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Original Article

Complementary and Alternative Medicine for Duchenne and Becker Muscular Dystrophies: Characteristics of Users and Caregivers

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ABSTRACT

BACKGROUND: Complementary and alternative medicine is frequently used in the management of chronic pediatric diseases, but little is known about its use by those with Duchenne or Becker muscular dystrophy. **METHODS:** Complementary and alternative medicine use by male patients with Duchenne or Becker muscular dystrophy and associations with characteristics of male patients and their caregivers were examined through interviews with 362 primary caregivers identified from the Muscular Dystrophy Surveillance, Tracking, and Research Network. **RESULTS:** Overall, 272 of the 362 (75.1%) primary caregivers reported that they had used any complementary and alternative medicine for the oldest Muscular Dystrophy Surveillance, Tracking, and Research Network male in their family. The most commonly reported therapies were from the mind-body medicine domain (61.0%) followed by those from the biologically based practice (39.2%), manipulative and body-based practice (29.3%), and whole medical system (6.9%) domains. Aquatherapy, prayer and/or blessing, special diet, and massage were the most frequently used therapies. Compared with nonusers, male patients who used any therapy were more likely to have an early onset of symptoms and use a wheel chair; their caregivers were more likely to be non-Hispanic white. Among domains, associations were observed with caregiver education and family income (mind-body medicines [excluding prayer and/or blessing only] and whole medical systems) and Muscular Dystrophy Surveillance, Tracking, and Research Network site (biologically based practices and mind-body medicines [excluding prayer and/or blessing only]). **CONCLUSIONS:** Complementary and alternative medicine use was common in the management of Duchenne and Becker muscular dystrophies among Muscular Dystrophy Surveillance, Tracking, and Research Network males. This widespread use suggests further study to evaluate the efficacy of integrating complementary and alternative medicine into treatment regimens for Duchenne and Becker muscular dystrophies.

Keywords: Becker muscular dystrophy, complementary therapies, Duchenne muscular dystrophy, neuromuscular diseases

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Introduction

Complementary and alternative medicine (CAM) has traditionally been described as medical practices and use of therapies not regarded as conventional medicine. Currently the National Center for Complementary and Alternative

TABLE 1.
Reported Use of Complementary and Alternative Medicine in Male Patients With Duchenne or Becker Muscular Dystrophy, Muscular Dystrophy Surveillance, Tracking, and Research Network

CAM Domain and/or Therapy	Use	Provider Recommended
	n (%) [*]	n (%) [†]
Biologically based practices [‡]	142 (39.2)	81 (57.0)
Herbs, mouth	61 (16.9)	16 (26.2)
Herbs, skin	25 (6.9)	3 (12.0)
Special diet	78 (21.5)	56 (71.8)
Megavitamins	29 (8.0)	16 (55.2)
Glycoproteins	11 (3.0)	1 (9.1)
Manipulative and body-based [‡]	106 (29.3)	29 (27.4)
Massage	78 (21.5)	29 (37.2)
Chiropractic manipulation	54 (14.9)	6 (11.1)
Osteopathic manipulation	10 (2.8)	2 (20.0)
Mind-body medicine [‡]	221 (61.0)	99 (44.8)
Aquatherapy	136 (37.6)	89 (65.4)
Hippotherapy	48 (13.3)	16 (33.3)
Self-hypnosis	2 (0.6)	0 (0.0)
Prayer and/or blessings	126 (34.8)	2 (1.6)
Companion animals	21 (5.8)	2 (9.5)
Whole medical systems [‡]	25 (6.9)	5 (20.0)
Acupuncture	7 (1.9)	2 (28.6)
Homeopathy	21 (5.8)	4 (19.0)
Other	32 (8.8)	17 (53.1)

Abbreviation:

CAM = Complementary and alternative medicine

* Denominator used to calculate the percentage is the number of male patients with Duchenne or Becker muscular dystrophy included in this study (n = 362).

† Denominator used to calculate the percentage is the number of users for each specific CAM therapy or domain.

‡ Total number of users for each CAM domain was less than sum of the number of users for individual CAM therapies within the domain because of the use of more than one CAM therapy.

TABLE 2.
Comparison of Selected Characteristics of Male Patients With Duchenne or Becker Muscular Dystrophy by Complementary and Alternative Medicine Use, Muscular Dystrophy Surveillance, Tracking, and Research Network

Characteristic	Nonusers (n = 90)	Any CAM (n = 272)	CAM Domains		
			Biologically Based Practices (n = 142)	Manipulative and Body-Based Practices (n = 106)	Mind-Body Medicine (n = 221)
Disease Phenotype [*]					
Early onset	69 (76.7)	232 (85.6)	123 (87.2)	92 (87.6)	192 (87.3)
Late onset	21 (23.3)	39 (14.4)	18 (12.8)	13 (12.4)	28 (12.7)
Number of years since diagnosis	9.4 ± 5.7	9.9 ± 5.7	10.0 ± 5.9	10.0 ± 5.8	10.0 ± 5.6
Used wheel chair [†]					
Yes	52 (59.8)	201 (73.9)	105 (73.9)	77 (72.6)	169 (76.5)
No	35 (40.2)	71 (26.1)	37 (26.1)	29 (27.4)	52 (23.5)
Age first used wheel chair (yr)	9.9 ± 2.9	9.3 ± 2.6	9.1 ± 2.4	9.2 ± 2.4	9.5 ± 2.7
Used NIPPVD					
Yes	20 (23.0)	70 (25.9)	37 (26.4)	29 (27.6)	60 (27.4)
No	67 (77.0)	200 (74.1)	103 (73.6)	76 (72.4)	159 (72.6)
Age first used NIPPVD (yr)	16.1 ± 3.4	15.0 ± 3.3	14.5 ± 3.4	15.5 ± 3.3	14.9 ± 3.2
Vital status at interview					
Living	79 (87.8)	251 (92.3)	133 (93.7)	97 (91.5)	204 (92.3)
Deceased	11 (11.2)	21 (7.7)	9 (6.3)	9 (8.5)	17 (7.7)

Abbreviations:

CAM = Complementary and alternative medicine

NIPPVD = Noninvasive positive pressure ventilation devices

Categorical variables were presented as N (%) and analyzed by the chi-square test or Fisher exact test; continuous variables were presented as mean ± standard deviation and analyzed by the t test. Nonusers were the comparison group. Because of missing values, the total for some categories may not match; because of rounding, percentages may not total 100.

* Significant associations between disease phenotype and use of any CAM ($P < 0.05$), biologically based practices ($P < 0.05$), manipulative and body-based practices ($P < 0.05$), mind-body medicine (with or without prayer and/or blessings only) ($P < 0.05$), and aquatherapy ($P < 0.05$).

† Significant associations between wheel chair use and use of any CAM ($P < 0.05$), biologically based practices ($P < 0.05$), mind-body medicine (with or without prayer and/or blessings only) ($P < 0.01$), massage ($P < 0.01$), and aquatherapy ($P < 0.01$).

Medicine endorses the term “complementary health approaches” to describe those medical practices and products used to manage disease.¹ The evolving views can complicate studies of CAM use because of changes in definitions and designations of certain therapies as CAM. Historically, estimates of CAM use in different countries have ranged from 9% to 73%.² A recent US survey estimated that one in nine children used some form of CAM,³ and other US studies observed CAM use was higher among children with chronic conditions.⁴⁻¹⁴ In addition, disease prognosis and severity,^{4,5} as well as caregiver characteristics,¹¹⁻¹⁴ have been found to influence CAM use in children.

Although some CAM therapies have been increasingly used in pediatric populations, little data exist regarding CAM use among those affected with Duchenne or Becker muscular dystrophy. Samdup et al.¹⁵ conducted a clinic-based study among Canadian children with chronic medical conditions and observed three of 15 (20%) with Duchenne muscular dystrophy used CAM. A study using data from a population-based cohort of male patients with Duchenne or Becker muscular dystrophy identified by the Muscular Dystrophy Surveillance, Tracking, and Research Network (MD STARnet) estimated that 80% of families used CAM for their children.¹⁶ This analysis also evaluated the impact of caregiver characteristics on CAM use and observed caregivers who reported use of whole medical system therapies for their children were more likely to have college education and a higher family income.¹⁶

With clinical trials investigating the effectiveness of novel therapies for Duchenne and Becker muscular dystrophies increasingly being implemented,^{17,18} information related to patient characteristics and CAM use is important to monitor

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