



Complementary and Alternative Therapy Use in Multiple Sclerosis: A Cross-Sectional Survey

Multipl Sklerozda Alternatif ve Tamamlayıcı Tedavi Kullanımı: Kesitsel Bir Anket Çalışması

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Summary

Objective: In this study, we aimed to document the use of alternative and complementary therapy (ACT) in multiple sclerosis (MS) patients, and the relationship with socio-demographic characteristics and clinical data of the ACT users.

Materials and Methods: We evaluated 101 MS patients followed in our outpatient clinic and living in Egean district, mostly in central İzmir. All of them completed a questionnaire related to the use of ACT. Patients who had used any type of ACT were statistically compared with patients who had never used such a treatment in terms of their socio-demographic and clinical variables.

Results: Of the 101 patients reviewed, 65% were women. The majority of the patients had relapsing-remitting MS (90.1%). Sixty eight percent of participants reported never using ACT. Twenty six of the patients had tried an alternative treatment once. Only half of them reported some benefit. However, only six patients were still on this treatment.

Conclusion: We conclude that our patients who were mostly living in the central city and had medium to high educational levels, did not have knowledge about ACT. The patients using such therapies mostly did not experience a meaningful benefit. No statistically meaningful difference was found between the alternative treatment users and non-users regarding EDSS scores, MS subtype, disease duration, age, educational level and residential district. (Turkish Journal of Neurology 2015; 21:13-5)

Key Words: Multiple sclerosis treatment, alternative therapy, complementary therapy

Conflicts of Interest: The authors reported no conflict of interest related to this article.

Özet

Amaç: Multipl skleroz (MS) hastaları arasında alternatif ve tamamlayıcı tedavilerin (ATT) kullanımının, ATT kullanan bireylerin sosyo-demografik özellikleri ile hastalığa ilişkin verilerin değerlendirilmesi amaçlanmıştır.

Gereç ve Yöntem: MS polikliniğimizde takip edilen, Ege bölgesinde, çoğunluğu İzmir şehir merkezinde yaşayan, 101 MS hastasına, ATT kullanımına ilişkin sorular içeren bir anket verildi. ATT kullanan ve kullanmayan hastalar sosyo-demografik ve klinik özellikleri açısından istatistiksel olarak karşılaştırıldılar.

Bulgular: Ankete katılan hastaların çoğunluğu kadındı (%65). Hastaların çoğu relapsing-remitting tipte (RRMS) idi (%90,1). Tüm bireylerin %68'i ATT'den haberdar olmadığını belirtti. Yalnızca 26 hasta herhangi bir zamanda ATT kullanmıştı ve 6 kişi bu tedaviye devam etmekteydi. Alternatif ve tamamlayıcı tedavi kullanmış olanlardan %50'si anlamlı bir fayda görmemişti.

Sonuç: Çoğunluğu İzmir şehir merkezinde yaşayan ve eğitim düzeyi iyi olan MS hastalarımızın çoğu ATT hakkında bilgi sahibi değildi. Bu tür tedavileri düzenli uygulayan ve faydasını gören herhangi bir hasta yoktu. Alternatif ve tamamlayıcı tedavileri uygulayan ve uygulamayan hasta grupları

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arasında EDSS ile belirlenen engellilik düzeyi, MS tipi, hastalık süresi, yaş, eğitim düzeyi ve yaşadıkları bölge açısından anlamlı bir fark izlenmedi. (Türk Nöroloji Dergisi 2015; 21:13-5)

Anahtar Kelimeler: Multipl skleroz tedavisi, alternatif tedavi, tamamlayıcı tedaviler

Çıkar Çatışması: Yazarlar bu makale ile ilgili olarak herhangi bir çıkar çatışması bildirmemiştir.

Introduction

Multiple sclerosis (MS) is an autoimmune, demyelinating and inflammatory disease that is the second biggest cause of disability in young adults after traffic accidents. A wide variety of symptomatic problems can be seen in MS patients. Cognitive disorders, depression, fatigue and mood swings are often seen as the disease progresses. In addition, spasticity, tremor, seizures, sphincter and sexual dysfunctions also impair the quality of life. It is known that MS patients resort to a variety of complementary or alternative treatments in order to alleviate the symptoms or stop disease activity. Exercise, meditation, yoga, relaxation, acupuncture, cannabis, massage, dietary changes, vitamins, therapeutic herbs or mineral supplements are a few examples of such means and methods. (1,2,3,4,5) There is, however, little evidence for the benefit of these applications (6). As with many other chronic diseases, the use of alternative and complementary treatment (ACT) is getting more widespread for MS and there is a growing accumulation of knowledge about them globally. Physiotherapy may improve mobility, mood and subjective well-being in chronic MS but these effects are transitory (7). Using a questionnaire, we evaluated our MS patients being followed in İzmir Bozyaka Training and Research Hospital, residing primarily on central Izmir, in terms of their knowledge of alternative and complementary treatments.

Materials and Methods

101 multiple sclerosis patients living in the Aegean district urban areas, counties or villages were given a questionnaire asking if they know about certain ACTs, how much they used each one of them and what were the origins of these treatments. The patients were given a verbal explanation as to what ACTs are. The results and sociodemographic data from people who use or do not use ACTs were analyzed using t-test and Chi-square statistics. For all tests, a p value of 0.05 was considered statistically significant.

Results

Among all the MS patients who participated in the study, 91 were relapsing-remitting MS (RRMS), 8 were secondary progressive MS (SPMS) and 2 were primary progressive MS (PPMS). 66 of the patients were female and 35 were male, with mean age of 38.9 ± 8 (17-64). The level of disability, evaluated with Extended Disability Status Scale (EDSS), was 2.8 ± 1.3 and the disease duration was 7.0 ± 4.8 years. A summary of the clinical properties of the patients is given in Table 1. 56.4% of the patients had 11 years or more education. A large majority of the patients (68%) reported not having any knowledge about ACT. Among the ones who knew about them, the portion who thought they

are useful were only 23%. Twenty six patients (25.7%) used ACT at one time but only 6 of them continued these practices ever since. The patients used yoga, reiki, bioenergetics (15 patients) and medicinal herbs (10 patients). One patient received ozone treatment. Half of the patients who received ACT reported not seeing any benefits from these treatments. When they were asked how did they learn about those ACTs, 70% reported that they heard about them from their relatives. The source was the press and Internet in 17% of the patients. 3% of the patients heard about them from other MS patients. 75% of the patients did not use an MS-specific diet. There were no meaningful relationship between disease duration, age, EDSS score and ACT use (t-test; for all tests $p > 0.05$). Education level, MS type, geography of residence (city, county, village) and ACT were also not associated (Chi-square).

Discussion

Treatments or procedures described to alleviate a certain state without any safety and reliability studies are called alternative treatments. Diet, exercise, cognitive conditioning and lifestyle changes may also be counted among alternative treatments. Acupuncture, yoga, aromatherapy, relaxation, medicinal herbs and massage can be given as examples. The alternative treatments practiced to complement classical treatment methods are called complementary treatments. The interest shown by MS patients towards alternative and complementary treatments can be interpreted as a symptom of the psychosocial difficulties they experience (8). In a cross-sectional study using the quality of life scale SF-12, it was suggested that MS patients resort to ACT when their physical well-being is impaired (9). In this study, even though more than half of the MS patients had reasonably good

Table 1. Demographics and clinical findings of multiple sclerosis patients

Patients (n=101)	Socio-demographic-clinical features
Female/male	66/35 (65.3% vs. 34.7%)
Age (years)	38.9 ± 8 (17-64)
MS type	RRMS (n=91) 90%
	SPMS (n=8) 8%
	PPMS (n=2) 2%
EDSS	2.8 ± 1.3
Disease duration (years)	7.0 ± 4.8
Education level	Low (≤ 10 years) (n=44) 43.6%
	High (≥ 11 years) (n=57) 56.4%

MS: Multiple sclerosis, EDSS: Expanded disability status scale, RRMS: Relapsing-remitting MS, SPMS: Secondary progressive MS, PPMS: Primary progressive MS

educational level, only 70% had knowledge about ACT. Among those who had knowledge of them, only a quarter of them believed their usefulness. Only half of the 26 patients who did use ACT believed that the treatment had any usefulness. Only 6 patients had been continuing their treatment. The information on ACT was often acquired through relatives, except for one fifth of the patients who used the press and Internet. A quarter of the patients tried a disease-specific diet. There were no statistically significant differences between people who practiced ACT and those who did not, in terms of disease type, disease duration, EDSS score, age, geographic location and education level. In a study encompassing Scandinavian countries, between 46 and 59% of 3000 MS patients used ACT and that these practices varied greatly (10). The reasoning behind using ACT was reported as the desire to strengthen and protect the body without necessarily having a specific goal. In another study, the reasons that turned people to ACT included hopes of finding an active treatment, ineffectiveness of the traditional treatments and weak patient-doctor relationship (11). According to the literature, the most commonly used treatments are special diets, minerals and vitamins, acupuncture and medicinal herbs. Even though being a topic that is frequently visited in the literature, there is no solid evidence for its benefits (12,13,14). These treatments were often seem to be practiced as complementary to the traditional treatment regimen (15). There were no significant differences observed between the 5 Scandinavian countries in terms of ACT use frequency, variations and purpose. In a 5-year follow-up study on ACT use in MS patients, it was reported that these treatments had no effect on the disease progress and that their prevalence decreased by half by the end of 5 year (8). In a study including 1573 MS patients in Germany, it was found that there was a tendency towards ACT, and that this tendency was especially visible in people with high education levels, white-collar careers, female and functionally independent (16). Studies conducted in different countries showed that even though the patients resort to classical MS treatments, they also seek alternative treatments as well (17). Therefore, health-care professionals must be cognizant of this tendency and inform patients about these treatments when necessary (18). In our study, the use of ACT in Turkey has been found to be much lower than expected. The reason could be that the outpatient clinic patients had strong patient-doctor communication, low disability levels with very little need for additional treatments but maybe also hesitant to report ACT use because of the same reasons. Relatively high reports for yoga and reiki might also suggest a strong tie between the patient group and a specific center where these treatments were practiced. In addition, the knowledge of our patients on ACT is also very little. This finding can be explained by the low Internet use in this group. An important limitation of our study was the smallness of our study groups. However, due to the fact that no prior cross-sectional studies exists in the literature on the use and variations of alternative and complementary treatments in MS patients in Turkey we wanted to share these findings.

Conclusions

In this cross-sectional questionnaire study conducted in Aegean district, we found that MS patients primarily residing in

central Izmir did not know about ACTs, those who knew about them did not make use of them, and those who did use them did not find them effective and dropped out. In this questionnaire, we found that despite the popular belief, MS patients who live in the city of İzmir did not commonly know of ACTs or use them. Considering the increasingly prominent wave of popularity and misinformation about the ACTs, larger scale studies will be beneficial in determining the trends affecting the patients and guiding health-care workers.

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