stories of other patients. Regarding the perception of developing MS, a majority had no idea, a few attributed it to the evil eye, to lifestyle and bad habits, and approximately 5.3% viewed it as a punishment from God. The majority of patients (53%) did not disclose the use of CAM to their physician. Regarding disclosure of CAM to the primary physician, older (p=0.43), female patients (p=0.19), or with higher EDSS were found less likely to disclose (p=0.31), though this result is not statistically significant (Table 5).

Discussion. Our study identified a high proportion of CAM use in patients with MS; approximately 83% of the patients had used at least one type of CAM during the previous 6 months. This trend of using CAM by the MS patients is probably provoked by the chronic, disabling nature of the disease as well as due to the low number of accessible treatment options. These findings show a much higher percentage of CAM use in patients with MS from Kingdom of Saudi Arabia as compared to similar studies carried out for CAM use among MS patients elsewhere.^{6,12} The current study

Table 3 - Modes of CAM used by patients.

Variables	n (%)
Relaxation therapy/meditation	14 (12.6)
Support groups	1 (0.9)
Sound therapy	2 (1.8)
Cognitive-behavioral therapy/psychological	1 (0.9)
Yoga	1 (0.9)
Reflexology	2 (1.8)
Vitamins and minerals	25 (22.5)
Special dietary pattern (goat milk, salt-free, fat-free gluten free, camel milk)	8 (7.2)
Energy medicine	1 (0.9)
Others	
Cupping (Hejama)	23 (20.7)
Acupuncture	2 (1.8)
Bee venom	7 (6.3)
prayers	18 (16.2)
Going to Sheikh	6 (5.4)

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Table 4 - Association of CAM use.

Characteristics	CAM use		P-value	
	Yes	No		
	n (%)			
Gender				
Male	40 (36)	9 (40.9)	0.67	
Female	71 (64)	13 (59.1)	0.67	
Age (years)				
<30	42 (37.8)	8 (36.4)	0.07	
≥30	68 (62.2)	14 (63.6)	0.87	
Educational level				
No education	4 (3.6)	1 (4.5)		
Elementary	2 (1.8)	0		
Middle	5 (4.5)	0	0.75	
High school	22 (19.8)	6 (27.3)		
Graduate/PG	78 (70.3)	15 (68.2)		
Disease duration				
>10 years	47 (42.3)	14 (63.6)		
5-10 years	39 (35.1)	6 (27.3)	0.32	
<5 year	23 (20.7)	2 (9.1)		
EDSS				
<2.5	45 (40.5)	6 (27.3)		
2.5-4.5	56 (50.5)	12 (54.5)	0.31	
>4.5	10 (9)	4 (18.2)		

CAM - complementary and alternative medicine, EDSS - extended disability status scale.

Table 5 - Associations of CAM disclosure.

Characteristics	Discl		P-value	
	Willing to tell only family members/friends	Willing to tell physicians	Not willing at all	
		n (%)		
Gender				
Male Female	7 (26.9) 19 (73.1)	24 (46.2) 28 (53.8)	9 (28.1) 23 (71.9)	0.19
Age (years)				
<30 >30	12 (46.2) 14 (53.8)	16 (31.4) 35 (68.6)	14 (43.8) 18 (56.2)	0.43
Marital status				
Married Unmarried EDSS	10 (38.5) 16 (61.5)	26 (50) 26 (50)	17 (53.1) 15 (46.9)	0.52
<2.5	11 (42.3)	19 (36.5)	15 (46.9)	
2.5-4.5 >4.5	12 (46.2%) 3 (11.5)	28 (53.8) 5 (9.6)	16 (50) 1 (3.1)	0.056

CAM - complementary and alternative medicine, EDSS - extended disability status scale

supports the finding of similar studies that CAM is used by patients suffering from general neurological disorders as well as non-neurological conditions, such as cardiovascular diseases. Studies on the use of CAM among Saudi patients with other chronic conditions, such as dermatological disease, liver disease,

neurological disorders, diabetes mellitus and asthma, in variable age groups (from pediatrics-adults) also showed a prevalence ranging from 55-80%. 10,14 Consistent with the other studies, this study shows that CAM treatments are commonly used in combination with conventional treatments (82.0%), as shown in Table 2. while the exclusive use of CAM was recorded in 18% of patients.¹⁵ The exclusive use of CAM ranged from 9.4-29% in some of the studies.¹⁵ In the current study a significant number of patients used vitamins and minerals, cupping, prayers, meditation, a special diet or bee venom or visited a religious scholar. Previous studies also showed a high use of vitamins and mineral supplements, oil supplements, herbal medicine and special dietary patterns as CAM. As Kingdom of Saudi Arabia is a traditional religious country, cupping (Hejama), special methods of prayer like reciting the Holy Quran and visiting a religious scholar were also commonly used modes of CAM, as observed in previous studies on the same subject. 4,14 This correlation with religion and spiritual practices of CAM was already suggested in previous studies.^{8,16} Also consistent with the literature, our study identified the main reason for CAM use was to improve overall health, and less often to treat specific symptoms or problems.^{8,17} Treatment for specific problem/health issues, such as bladder symptoms, fatigue, balance issues, tremors, spasticity, stress and MS relapses were also less commonly mentioned reasons to use CAM. Nineteen percent of the patients were using CAM to address multiple issues, as shown in Figure 1. The majority of our study population received information about CAM from the social media (62.2%), reflecting the exposure to internet and social media as suggested previously.¹⁸ It is recognized that patients/people are using the internet as a source of knowledge. Contrary to previous research, no statistically significant association between increased CAM use and poorer health was found, rather, patients with better EDSS were found to be using more CAM.¹⁷ Among non-users of CAM it was interesting to discover that the prevalence of an EDSS of less than 2.5 and of an EDSS of more than 4.5 were lower than the prevalence of an EDSS of 2.5-4.5 (p=0.31). We could say that an extreme of EDSS (very high or low) was associated with the non-use of CAM. This behavior could be explained by the fact that patients in good health were satisfied with the conventional treatment and patients with relatively significant disability were hopeless about all forms of management strategies; however, we need to study large numbers of patients, as well as the other subtypes of MS, to test this hypothesis about the trends in using CAM. Also contrary to the established results, no gender difference was found between CAM users

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and non-users, but older age (>30 years) was associated with a relatively high percentage of CAM use (p=0.87).¹⁷ Another interesting result in our study that the majority of our CAM using patients was highly educated (70.3%) supporting the finding of previous studies that patients with higher income and higher education level use more CAM.¹⁷ In our cohort of patients, less than half of the patients were willing to disclose the use of CAM to their physicians. That is a reason for concern, due to potential drug interactions and also the adverse side effects from CAM use.^{8,14,17} There is a common belief among CAM users that CAM is harmless, which may be a false perception.¹⁷ Certain methods could have serious side effects if not supervised properly by trained staff, which is true for instance for the use of bee venom.¹⁹ Adverse events related to bee venom therapy are quite frequent and this therapy should be properly supervised.^{8,19,20} The high proportion of non-disclosure to physicians was previously suggested in studies from the United States and Australia, and the trend of nondisclosure has not changed in recent years. 7,17 We did not examine the reasons behind non-disclosure of CAM use, although the general perception of people of CAM use is that it is a harmless mode of treatment. 8,14,17 The possible reasons behind this attitude may be associated with the characteristics of the patient, the doctorpatient counseling style or fear of lacking medical knowledge about CAM use.8,17 Health status was found to predict whether patients disclose CAM use to their physicians or not. Our results support previous research by identifying that being in good health (EDSS less than 4.5) was a significant and independent predictor of disclosing CAM use (90%). Non-disclosure of CAM to physicians has been documented in previous research, but no predictors of disclosure about CAM were identified.^{7,17} A possible explanation for our study findings is that those in better health had more confidence in using CAM, which may have prompted them to tell their doctor about CAM use. Women were found to disclose less compared to men.

As described in the previous literature, CAM use can have adverse effects, so patients should be encouraged to inform their treating physicians about it. However, it is the responsibility of health care providers to enquire about the use of CAM. 8,17,19 This level of information can be achieved by directly asking questions about CAM in a non-judgmental way, to avoid the risk of drug interactions and potential adverse events from CAM. 8,17,19 Doctors need to be aware that the sociodemographic and health characteristics of the individual may influence whether they seek advice or tell their doctor about their CAM use and to take this into account in the doctor-patient consultation. 17 There are

certain strategies proposed to encourage more people to disclose their use of CAM, such as focusing on patients' values and goals as a holistic approach of enhancing chronic disease management. 8,20 These positive inquiries about the use of CAM have been shown to increase patient disclosure of CAM use by a factor of 19.8,20 These issues point towards the need that more research is required to explore the characteristics of CAM users and factors which have influence on patients' decisions to discuss these with their primary care physician or at least to inform them about their CAM use. This may prevent suffering from dangerous side effects of some of the commonly used methods.^{8,14,19} Despite the worldwide interest in CAM, it is not adequately represented in medical education in Kingdom of Saudi Arabia and even in developed countries.²¹ There are promising changes in some medical school curriculam in Kingdom of Saudi Arabia as they start to offer courses on CAM.²² Moreover, medical students agree that CAM practices need to be included in their medical school curriculum.²² In another study, 43% of interviewed students were satisfied with their study of CAM.²³

Limitations. We recognize that our study has some limitations, including the fact that it may have been difficult for patients to recall the non-prescribed medications used in the last 6 months. Patients were surveyed at a single hospital and the majority of the MS types were RMS, which might not be representative of the overall population of MS patients in Kingdom of Saudi Arabia.

In conclusion, this study indicates that CAM use is common among patients with MS in Kingdom of Saudi Arabia, and the factors and patient behaviors associated with this use were identified. We recommend that clinicians consider the results of this study and spend more time discussing CAM use to ensure patient safety and medication effectiveness, as these changes should have a positive influence on clinical practice and economic burdens. Further research is needed to determine the health-related costs of personal use of these non-prescription medications and costs spent to manage the adverse events resulting from their use. Measures and policies to endorse the appropriate use of CAM by the Saudi society must be implemented promptly.

Acknowledgements. The authors gratefully acknowledge FirstEditing.com for English language editing.

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