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RESEARCH SURVEY

The Use of Complementary and Alternative Medicine in Children with Chronic Medical Conditions

ABSTRACT

Samdup DZ, Smith RG, Song SI: The use of complementary and alternative medicine in children with chronic medical conditions. Am J Phys Med Rehabil 2006;85:842–846.

Objectives: The objectives of this study were to examine whether progressive medical conditions lead to greater use of complementary and alternative medicine (CAM) as compared with more stable conditions, to see whether disease severity influences CAM use, and to identify the main motivations behind CAM use.

Methods: Subjects were selected from outpatient clinics at Hotel Dieu Hospital. Surveys were conducted by mail and telephone. Medical diagnosis and severity were obtained from medical files. Statistical tests included χ^2 , Kruskal-Wallis, and correlations.

Results: One hundred ninety-four children were surveyed. The “progressive” group included 15 patients with Duchenne muscular dystrophy and 22 patients with cystic fibrosis. The “nonprogressive” group included 85 patients with cerebral palsy (CP), 49 with diabetes mellitus, and 23 with spina bifida. Twenty-three percent were using CAM. CP had the highest use; diabetes mellitus had the lowest. Popular therapies included massage and dietary/herbal remedies. Progressiveness had no impact on CAM use. Within the CP group, greater disease severity was associated with higher use ($P < 0.001$). The main reason for CAM use was to complement conventional medicine.

Conclusions: Disease progressiveness had no impact on CAM use, but severity within the CP group did. Complementing conventional medicine was the main motive. Understanding the reasons and patterns of use of CAM is beneficial in efforts to improve the care of children with chronic medical conditions.

Key Words: Complementary and Alternative Medicine (CAM), Chronic Illness, Progressive and Nonprogressive Disease, Disease Severity

The use of complementary and alternative medicine (CAM) is increasing worldwide. In a systematic review, the prevalence of CAM use ranged from 9 to 65%.¹ In Japan, 65% of adults use CAM,² whereas in the United States, the use of CAM increased from 34% in 1990 to 42% in 1997.^{3,4} The most recent comprehensive information about use of CAM by Canadians⁵ indicated that 73% of the respondents had used at least one CAM in their lives. The authors estimated that during the year 1997, Canadians spent approximately CDN \$1.8 billion out of pocket on visits to CAM providers and additional CDN \$2 billion on herbs, vitamins, diet programs, and books.

CAM has been defined by The American Academy of Pediatrics⁶ as "strategies that have not met the standards of clinical effectiveness, either through randomized controlled clinical trials or through the consensus of the biomedical community" and by the National Center for Complementary and Alternative Medicine⁷ "as a group of diverse medical and health care systems, practices and products that are not presently considered to be part of conventional Western medicine."

Users of CAM are normally females, white, and higher educated.^{1,8} Chiropractic was the most commonly used CAM therapy both in the United States and Canada,^{5,8} whereas other commonly used therapies were multivitamins, aromatherapy, massage, music, herbal remedies, and spiritual healing.^{9,10}

The pediatric use of CAM is increasing and ranges from 11% in Quebec to 70% in youths in the northwestern United States.^{11,12} CAM therapy in children was associated with parental CAM use^{13,14} and higher parental education.¹⁵ Use is especially increasing in children with chronic illness and disability. CAM use in children with Autism ranges from 30 to 52%,^{15,16} attention deficit hyperactivity disorder from 54 to 68%,^{17,18} cancer 31 to 84%,^{19,20} chronic inflammatory disease 72%,²¹ and arthritis 34%.²² Parents are more exposed to CAM through the media, parent-to-parent contacts, and sophisticated internet marketing. However, what reasons motivate children or their parents to seek CAM? Does the nature of the child's medical condition in terms of severity, chronicity, disease progression, or projected course influence the pattern and extent of use?

Most studies in children address the role of illness characteristics in the use of CAM in single pediatric conditions, but few studies compare the use of CAM in multiple pediatric conditions. Thus, with respect to our specific pediatric population base, we sought to answer the following questions:

1. Are progressive conditions associated with higher use of CAM when compared with conditions that are more stable?
2. Does greater disease severity lead to more CAM use?
3. Is the main motivation for the use of CAM, to complement conventional medicine, or to seek a substitute out of dissatisfaction with conventional treatment? We hypothesized that the use of CAM would be higher among children with progressive conditions than those with nonprogressive chronic conditions, and that within a single condition, those children with more severe disease would exhibit higher use. We also hypothesized that the primary motivation for use of CAM would center on complementing conventional medicine.

METHODS

We conducted this survey in children with chronic medical conditions in Kingston, Ontario, Canada. Patients with cerebral palsy (CP), spina bifida (SB), and Duchenne muscular dystrophy (DMD) were contacted using a database at the Child Development Centre (CDC) at the Hotel Dieu Hospital in Kingston, Ontario. Patients with cystic fibrosis (CF) and diabetes mellitus (DM) were contacted from the database provided by the CF and DM clinics at the same hospital. Our DM group was comprised entirely of type 1 insulin-dependent diabetes.

The parents/guardians of each patient were mailed an information letter, consent, and survey form. They were informed that if they could not be reached by mail, they would be contacted by telephone for the survey and a verbal consent would be requested at that time. The survey collected information on age, sex, and medical diagnosis. After providing a definition of CAM therapies, parents/caretakers were asked whether they currently use CAM and if so, the type of CAM, duration of use, and motives for use (dissatisfaction with *vs.* complementing conventional medicine) were sought. We sought addition satisfaction scores for conventional medicine and CAM were collected, on a scale of 1–10 (10 representing highest satisfaction).

Of the pediatric conditions represented in this study, CP and SB were the only conditions where disease severity could be reliably assigned. Therefore, they are the only conditions for which the impact of disease severity was examined. For CP, severity is measured on a scale of 1–5 in the Gross Motor Function Classification System (GMFCS), with 5 reflecting greatest severity.²³ In SB, the level of spinal lesions generally reflects severity. These levels are thoracic, lumbar, and sacral, with tho-

racic lesions being most severe and sacral lesion least severe. The severity values were obtained from the patient's medical charts and confirmed by CDC physiotherapists. When categorizing the five diagnoses as progressive or nonprogressive, DMD and CF were grouped in the "progressive" disease category, whereas DM, CP, and SB were grouped in the "nonprogressive" disease category.

This study was approved by the Queens University Health Sciences and affiliated teaching hospitals research ethics board.

Statistical Analysis

All statistical tests were set to a significance level of $P < 0.05$. The χ^2 test was used for the comparison of CAM use and motives for use among individual diagnostic groups and also between the "progressive" and "nonprogressive" categories. The Kruskal-Wallis test was used to compare groups as to duration and frequency of CAM use. The Spearman correlation test was used to compare satisfaction ratings among the groups for conventional medicine *vs.* CAM. The Cochrane Armitage trend test compared different severity groups within CP (by GMFCS value) and within SB (by level of lesion) for differences in magnitude and motive for CAM use.

RESULTS

A total of 194 children participated in this study, 15 with DMD, 22 with CF, 49 with DM, 85 with CP, and 23 with SB.

Table 1 shows the characteristics of the participants. The number currently using some form of CAM was 23% (44 of 194). There were significant differences in CAM use across the five individual diagnoses ($P < 0.001$). The highest use was in the CP group (35%) and the lowest in the DM group (6%). There were no differences among the five individual diagnoses with respect to duration of use ($P = 0.492$). Similarly, no difference was seen with respect to frequency of use ($P = 0.673$). Patients

with CF and DMD, who comprise the "progressive group," showed a 19% use of CAM, whereas patients with DM, CP, and SB comprising the "nonprogressive" group showed a 24% use ($P = 0.665$). No significant differences were found with respect to duration ($P = 0.315$) or frequency of use ($P = 0.550$). Most who were using CAM had been long-term users (1 yr or more).

The main types of CAM included: massage (33%), dietary/herbal therapies (23%), chiropractic (21%), hydrotherapy (9%), and others (14%), which included acupuncture, craniosacral, and hypnotherapy. One patient with CP had used hyperbaric oxygen therapy.

No differences were found among the five groups with respect to satisfaction with conventional medicine ($P = 0.474$) or CAM ($P = 0.116$). An analysis of motivation for CAM use revealed no difference between the progressive and nonprogressive groups ($P = 1.000$). In both the groups, 86% indicated that they used the therapies for the purpose of complementing conventional medicine, whereas 14% cited dissatisfaction with conventional therapies (Table 2). No significant differences were found between the two groups with respect to their satisfaction with conventional medicine ($P = 0.710$) or with CAM use ($P = 0.642$).

Within the CP group, greater severity was significantly associated with more use of CAM ($P < 0.001$). With SB, severity of lesions did not affect the use of CAM ($P = 0.411$). Motive for CAM use did not differ by severity of the condition in the CP group ($P = 0.998$) or in the SB population ($P = 0.500$) (Table 3). GMFCS groups within the CP did not differ in satisfaction ratings for conventional medicine ($P = 0.482$) or CAM ($P = 0.262$).

DISCUSSION

We compared the use of CAM in children with chronic progressive disorders and more stable disorders. Our study did not detect an influence of progressiveness of the disease on the use of CAM.

TABLE 1 Use of complementary and alternative therapy

Medical Conditions	Size (N)	CAM Users	Percent of CAM Users	P
Duchenne muscular dystrophy	15	3	20.0	<0.001 ^a
Cystic fibrosis	22	4	18.2	
Diabetes mellitus	49	3	6.1	
Cerebral palsy	85	30	35.3	
Spina bifida	23	4	17.4	
Progressive <i>vs.</i> nonprogressive conditions				0.665 ^b
Duchenne muscular dystrophy + cystic fibrosis	37	7	18.9	
Diabetes mellitus + cerebral palsy + spina bifida	157	37	23.6	

^a Pearson χ^2 test for overall differences.

^b Fisher exact χ^2 test.

CAM, complementary and alternative medicine.

TABLE 2 Motives for use of complementary and alternative therapy

Medical Conditions	Size (n)	Dissatisfaction with Conventional Medicine	Complementing Conventional Medicine	P
Duchenne muscular dystrophy	3	0 (0%)	3 (100%)	0.998 ^a
Cystic fibrosis	4	1 (25%)	3 (75%)	
Diabetes mellitus	3	0 (0%)	3 (100%)	
Cerebral palsy	29	4 (13.8%)	25 (86.2%)	
Spina bifida	4	0 (0%)	4 (100%)	
Progressive versus nonprogressive conditions				1.000 ^b
Duchenne muscular dystrophy + cystic fibrosis	7	1 (14.3%)	6 (85.7%)	
Diabetes mellitus + cystic fibrosis + spina bifida	36	4 (11.1%)	32 (88.9%)	

^a Pearson χ^2 test for overall differences.^b Fisher exact χ^2 test.**TABLE 3** Motive for use of complementary and alternative therapy within cerebral palsy and spina bifida group

Medical Condition	Size (n)	Dissatisfaction with Conventional Medicine	Complementing Conventional Medicine	P
Cerebral palsy				0.998 ^a
GMFCS1	5	0 (0%)	5 (100%)	
GMFCS2	4	1 (25%)	3 (75%)	
GMFCS3	4	1 (25%)	3 (75%)	
GMFCS4	5	1 (20%)	4 (80%)	
GMFCS5	11	1 (9.1%)	10 (90.9%)	
Spina bifida				0.500 ^a
Thoracic	1	0 (0%)	1 (100%)	
Lumbar	2	0 (0%)	2 (100%)	
Sacral	1	0 (0%)	1 (100%)	

^a Cochrane Armitage trend test.

GMFCS, Gross Motor Function Classification System.

This was surprising because we expected parents would be more likely to experiment with CAM use if their child had a progressive illness, which was not likely to improve with conventional therapies. It is possible that our small sample size could have failed to detect a difference or that the finding relates to other characteristics of the conditions we studied. A study from Arizona compared the use of CAM in children with correctable conditions with those with lifelong disability and found that the noncorrectable conditions had significantly higher use of CAM (76 vs. 24%).¹³

Children with CP had a significantly higher use of CAM (35.5%) as compared with other diagnostic categories. Because certain CAM therapies such as aquatherapy and massage are being integrated as part of mainstream therapy for CP, this could contribute to the apparent higher use. The use of CAM therapies increased with severity of cerebral palsy ($P < 0.001$), which was also observed by Hurvitz et al.¹⁴ in their population of CP children. Although Egede et al.²⁴ found adult diabetes

is an independent predictor of CAM use, in our study, the juvenile diabetes group had the lowest use.

The most common CAM use in our population was manipulative methods, including massage (33%), chiropractic (21%), and hydrotherapy (9%). This was similar to the Hurvitz findings, whereas Martel et al.¹⁹ more commonly reported spiritual/mental strategies. The type of CAM use seems to depend on the underlying diagnosis of the child and the availability and recommendations of health caregivers.

The motive for CAM use was primarily for complementing conventional medicine rather than dissatisfaction as noted in the Hurvitz study. Other studies identified reasons such as enhancing child well-being,²⁵ CAM products being natural and organic,¹² and pain relief.²²

There are several limitations to this study. CAM therapy such as hydrotherapy and hypnotherapy is gaining popularity and is now regularly recommended by physiotherapists in our institution

for children with physical disabilities because of purported benefits to tone and flexibility. The sample size was relatively small and the geographic availability of certain CAM may have resulted in regional bias. We did not determine if ease of access or cost influenced the types of CAM used. Finally, the retrospective, cross-sectional nature of the study may have affected the parent's ability to remember.

Parents/caretakers have not lost faith in conventional medicine, because only 14% in this study cited dissatisfaction as motivation for CAM use. Physicians and medical caretakers need to become more knowledgeable with regard to CAM that is harmful or safe to provide effective guidance to patients. Including CAM therapies in the medical school curriculum may be a good idea to sensitize future clinicians to these issues. CAM use may change over time as therapies that prove to be safe and effective may become part of conventional healthcare practice. Clinicians must be cognizant of the need to ask about CAM use as a result of possible negative interactions with conventional treatments. Because CAM use is definitely here to stay, we need more evidence-based CAM therapies using proper scientific research techniques so that clinicians can provide reliable information and advice to patients who can then make informed decision about their health.

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