

# Use of Complementary and Alternative Medical Therapies in a Pediatric Neurology Clinic

Isaac Soo, Jean K. Mah, Karen Barlow, Lorie Hamiwka, Elaine Wirrell

**ABSTRACT:** *Background:* Complementary and alternative medicine (CAM) is increasingly used in adults and children. Studies on CAM in neurological disorders have focused on the adult population and its use among pediatric neurology patients has not been well characterized. *Objectives:* The purpose of this study was: 1) To characterize the prevalence of CAM in pediatric neurology patients; 2) To determine the perceived effectiveness of CAM in these children; 3) To compare the cost of CAM with conventional therapies; and 4) To describe caregiver or patient-related variables associated with the use of CAM. *Methods:* This was a cross-sectional survey of patients and families attending the Alberta Children's Hospital neurology clinic between February and May 2004. Patients were considered eligible if they were between two and 18 years of age and had a known history of neurological disorders. Caregivers completed several self-administered questionnaires regarding their socio-demographic profile, their child's neurological illness, and their experience with CAM. Caregivers also rated their child's quality of life using the Pediatric Quality of Life Inventory. *Results:* One hundred and five of 228 (46%) families completed the survey. The mean age of the neurology patients was  $9.8 \pm 4.5$  years. Forty-six (44%) out of 105 patients received one or more types of CAM, with the most common types being chiropractic manipulations (15%), dietary therapy (12%), herbal remedies (8%), homeopathy (8%), and prayer/faith healing (8%). Caregivers' sociodemographic variables or pediatric health-related quality of life were not significantly associated with the use of CAM. Fifty-nine percent of CAM users reported benefits, and only one patient experienced side effects. There was no significant difference in the total median cost of CAM compared to conventional therapies (\$31.70 vs. \$50.00 per month). Caregivers' personal experience or success stories from friends and media were common reasons for trying CAM. *Conclusions:* The use of CAM was common among pediatric neurology patients. Over half of the families reported benefits with CAM, and side effects were perceived to be few. Physicians should initiate discussion on CAM during clinic visits so that the families and patients can make informed decisions about using CAM. Further studies should address the specific role of CAM in children with neurological disorders, and to determine the potential interactions between CAM and conventional therapies in these patients.

**RÉSUMÉ:** Utilisation de thérapies médicales complémentaires et alternatives dans une clinique de neurologie pédiatriques. Contexte: La médecine complémentaire et alternative (MCA) est de plus en plus utilisée chez les adultes et chez les enfants. Il existe des études sur l'utilisation de la MCA pour traiter les maladies neurologiques chez l'adulte, mais son utilisation chez l'enfant a été peu étudiée. Objectifs: Les buts de cette étude étaient : 1) de caractériser la prévalence de l'utilisation de la MCA chez les patients pédiatriques atteints de maladies neurologiques; 2) d'en déterminer l'efficacité ressentie par les patients; 3) d'en comparer le coût à celui des traitements conventionnels; 4) de décrire les caractéristiques du soignant et du patient qui ont recours à la MCA. Méthodes: Il s'agit d'une étude transversale de patients et de familles suivis à la clinique de neurologie de l'Alberta Children's Hospital entre février et mai 2004. Pour être éligibles à l'étude, les patients devaient être âgés de 2 à 18 ans et être atteints d'une maladie neurologique. Ils devaient compléter eux-mêmes plusieurs questionnaires concernant leur profil sociodémographique, la maladie neurologique de leur enfant et leur expérience de la MCA. Les soignants devaient également évaluer la qualité de vie de leur enfant au moyen de l'Inventaire systémique de qualité de vie, version pédiatrique. Résultats: Cent cinq des 228 familles (46%) ont retourné le questionnaire complété. L'âge moyen des patients était de  $9,8 \pm 4,5$  ans. Quarante-six (44%) des 105 patients avaient reçu un ou plusieurs types de MCA, les plus fréquents étant des manipulations chiropractiques (15%), un traitement diététique (12%), des herbes médicinales (8%), un traitement homéopathique et des pratiques de guérison par la prière et par la foi (8%). Les variables sociodémographiques des soignants ou la qualité de vie liée à la santé chez l'enfant n'étaient pas associées de façon significative à l'utilisation de la MCA. Cinquante-neuf pour cent des utilisateurs de la MCA ont rapporté qu'ils en avaient tiré des bénéfices et seulement un patient a eu des effets secondaires. Il n'existait pas de différence significative quant au coût médian total de la MCA par rapport aux traitements conventionnels (\$31,70 contre \$50,00 par mois). Les raisons principales motivant l'utilisation de la MCA étaient l'expérience personnelle des soignants, des témoignages d'amis ou des publications dans les médias faisant état du succès de ces thérapies. Conclusions: L'utilisation de la MCA était fréquente chez les patients pédiatriques atteints de maladies neurologiques. Plus de la moitié des familles ont rapporté des bénéfices de l'utilisation de la MCA. Ces thérapies étaient perçues comme ayant peu d'effets secondaires. Les médecins devraient aborder ce sujet pendant les visites afin que les familles et les patients puissent prendre des décisions éclairées. Le rôle spécifique de la MCA chez les enfants atteints de maladies neurologiques ainsi que les interactions possibles entre la MCA et les thérapies conventionnelles chez ces patients devraient faire l'objet d'études plus poussées.

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From the Faculty of Medicine, University of Alberta (IS), Edmonton, AB, Canada; Division of Pediatric Neurology, Department of Pediatrics, Faculty of Medicine, University of Calgary (JM, KB, LH, EW), Calgary, AB, Canada.

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Reprint requests to: Jean K. Mah, Alberta Children's Hospital, 1820 Richmond Road SW, Calgary, Alberta, Canada T2T 5C7.

Complementary and alternative medicine (CAM) refers to a broad domain of healing practices that are outside of conventional biomedicine.<sup>1</sup> Complementary and alternative medicine is popular among adults.<sup>2</sup> People who use CAM consider them 'natural' and thus safer than conventional medicines. Parents may also decide to try CAM in their children for the same reasons. In pediatrics, the use of CAM has been described in general<sup>3</sup> and subspecialty services including dermatology,<sup>4</sup> pulmonary,<sup>5</sup> oncology,<sup>6</sup> and rheumatology.<sup>7</sup> However, the use of CAM among pediatric neurology patients remains largely undefined. The purpose of this study was to determine the prevalence of CAM among children attending the pediatric neurology clinic at the Alberta Children's Hospital in Calgary, Alberta. In addition, the study examined perceived adverse effects or benefits of CAM, the self-reported cost of CAM and conventional therapies, and whether the use of CAM was associated with disease-specific factors, pediatric health-related quality of life, or sociodemographic characteristics. The results would hopefully lead to a better understanding of CAM used among pediatric neurology patients, and may guide further formal investigations into efficacy and adverse effects of these therapies.

## METHODS

This study was based on a convenience sample of pediatric patients and caregivers who attended the Alberta Children's Hospital (ACH) pediatric neurology ambulatory clinic between February and May 2004. Each patient was considered eligible to participate if: 1) the child was between two to 18 years old; 2) the child had a known history of neurological illness for six months or longer; and 3) the caregiver was able to complete the questionnaires. Patients new to the neurology clinic were excluded as the study focused on CAM use among children with chronic neurological disorders. Informed consent was obtained from all participants, and each family was assigned a non-descript study number. Patient confidentiality was maintained by not including any personal identifiers on the questionnaires. Caregivers either completed the survey during their child's clinic visit, or returned the completed survey by mail. The study was approved by the University of Calgary Conjoint Health Research and Ethics Board.

The caregivers completed a self-administered questionnaire regarding their sociodemographic profile (including age, ethnicity, marital status, education, employment, and family income) and their child's neurological illness. The caregivers also indicated their experience with CAM, and rated their child's quality of life using the Pediatric Quality of Life Inventory (PedsQL). The PedsQL (version 4.0) is a 23-item multidimensional instrument developed by Varni et al<sup>8</sup> to measure pediatric health-related quality of life. It has been validated for use in children between two to eighteen years of age.<sup>9</sup> Different types of CAM were classified based on Tataryn's<sup>10</sup> framework of body, mind, energy, and spirit paradigm. Descriptive statistics with means, medians and proportions were used to characterize study participants overall and within subgroups. Categorical variables were analyzed using Fisher exact test. Comparisons of continuous variables were made using Student's t-test or Wilcoxon signrank test. All tests

were two-tailed, and p-values less than 0.05 were considered statistically significant.

## RESULTS

A total of 468 children were seen at the Alberta Children's Hospital neurology clinic between February and May 2004. Two hundred and forty patients were excluded because they were either new to the clinic (n=184), younger than two-years-old (n=54), or unable to participate due to limited English language comprehension (n=2). Thus, a total of 228 families were eligible to participate in the study. The 103 (45%) families failed to return the survey, and twenty (8.8%) families had incomplete responses. Analysis was based on the remaining 105 (46%) families.

The mean age of the pediatric neurology patients was 9.4 (standard deviation, 4.3) years, and 64 (61%) were male. Among the 105 children, 62 (59%) had epilepsy, 19 (18%) had headaches, 13 (12%) had neuromuscular disorders, and 11 (11%) had brain injuries and developmental delay as their chief neurological complaints. Their median duration of illness was 30 months (interquartile range (IQR) 16 to 65 months), and their median PedsQL physical and psychosocial scores were 82.1 (IQR, 56 to 94) and 66.7 (IQR, 53 to 81) respectively. Caregivers' mean age was 41.4 (standard deviation, 7.7) years. Additional caregivers' sociodemographic profiles were summarized in Table 1.

A total of 46 (44%) children received CAM, including 24/62 (39%) with epilepsy, 11/19 (58%) with headaches, 6/11 (55%)

**Table 1: Caregivers' Sociodemographic Characteristics**

	Frequency
<i>Relationship to child</i>	
• Mother	94
• Father	8
• Legal guardian	3
<i>Ethnic background</i>	
• White	89
• Non-white	16
<i>Marital status</i>	
• Single, never married, separated, or divorced	20
• Married/common-law	85
<i>Highest level of education</i>	
• High School or less	29
• Trade certificate, diploma, or university degree	76
<i>Employment status</i>	
• Full-time homemaker or work at home	34
• Unemployed or looking for work	4
• Full-time or part-time work outside home	67
<i>Family net annual income</i>	
• \$50,000 or less	39
• More than \$50,000	56
• Unknown	10

**Table 2: Frequency, Types, and Proportions of CAM\* perceived by families to be helpful in pediatric neurology patients**

Types of CAM based on Tatarzyn's framework <sup>10</sup>	Brain Injury		Epilepsy		Headache		Neuromuscular Disease		Overall helpfulness of CAM		
	H†	N‡	H	N	H	N	H	N	H	N	H%
<b>Body</b>											
a. Physical substance											
-Dietary therapy		1	8	1	2	1			10	3	77
-Herbal remedies	1	1	4	1	1			1	6	3	67
-Vitamin therapies		2	2	2			1		3	4	43
-Natural supplements		1	1	2		2		1	1	6	14
-Aromatherapy			3	2					3	2	60
-Aquatherapy								2	0	2	0
b. Physical manipulation											
-Massage		1	3	1	1			1	4	3	57
-Chiropractic		1	7	3	1	3	1		9	7	56
<b>Body-mind</b>											
-Meditation					1				1	0	100
-Biofeedback				1		1			0	2	0
-Relaxation training	2		1		1				4	0	100
-Sensory integration					1				1	0	100
<b>Body-energy</b>											
-Acupressure					1				1	0	100
-Acupuncture			1	2		2		2	1	6	14
-Chinese medicine			1	1					1	1	50
-Homeopathy		1	2	5				1	2	7	22
-Reflexology				1					0	1	0
-T'ai chi / Yoga			1		2				3	0	100
<b>Body-spirit</b>											
-Prayer / faith-healing	1		6	2					7	2	78
<b>Total</b>	4	8	40	24	11	9	2	8	57	49	54

\* Complementary and alternative medicine; †H = helpful; ‡N = not helpful

with brain injuries, and 5/13 (38%) with neuromuscular disorders. Fifteen (33%) patients utilized only one type of CAM, while 31 (67%) patients utilized two or more types of CAM. Among the 46 patients who utilized CAM, a total of 106 CAM were tried (Table 2). The five most frequent types of CAM were chiropractic manipulations (n=16, 15%), dietary therapy (n=13, 12%), herbal remedies (n=9, 8%), homeopathy (n=9, 8%), and prayer/faith healing (n=9, 8%). Among the 13 patients who tried dietary therapy, none of them were on the ketogenic diet. The median duration of CAM was 18 months (IQR, six to 65 months), and a CAM provider was consulted once over the past 12 months (IQR, 0 to 6 times).

The use of CAM among pediatric neurology patients was largely influenced by their caregivers' experience of CAM. The CAM use or non-use was consistent for both caregiver and child in 78 (74%) families. Caregivers' sociodemographic variables including education, marital status, employment, income, and ethnicity were not significantly associated with the use of CAM, nor were patients' age, gender, diagnosis, or duration of symptoms. Twenty-one out of 46 families (46%) cited personal

experience, others' success stories, or information obtained from the media as reasons for trying CAM. Other families used CAM because of spiritual/culture beliefs (20%) or dissatisfaction with conventional medicine (14%). There was no significant association between pediatric quality of life as measured by PedsQL scores and either the decision to use CAM or the number of CAM that had been tried.

The total median self-reported cost of CAM was \$31.70 per month (IQR, \$8.80 to \$106.70). This included a median cost of \$3.00 per month (IQR, \$0 to \$24.20) for medications, and \$33.30 (IQR, \$8.30 to \$83.30) for the purchase of specialty foods, traveling expenses, CAM practitioner appointments, and other miscellaneous costs. In comparison, the total median cost of conventional therapies was \$50.00 per month (IQR, \$16.70 to \$150.00). This included a median cost of \$37.50 (IQR, \$10.00 to \$108.30) for conventional medications, and \$30.00 (IQR, \$10.00 to \$62.50) for other related expenses. Although there was a statistically significant difference between the cost of CAM and conventional medications (p=0.017) among the 14 patients who used both types of treatment, the overall cost of CAM and

conventional treatments were not significantly different for these patients.

Among CAM users, 27 out of 46 (59%) caregivers perceived at least one type of CAM to be helpful for their children. Complementary and alternative medicine was perceived to be effective in 17/24 (71%) patients with epilepsy, 5/11 (45%) patients with headaches, 4/6 (67%) patients with brain injury, and 1/5 (20%) patient with neuromuscular diseases. In regards to the types of CAM, families perceived that dietary therapy (10/13), herbal remedies (6/9), relaxation training (4/4), prayer/faith healing (7/9), and T'ai chi or Yoga (3/3) were particularly beneficial, with greater than 65% response rate (Table 2). Acupressure, meditation, and sensory integration were also perceived by a single patient to be helpful. Only one patient reported possible side effects related to CAM. This patient received homeopathy and experienced a transient increase in seizure activity. Two families changed their child's conventional medicines while taking CAM without involving their attending physicians. Thirty-eight (83%) caregivers whose children used CAM felt comfortable discussing CAM with their family practitioner, pediatrician, or neurologist. Twenty-two (48%) caregivers recommended massage therapy (32%), prayer/faith healing (23%), or dietary supplements (23%) to other families.

## DISCUSSION

The use of CAM was found to be substantial among our pediatric neurology patients. To our knowledge, there have been no published studies on the use of CAM in children with chronic neurological illness. Previous studies reported the prevalence of CAM to be between 9% and 70% in children, with higher proportions of CAM use among those with chronic conditions.<sup>11</sup> The observed association between CAM use and chronic disease warrants further consideration. We speculate that conventional medications may be perceived by families to have limited effectiveness in chronically ill children, and CAM may offer hope when conventional treatment fails. Subsequent longitudinal studies will determine if the use of CAM is associated with improved health-related quality of life in children with neurological disorders.

Similar to other studies, the use of CAM among pediatric neurology patients appeared to be influenced by parental use of CAM, and sociodemographic status did not differ significantly between CAM and non-CAM users.<sup>12,13</sup> Even though the cost of CAM appeared to be more affordable than conventional medications, our study found that the total costs did not differ significantly for each family. In addition, previous studies showed that most types of CAM were used as adjunctive treatments rather than replacement therapies.<sup>14</sup> Rather than reducing costs, CAM use in fact raised the overall treatment expense. Since public health care insurance generally would not subsidize CAM, the decision to use CAM could impose additional financial burden for some families.<sup>2</sup>

In our study the majority of caregivers reported benefits or improvement in their children with CAM, especially in patients with brain injury or epilepsy. Adult studies have suggested that acupuncture<sup>15</sup> and dietary supplements such as riboflavin<sup>16</sup> or coenzyme Q10<sup>17</sup> may be effective for migraine headaches, while the benefit of spinal manipulation remains inconclusive.<sup>18</sup> The role of herbal remedies and dietary supplement for seizures is

unclear,<sup>19</sup> and acupuncture was not beneficial in patients with refractory epilepsy.<sup>20</sup> Compared to adults, there is a paucity of systematic reviews on pediatric CAM.<sup>21</sup> Examples of CAM that have become conventional treatment include ketogenic diet for pediatric refractory epilepsy<sup>22,23</sup> and biofeedback-relaxation training for chronic pediatric headaches.<sup>24-26</sup> Other studies considered acupuncture<sup>27</sup> or magnesium supplement<sup>28</sup> for pediatric migraine, and EMG biofeedback or acupuncture for children with cerebral palsy.<sup>29,30</sup> However, common methodological limitations on CAM research include: 1) significant variation in the use of CAM among study participants, including multiple CAM and unregulated dosages; 2) difficulty in establishing placebo treatments for CAM; and 3) the concurrent use of conventional medications for health promotion or prevention of specific symptoms. Efforts to conduct more stringent randomized clinical trials as well as more systematic reviews of CAM for children with neurological disorders are needed.

In addition to evaluating the efficacy of CAM, it is also important to understand their potential adverse effects. As reviewed by Cuzzolin et al<sup>31</sup> and Niggemann and Gruber,<sup>32</sup> the administration of herbal preparations has been associated with fatal colitis, hepatitis, burns, and multi-organ failure in children. Other complications included pneumothorax and infection from acupuncture, heavy metal poisoning from Asian or homeopathic remedies, and stroke from physical manipulations. In addition, herbs with anti-platelet (ginkgo, garlic, ginseng, and ginger) or anti-coagulant (red clover and chamomile) properties can potentiate the effects of non-steroidal anti-inflammatory drugs and warfarin, and fish oil can interfere with anti-thrombotic treatment. Dietary supplements may also reduce seizure threshold (ginkgo, evening primrose oil and starflower), interact with anti-epileptic drugs (Shankpushpi with phenytoin), or alter drug levels by inhibiting the cytochrome P-450 isoenzymes (grapefruit juice, garlic, Echinacea, licorice, and chamomile).<sup>19</sup> Ephedra has been associated with hemorrhagic stroke or seizures, while valerian and kava-kava may cause liver toxicity, extrapyramidal symptoms, or central nervous system depression. Infants and young children may be more susceptible to the adverse effects of these products.<sup>33</sup>

Despite available medical literature, many families may choose CAM based on inadequate knowledge or inaccurate information.<sup>2</sup> The most common prompts for CAM use in our study included personal experience, word-of-mouth success stories, or advertisement from the media, and not from physicians or other scientific sources. The testimonials that patients rely on for medical advice tend to focus on the positive effects of CAM while emphasizing the side effects of conventional treatments.<sup>34</sup> As patients may not voluntarily disclose their use of CAM,<sup>35</sup> it is important for physicians to inquire about CAM use during clinic visits, and to assist families in making informed decisions about their treatment options. A number of websites such as the National Institutes of Health [access via <http://nccam.nih.gov/>] and the Pediatric Integrative Medicine Project [access via <http://www.holistickids.org>] provide helpful resources for physicians and families.<sup>36</sup>

Potential limitations in our study include small sample size and low response rate. The low response rate is common in research involving self-administered questionnaires.<sup>37</sup> To respect

patients' privacy, we did not collect information on families who chose not to complete the survey. We recognized that those who participated in the study may be more likely to have used CAM, and this could lead to over-reporting of CAM use among child neurology patients. However, our results were consistent with reported prevalence of CAM in children.<sup>11</sup> As the small sample size limited the generalizability of our findings, further multicenter collaborative study on the use of CAM in pediatric neurological disorders will be helpful.

The high interest in CAM was reflected by their frequent use in the pediatric neurology population. The majority of caregivers found CAM to be helpful, and the positive aspects of CAM use were augmented by their infrequent side effects. Even though the cost of CAM was less than conventional medications, there was no significant difference in their overall cost per family. Despite the popularity of CAM, potential interactions between conventional medications and CAM are not well known and of concern for physicians. Further studies to investigate drug interactions, effectiveness, adverse effects, and cost-benefits of CAM are required. With that foundation of knowledge it would then be possible to advocate coverage of efficacious therapies and avoid unsafe therapies for patients.

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