

Preference of patients with neuromuscular diseases concerning complementary and alternative medical methods

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Abstract

Objective: Complementary and alternative medicine (CAM) is the term for medical products and practices that are not part of standard medical care. Neuromuscular diseases (NMDs) are disorders of the neurons, peripheral nerves, neuromuscular junction, muscles. They are clinically progressive and medical treatment is limited.

Methods: The aim of this study is to evaluate the use of CAM in NMDs and investigate the preferences of patients concerning the CAM methods that are frequently used. Patients and their caregivers who were followed up at the NMDs unit in the Department of Physical Medicine and Rehabilitation were included. Demographic data of the patients were collected; their functional activity scores, wheelchair usage, and use of CAM were questioned. A total of 246 patients were included; 108 patients used CAM. Patient-specific diet, nutritional support, mental body treatments, manipulative techniques, and energy techniques were investigated.

Results: The most commonly used CAM method was dietary supplements. The use of CAM was significantly higher in patients with high socioeconomic and low education status ($p=0.004$). There was a significant relationship between wheelchair use and the use of CAM ($p=0.001$). The percentage of patients who benefited from CAM was 48.6%. It was shown that CAM was used at high rates in addition to medical therapies in NMDs, the biological-based therapies ranked first, and that using CAM was more common in the patients who were more immobile and in those with better socioeconomic status and low educational level.

Conclusion: Complementary and alternative medicine is frequently used in NMDs. Further evidence-based studies should be performed in order to assess efficacy of integrating this common use to the NMDs.

Keywords: Alternative medicine, complementary therapies, neuromuscular diseases

INTRODUCTION

The National Center of Complementary and Alternative Medicine (NCCAM) of the National Institute of Health defines complementary alternative medicine (CAM) as a group of diverse medical and healthcare systems, practices, and products not presently considered to be part of conventional medicine (1).

The practice of CAM is very common in chronic diseases. One recent study reported the practice of CAM to be 40% in adults and as 11% in children in the United States of America in 2007; this rate was found to vary greatly from 6 to 65% among adults (2). CAM is widely used in the pediatric population including those with chronic diseases as well as disabilities. It has been reported that prognosis and severity of disease affect the use of CAM (3-5). Research has shown that patients with chronic diseases in particular practice CAM alone or in combination with modern therapeutic methods before or after the diagnosis or in both periods. Considering the fact that patients do not provide correct information about or hide their practice of CAM, the rate of using CAM methods may be higher (6). The methods employed may vary depending on the geographic location of the country, ethnicity, educational level, socioeconomic factors, religious beliefs, lifestyles, and culture (7).

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Neuromuscular diseases (NMDs) are disorders of the neurons, peripheral nerves, neuromuscular junction, and the muscles moving our body. Most of these diseases are progressive, have high rates of disability, and have limited response to medical therapy. Practice of CAM methods is common in this group of patients (8, 9). A rate of 46% has been reported for NMDs in studies investigating the rate of use of CAM methods in pediatric patients with neurologic conditions (10, 11). Practice of CAM has been reported to range from 20% to 75% in patients with Duchenne muscular dystrophy (DMD) (10, 11). Factors such as the progressive nature of NMDs and their potential to lead to disability may increase using complementary therapies in addition to medical therapy and rehabilitation. CAM methods may cost as much as conventional therapies. The present study was aimed at determining the prevalence of the use of CAM methods and factors affecting their use among individuals with NMDs.

METHODS

Ethics Statement

Planned as a cross-sectional survey, the present study included patients who presented to the NMDs outpatient clinic between May 2017 and May 2018 after the approval was obtained from the local ethics committee at İzmir Tepecik Training and Research Hospital (Ethics Committee No: 2017.13.7). Adult patients and caregivers of the pediatric patients with NMDs were included in the study, and patients with mental retardation and those who did not give their informed consent in writing were excluded.

Measurement

The demographic data of the patients and caregivers including age, sex, educational level, socioeconomic status, and health insurance were recorded.

Complementary and Alternative Medicine education levels of the decision-makers were taken.

The education levels of caregivers aged under 18 years were evaluated.

The educational level of the patient themselves (aged 18 years of age and above) was evaluated.

Middle school, primary school and illiteracy were considered low level of education. High school, university, and college education constituted higher levels of education.

The economic level was determined by the income level.

Income level was assessed to determine if it met the basic needs of the family for life or income equaled expenditure; low income meant that it did not meet requirements and high income level indicated that surplus money was left.

The diagnosis and duration of the disease and the use of wheelchair were queried. Diagnoses were classified as muscular, neuronopathies/neuropathy and neuromuscular-junction diseases. Their use of CAM was categorized under five headings according to the classification by the NCCAM (Table 1) (12). All assessments were made by the researcher in face-to-face interviews. The patients' use and preference of alternative therapies were recorded.

Statistical Analysis

The descriptive features of the patients are expressed as percentage. The rate of CAM use and continuous variables including age, age at the time diagnosis, and duration of disease were evaluated using Student's *t*-test in independent groups. Categorical variables such as sex and educational level were evaluated using the Chi-square test. *P* values <0.05 were considered significant. All statistical analyses were performed using the Statistical Package for the Social Science (SPSS) v20.0 (SPSS IBM Corp.; Armonk, NY, USA).

RESULTS

The demographic and descriptive features of the 246 patients included in this study are summarized in Table 2. A great majority of the patients had muscular diseases (71.5%), including myopathies, DMD, and Becker muscular dystrophy (BMD), respectively. Fifty-six patients (22.8%) were using wheelchairs. The demographic features of 129 caregivers are given in Table 3. At least one CAM method was practiced by 108 (43.9%) of the patients. The number of practiced methods varied from one to three; 10 (9%) and 4 (3.7%) patients were using two and three methods, respectively (Table 4).

The most frequently applied CAM method was biologic-based therapies (80.5%) (Table 5). Of the patients with DMD, 81.5% used biologic-based therapies, 8% used mental and physical methods, 8% used manipulative physical methods, and 4% used energy therapies. All patients with amyotrophic lateral sclerosis (ALS), facioscapulohumeral muscular dystrophy, and BMD had used biologic-based nutritional supplements (Table 6).

Table 1. Categories of complementary and alternative medicine methods

1. Biologic-based therapies
Specific diet, nutritional supplements, topical therapies (creams, oils)
2. Mental and physical methods
Praying, meditation, visiting shrines, talismans, music, dance
3. Manipulative, physical based methods
Hydrotherapy, massage, manipulation, thermal spring, chiropractic methods
4. Energy healing
Bioenergy, Reiki, magnetic field
5. Alternative medical systems
Homeopathy, Ayurveda, naturopathy

Table 2. Demographic features and diagnoses of the patients (n=246)

	n	%	Means ± SD
Age			24.20±17.82
Sex			
Women	96	39	
Men	150	61	
Education			
Illiterate	4	1.6	
Literate	3	1.2	
Primary School	48	19.5	
Middle School	22	8.9	
High School	28	11.4	
University	20	8.1	
Social Security			
Yes	245	99.6	
No	1	0.4	
Socioeconomic Status			
Income < expense	118	48	
Income = expense	124	50	
Income > expense	4	2	
Diagnostic group			
Muscle	176	71.5	
Nerve	63	25.6	
Muscle-Nerve	7	2.8	
Diagnosis			
DMD	52	21.1	
BMD	25	10.2	
LGMD	8	3.3	
FSHMD	3	1.2	
MD	24	9.8	
ALS	11	4.5	
PNP	41	16.7	
SMA	18	7.3	
MG	3	1.2	
Others Myopathy	61	24.8	
Age at first diagnosis (year)			16.10 ± 16.44
Time since diagnosis (year)			8.56 ± 8.15
n: number of patients; SD: standard deviation; DMD: duchenne muscular dystrophy; BMD: becker muscular dystrophy; LGMD: limb girdle muscular dystrophy; FSHMD: facioscapulohumeral muscular dystrophy; MD: muscular dystrophy; ALS: amyotrophic lateral sclerosis; PNP: polyneuropathy; SMA: spinal muscular atrophy; MG: myasthenia gravis			

No significant correlation was found between CAM use and age ($p=0.436$), sex ($p=0.175$), age at the time of diagnosis ($p=0.553$), or duration of disease ($p=0.558$). The use of CAM was found to be significantly more common among those with higher socioeconomic status ($p=0.001$). It was also found to be significantly more common among those with low educational level and high socioeconomic status ($p=0.004$) and among patients using wheelchairs ($p=0.001$).

Table 3. Demographic characteristics of caregivers (n=129)

	n	%
Education		
Illiterate	4	3.1
Literate	7	5.4
Primary School	69	53.5
Secondary School	23	17.8
High School	19	14.7
University	7	5.4
Job		
Housewife	103	79.8
Public Sector	3	2.3
Private Sector	11	8.5
Self employed	8	6.2
Unemployed	3	2.3
Retired	1	0.8
Marital Status		
Married	123	95.3
Divorced	4	3.2
Widow	2	1.6
n: number of patients; %: percentage		

Table 4. Complementary and alternative medicine (CAM) use

	n	%
CAM Use		
Yes	108	43.9
No	138	56.1
Suggestion for CAM Use		
Self	15	13.9
Family	32	30
Friends	32	30
Media	5	5
Healthcare personnel	14	13
Other	10	9
CAM Benefits		
Yes	53	48.6
No	55	51.4
CAM Damages		
Yes	2	1.9
No	106	98.1
n: number of patients; %: percentage		
CAM: complementary and alternative medicine		

DISCUSSION

The present study investigated the use of CAM in NMDs and found that CAM use was very common among these patients. The most frequently used method was biologic-based therapy. The rate of using CAM methods was found to be significantly higher among patients with the poorest mobility and among those with higher socioeconomic status and lower educational level.

The use of CAM methods has been shown to be very common among adult and pediatric patients with NMDs due to the limited availability of medical therapies for these conditions (10). The prevalence of practicing CAM has been reported to be 46% and 87% in pediatric and adult neurologic patients, respectively (10, 13-16). One study reported that CAM methods were used in combination with traditional therapies by

80% of the patients with DMD/BMD (17). In the present study, prevalence of practicing CAM methods was 43.9%.

Socioeconomic status affects access to CAM. Individuals with higher socioeconomic status used CAM methods in addition to conventional therapies more commonly. It is known that socioeconomic status makes accessing CAM methods easier. D'Onise et al. reported that the use of CAM in combination with medical therapies was more common in patients with chronic diseases and among those with high socioeconomic status (18). Nabukera et al. reported that 80% of patients with DMD/BMD used CAM in combination with medical therapies and that practicing CAM was more common among the caregivers with higher educational level and higher family income (17). Similarly, the present study found CAM practice to be more common among individuals with higher socioeconomic status. Studies have emphasized that CAM use was associated with substantial costs and that cost-effectiveness studies should be performed for these methods (19, 20).

In the present study, the rate of CAM use was significantly higher among patients using wheelchairs. Okoro et al. reported on patients with and without functional disability (61.4% and 41.8%, respectively), finding that 86.9% of the patients used CAM and the rate of CAM use was highest in the group with functional disability, and that manipulative physical-based therapies, biologic therapies, and mental-physical therapies were used in this group (13). In NMDs, the progression of the disease is associated with decreased functional capacity, loss of mobilization, and increased disability. This leads to an increased need for alternative therapies by patients and caregivers. It has been reported that the rate of CAM use increased with the progression and severity of ALS (21, 22). Similar previous studies determined that applying CAM was more common in the group of ALS, spinal muscular atrophy, and DMD with rapid clinical progression (14, 15).

Table 5. Practiced methods of complementary and alternative medicine (n=108)

Biologic-based therapies	n=87 (80.5%)
Specific diet	7
Nutritional supplements	25
Coenzyme Q	14
Omega 3	10
Fish Oil	12
Carnitine	4
Resveratrol	1
Vitamin C	3
Cream	12
Mental and physical methods	n=8 (7.4%)
Praying	7
Visiting shrines	3
Talismans	2
Meditation	1
Dance	0
Manipulative, physical based methods	n=11 (10.2%)
Massage	6
Aquatic therapy	8
Thermal spring	5
Energy healing	n=2 (1.9%)
Bioenergy	3
Reflexology	1
Alternative medical systems	0
n: number of patients; %: percentage	

Table 6. Distribution of the practice of complementary and alternative medicine by diseases

Diagnosis (n)	Biologic- based therapies (n, %)	Mental and physical methods (n, %)	Manipulative, physical-based methods (n, %)	Energy healing (n, %)	Total (n, %)
DMD	22 (81.5%)	2 (7.4%)	2 (7.4%)	1 (3.7%)	27 (100%)
BMD	9 (100%)	0	0	0	9 (100%)
LGMD	4 (100%) / 0	0	0	0	4 (100%)
FSHMD	2 (100%) / 0	0	0	0	2 (100%)
MD	3 (60%) / 0	0	2 (40%)	0	5 (100%)
ALS	9 (100%) / 0	0	0	0	9 (100%)
PNP	16 (89%) / 0	0	2 (11%)	0	18 (100%)
SMA	7 (70%) / 0	2 (20%)	1 (10%)	0	10 (100%)
Other	15 (62%)	4 (17%)	4 (17%)	1 (4%)	24 (100%)
n: number of patients; %: percentage; DMD: duchenne muscular dystrophy; BMD: becker muscular dystrophy; LGMD: limb girdle muscular dystrophy; FSHMD: facioscapulo- lohumeral muscular dystrophy; MD: muscular dystrophy; ALS: amyotrophic lateral sclerosis; PNP: polyneuropathy; SMA: spinal muscular atrophy; MG: myasthenia gravis					

Studies have emphasized that the rate of CAM use was higher when the disease was clinically severe and medical therapy options were limited. In one study, 10% of patients with ALS believed that they would be cured with CAM therapy, 30% believed that they would improve, 50% believed that their disease progression would be slowed down or their close relatives would not face a worse situation than the current state of their disease (14, 15). In one study on the practice of CAM in children with cerebral palsy, cystic fibrosis or DMD, it was reported that CAM therapy was most frequently used among patients with cerebral palsy. It was also shown that there was no significant difference between patients with or without progressive disease regarding the use of CAM and that the main purpose of using CAM was to complement conventional medical therapy (23).

In the present study, the use of CAM was most often recommended by family members (30%) or friends (30%). In another study on 272 patients with DMD/BMD, it was reported that 75% of patients had a history of using at least one CAM method and that it was recommended by a health professional in 47% of cases (24). Especially in pediatric patients, 82% of the caregivers were mothers who implemented the CAM treatments (25). In one study, it was queried as to whether CAM was recommended by a health professional, and it was found to be as high as 70% (26). In the present study, the frequency of being recommended CAM methods by a health professional was 14%. Health professionals should be aware of the efficacy, dose, adverse effects, toxicity, and potential drug interactions of CAM methods.

It was found in the present study that biologic-based therapies were the most common CAM methods with a rate of 80.5% (nutritional supplementation 74%, specific diet 6.5%). The most frequently used nutritional supplements were herbs, coenzyme Q (Co-Q10), fish oil, and omega-3 fatty acids. In our country, access to herbs via herbalists is easy and it has been found that applying these was very common despite the lack of studies and evidence on their content and efficacy. A review by Woodman et al. noted that therapies with Chinese herbal supplements were used in patients with DMD, but did not lead to an improvement in creatine kinase levels, in magnetic resonance imaging findings, or in pathology, and might result in a cumulative effect of the drug in patients using corticosteroids (27).

The second most commonly used biologic-based nutritional supplement is antioxidant Co-Q10. There are studies indicating its beneficial effects in myofiber regeneration and mitochondrial proliferation in the cardiac and skeletal muscle tissues and in increasing survival rates; however, there are also other studies indicating that there is no firm evidence (28, 29). It was found in the present study that Co-Q10 use was mostly recommended by healthcare professionals and other patients using it and that its use was particularly common in patients with DMD/BMD. The third most commonly used nutritional supplement was omega-3 fatty acids eicosapentaenoic acid. They have been reported to provide protection against muscle degeneration and have beneficial cardiac effects via their anti-inflammatory effect

in DMD (30). The second most commonly used CAM method among our patients was physical-based manipulative methods. The most common form of these treatments was hydrotherapy. In their study, Hind. et al. reported that aquatic therapy was the most commonly used method for pediatric patients with neurologic conditions. They found that aquatic therapy (hydrotherapy) was particularly recommended by healthcare professionals because it had beneficial effects on motor performance. It has been suggested that aquatic therapy should be part of conventional therapy in patients with DMD/BMD (31).

In the present study, alternative medical approaches such as homeopathy, Ayurveda, and naturopathy were not used at all and energy techniques including bioenergy, Reiki, and magnetic field were not very common (1.9%). This may be due to the fact that these techniques are not commonly known in Turkey and thus access to these methods are relatively more difficult.

There are some limitations to this study. The use of CAM was queried under 5 headings according to the classification of NCCAM. Nonetheless, which methods are CAM and which are conventional may be controversial. For instance, hydrotherapy might be recommended to these patients as conventional therapy although it was considered as a CAM method in our survey. Another limitation was that the study was based on data from the patients and their relatives and whether the CAM use was beneficial was determined based on the patients' perception (self-reported data). The benefits of the modalities, however, should be determined using evidence-based methods.

In conclusion, it was shown that CAM was commonly used in addition to medical therapies in NMDs, biologic-based therapies were the most commonly used CAM method, and CAM practice was more common in patients with poor mobility and in those with better socioeconomic status and higher educational level.

Complementary and alternative medicine is frequently used in NMDs. Physicians specialized in this field should have sufficient knowledge and expertise of such approaches so that they can guide their patients properly and probable adverse effects can be averted.

Ethics Committee Approval: Ethics committee approval was received for this study from the ethics committee of İzmir Tepecik Training and Research Hospital (no: 2017.13.7).

Informed Consent: Written informed consent was obtained from patients and from parents of patients who participated in this study.

Peer-review: Externally peer-reviewed.

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