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Correlates of complementary and alternative medicine (CAM) use in Chicago area children with diabetes (DM)

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ABSTRACT

Aims: To correlate complementary and alternative medicine (CAM) use in children with diabetes mellitus (DM) with DM control and other family or disease characteristics.

Methods: Parents/guardians of children with DM were interviewed about demographics, clinical characteristics, CAM use, health care beliefs, psychosocial variables, and religious beliefs. The child's hemoglobin A1c (HgbA1c) value from the visit was collected. Statistical analyses included χ^2 , Fisher's exact test, and 2-sample t-tests.

Results: 106 families with type 1 DM were interviewed. 33% of children tried CAM in the last year; 75% of parents had ever tried CAM. Children most commonly tried faith healing or prayer; parents most commonly tried faith healing or prayer, chiropractic, massage, and herbal teas. Children were more likely to have used CAM if their parents or siblings used CAM or their family was more religious. They were more likely to have discussed CAM with their providers if they used CAM. Parents of child CAM users reported more problems with DM treatment adherence.

Conclusions: Children with DM used CAM. There were no differences in DM control, demographics, healthcare beliefs, stress, or quality of life between CAM users and non-users. Practitioners should inquire about CAM use to improve DM care for children.

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1. Introduction

Complementary and alternative medicine (CAM) is defined by the National Institutes of Health as “a group of diverse medical and health care systems, practices, and products that are not presently considered to be part of conventional medicine” [1]. Estimates of prevalence of CAM use in children range from 11% to 54% [2–8], depending on the definition of CAM, the population of children, and the method of study.

It is thought that children with chronic diseases may have higher rates of CAM use possibly because of frustration with conventional medicine and the desire to search for all possi-

ble resources to improve the chronic condition. Children with cystic fibrosis, asthma, cancer, inflammatory bowel disease, juvenile idiopathic arthritis, and attention deficit hyperactivity disorder (ADHD) have been studied. CAM use in children with these disorders ranges from 32% to 70% [9–17], again depending on the definition of CAM, the specific disorder, and the research methods. In one study of children with ADHD, only 12% reported CAM use, defined as using a chiropractor, massage therapy, homeopathy, acupuncture, or faith healing [18], while in another study of children with asthma, 89% reported CAM use, including 26 possible therapies, both nutritional supplements and activities [19].

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CAM use studies in DM have focused on adults. Yeh et al. found that 57% of survey respondents with DM had used CAM in the previous year, including 21 specific therapies or supplements [20], whereas Egede et al. required visiting a CAM practitioner to define CAM and found that only 8% of adults with DM were using CAM and older age and higher level of education were associated with CAM use [21].

Few data are available regarding the prevalence and correlates of CAM use in children with DM, which affects approximately 1/400-600 children [22]. In the majority of cases, DM requires conventional medical therapy which can be stressful and labor intensive for families. There has been recent interest in this subject in different countries. A Turkish study used a semi-structured interview and found that 52% of children with type 1 DM were using CAM [23] and a German study used a written questionnaire and found that 18.4% of children with type 1 DM were using CAM, including vitamins [24]. A pilot study in Chicago showed that CAM use was prevalent (19%) in children with DM [25]. The current study was conducted to confirm the prevalence in a different Chicago sample and to determine correlates of child CAM use. Specifically, it is the first study to date to examine the relationship of CAM use in children with type 1 DM with overall DM control. It was hypothesized that CAM use would be inversely related to DM control (primarily HgbA1c value), that specific demographic, clinical, health care belief, psychosocial and cultural variables would be related to CAM use and that families did not communicate these activities to the health care team.

2. Methods

2.1. Subjects

Parents/legal guardians of children <18 years of age with DM of at least 1-year duration who were followed at a University of Chicago DM specialty clinic were approached for interview. Families were excluded if their child had another chronic illness, they were not fluent in English, or their child was a primary patient of JM. All families were approached while waiting for their regular appointments in private examination rooms or another private area (convenience sample). The interview was administered by JM, who introduced herself as a researcher, not as a physician. Oral consent was obtained. Data was supplemented by the hemoglobin A1c (HgbA1c) value. A \$10 gift certificate to a local retail store was given as compensation for participation in the study. Confidentiality was maintained by storing all data in password-protected files accessible only to study personnel. After the medical record was accessed for the HgbA1c, all identifying information was removed from the data.

2.2. Data elements measured

This study used a semi-structured interview based on a conceptual model of demographic information, clinical disease characteristics, health care attitudes and beliefs, family stress and the child's general and DM-related quality of life, and cultural beliefs (Fig. 1) [26-31] to determine prevalence and

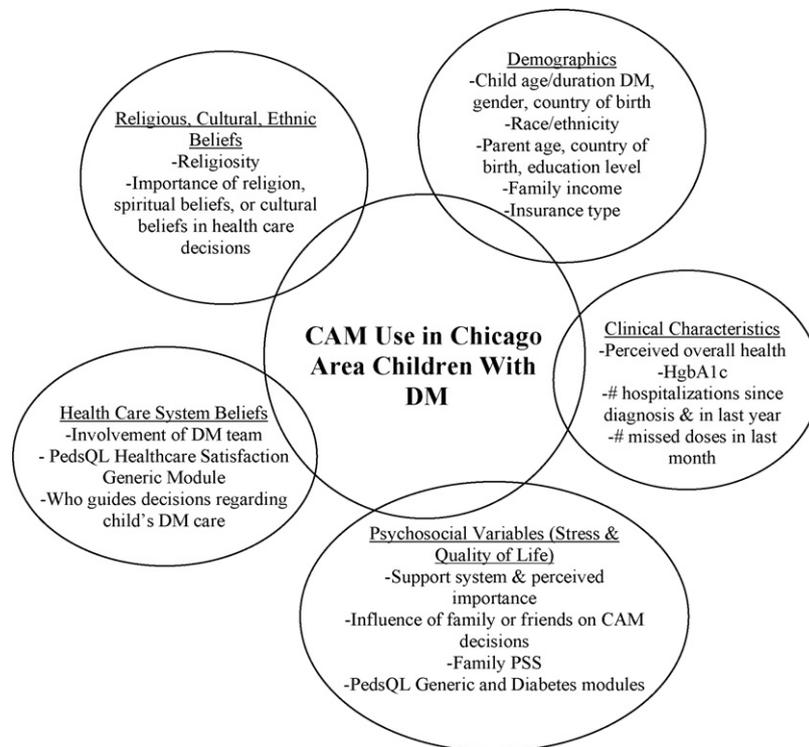


Fig. 1 – Conceptual model of CAM use in Chicago area children with DM.

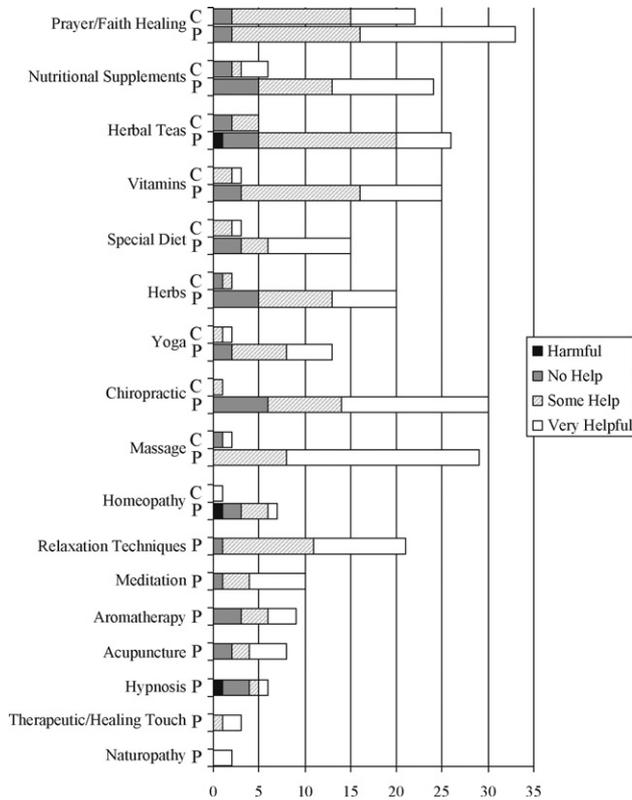


Fig. 2 – Types and prevalence of CAM use in parents (P) and children (C) and their parents' perceptions of effectiveness.

correlates of CAM use in children with DM in the Chicago area. It asked about CAM use in parents and in their children with DM, including the perceived effectiveness of specific therapies. The questions were open-ended and families were given an opportunity to add to or elaborate responses. Parents were asked, "Have you ever tried any treatments or therapies, not recommended by a doctor, for your own health?" Then they were asked about specific therapies as referred to in Fig. 2. For their children, parents were asked, "Have you ever tried any of these treatments or therapies for your child's diabetes, in the last year?" CAM use was defined as use of any therapy used (with the exception of ADA diet, carbohydrate counting, or multivitamins) within the past year for the purpose of helping the child's DM. Whenever possible, validated questionnaires were used, including the Family Perceived Stress Scale (PSS) to assess general current family stress levels [26,27], the Peds QL Healthcare Satisfaction Module [31] to assess families' overall satisfaction with care, the Peds QL Generic Core Scales [28,29] and Diabetes Disease-Specific Module Parent Proxy Reports [30] to assess the parents' views about their children's quality of life. Additional questions were adapted from previous studies about CAM use in children [12,25].

Overall DM control was assessed primarily by HgbA1c. Other variables which also helped in assessing DM control included the number of DM-related hospitalizations and the self-reported number of missed insulin doses. The primary clinical goal of type 1 DM management is normal or near-normal glycemia without complications or severe hypo-

glycemia and HgbA1c is the most common measure used to determine overall control [32].

2.3. Statistical methods

To identify the relationship between CAM use and other variables, univariate analyses were first conducted using χ^2 tests, Fisher's exact tests, or 2-sample t-tests. Those variables that were significant in univariate analysis were included in a multivariate analysis. Analyses were performed using Minitab 13.1 (Minitab, Inc., State College, PA) or Stata 9 (StataCorp LP, College Station, TX). Sample size calculations assumed a significance level of $\alpha=0.05$ and a power of 80%. Sample sizes were calculated based on a presumed prevalence of CAM use of 20%, which would be consistent with a prior pilot study [25]. In that study, the overall clinic population had a mean HgbA1c of 8.9%, so calculations were made to detect a one unit difference in HgbA1c, i.e., 1% [25]. Using these assumptions, the sample size needed to detect such a difference would be a total of 56 subjects.

3. Results

Two hundred forty-five families were available for interview; 125 families qualified for the study. Families did not qualify for the study if the child was 18 years or older ($n=23$), the child had another chronic medical condition such as asthma, celiac disease, trisomy 21, or hypothyroidism ($n=50$), parent was not fluent in English ($n=11$), guardian not available or state custody ($n=10$), or DM <1 year duration ($n=26$). One hundred eleven of the 125 qualifying families (89% response rate) were interviewed from August, 2006 through June, 2007. Because of the small sample size of children with type 2 DM (5%) in this cohort, statistical analyses were performed only on subjects with type 1 DM ($n=106$). The sample is summarized in Table 1.

Seventy-five percent of parents and 33% of children used CAM. There were few differences between CAM users and non-users (Table 2). There were no differences in HgbA1c value between CAM users and non-users (9.3% vs 9% in non-users, $p=0.53$) or any of the other clinical elements examined (Table 2). Children were more likely to have tried CAM if their parents used CAM (42% vs 7% if parents non-users, $p=0.001$) and if their siblings used CAM (89% vs 25% if siblings non-users, $p=0.000$). Families who tried CAM for their children were more likely to have discussed CAM therapies with the DM team (23% vs 7% in non-users, $p=0.020$) or the primary care physician (9% vs 0 in non-users, $p=0.034$). Children who tried CAM reported more problems adhering to their DM treatment plan, mean PedsQL treatment adherence score (SD): 80(10) vs 85(16) in non-users, $p=0.034$ (adherence score ranges from 0–100, with a higher score corresponding to fewer problems). Families who were more religious were more likely to try CAM for their children (54% if very religious vs 24% if somewhat religious, $p=0.001$). No families who identified as "not at all religious" tried CAM for their child.

Child, parent, and sibling CAM use, whether CAM was discussed with the diabetes team, religiosity, and reported difficulty adhering to DM treatment plan were included in a

Table 1 – Participants with Children with type 1 DM characteristics.

	Whole sample	Child CAM users	Child CAM non-users	p-value, users vs. non-users
n	106	35 (33)	71 (67)	
Child age, years	11.9 (3.8)	12.5 (3.8)	11.7 (3.9)	0.28 [†]
Duration DM, years	5.0 (2.8)	5.4 (2.8)	4.8 (2.7)	0.32 [†]
Child sex				
Male	47 (44)	18 (38)	29 (62)	0.30
Female	59 (56)	17 (29)	42 (71)	
Parent age, years	41 (8.5)	42 (7.7)	41 (8.8)	0.38 [†]
Parent/legal guardian interviewed	85 (80)	32 (38)	53 (62)	0.17 [*]
Mother	19 (18)	3 (16)	16 (84)	
Father	1 (1)	0	1 (100)	
Uncle	1 (1)	0	1 (100)	
Grandparent				
Race/ethnicity [‡]				
Black/African-American	31 (29)	10 (32)	21 (68)	0.71 [*]
White	72 (68)	25 (35)	47 (65)	
Other	3 (3)	0	3 (100)	
Interview location				
Urban	83 (78)	25 (30)	58 (70)	0.32
Suburban	23 (22)	10 (43)	13 (57)	
Home location				
Urban	38 (36)	11 (29)	27 (71)	0.80
Suburban	57 (54)	20 (35)	37 (65)	
Rural	11 (10)	4 (36)	7 (64)	
Insurance				
Private	71 (67)	26 (37)	45 (63)	0.26
Public aid	35 (33)	9 (26)	26 (74)	
Parent education				
HS or less	22 (21)	7 (32)	15 (68)	0.65 [*]
Some college	42 (40)	16 (38)	26 (62)	
4-year college or more	42 (40)	12 (29)	30 (71)	
Parent birth place				
US born	99 (93)	33 (33)	66 (67)	0.80
Foreign	7 (7)	2 (29)	5 (71)	
Annual Income				
<\$40K	29 (30)	6 (21)	23 (79)	0.16 [*]
\$40K or more	69 (70)	25 (36)	44 (64)	
Child's overall health				
Good or excellent	94 (89)	33 (35)	61 (65)	0.33 [*]
Fair or poor	12 (11)	2 (17)	10 (83)	
HgbA1c (%)	9.1 (1.9)	9.3 (2.3)	9 (1.7)	0.53 [†]

Data are n (%) or means (standard deviation). p-values are using χ^2 , except (*) using Fisher's exact test, (†) using paired t-test. (‡) 8% of sample was Hispanic.

multivariate logistic regression model. Families who were very religious were more likely to try CAM for their child (OR (95% CI) = 4.96 (1.43–17.25), $p = 0.012$). Child CAM users were more likely to have siblings who also used CAM (OR (95% CI) = 15.55 (2.84–84.98), $p = 0.002$). The other variables were not significant using multivariate analysis.

Types of CAM used by parents and children, and their perceived effectiveness, are summarized in Fig. 2, in descending order of prevalence of child CAM use. For parents, herbal therapies most often tried were St. John's Wort, echinacea, and ginkgo biloba. They most commonly tried green tea or chamomile tea. Nutritional supplements included fish oil,

flax seeds, coenzyme Q10, calcium supplements and B, C, and E vitamins. Special diets included vegetarian, soy, Atkins, Weight Watchers, and "eating once a day". Other therapies mentioned included pilates, reflexology, and laser treatments. Children tried similar therapies as well as cinnamon, "diabetic" teas, phycotene cream for skin lesions, hot water in the shower for relaxation, nopales (cactus) and celery drinks.

There were no significant relationships between child's specific use of prayer or faith healing and religiosity, importance of religion, spiritual, cultural, or ethnic beliefs in health care decisions. One family reported substituting insulin with prayer.

Table 2 – Relationships between child CAM users and elements of the conceptual model.

Conceptual model	No significant relationship between child CAM use and ...	Significant relationship between child CAM use and ...
Demographics	Child's age, parent's age, race, ethnicity, location of interview, home location, child's sex, which parent interviewed, main language at home, insurance type, parental education level, parental birth place, family income, household size	None
Clinical characteristics	Child's overall health, HgbA1c, duration of DM, whether the child had ever been hospitalized or hospitalized in the last year for a DM-related problem, number of missed medication doses	None
CAM	If parent's argued about child's CAM use, if child didn't take prescription medicines because using CAM instead	Parent CAM use, sibling CAM use
Healthcare system beliefs	Healthcare satisfaction, comfort discussing CAM with the DM team or the primary care doctor, family's belief of the DM team or the primary care doctor's opinions about CAM, who makes most decisions regarding child's DM care, opinion if DM team or primary care doctor's beliefs about healthcare are similar to their own	Actually discussing CAM with the DM team or the primary care doctor
Psychosocial variables (stress, quality of life)	How important is support for DM, amount of support for child's DM, source of family's support, child's overall, physical, psychosocial, or DM-specific quality of life (in general and related to worrying about DM), influence of family or friends on child's CAM use, family's overall stress	Problems adhering to DM treatment plan
Ethnicity, culture and religion	Importance of religion, spiritual beliefs, or cultural or ethnic beliefs in family's health care decisions	Family's religiosity

Families most commonly tried CAM for their child because CAM worked better than prescription treatments, or to improve overall health. They chose not to try CAM for their child because they were unsure if therapies would be safe or effective, or because CAM was not recommended by the health care team. When asked about the role of CAM therapies in the care of children with DM, most families indicated they were not sure, or thought CAM might improve overall health. Only two families indicated that CAM could replace prescription medicines and four thought CAM might be harmful. Most families who tried CAM for their child learned about the therapies by reading about them, at their church or place of worship, or from a friend or family member. Families who tried CAM for their child stated that “[prayer, yoga] helps to relax and decrease stress which helps keep the blood sugars under control” and “[we use acupuncture] for his overall health, it's a natural alternative or can be used in conjunction [with the diabetes treatment]”. Families who did not try CAM for their child stated: “We don't venture off the beaten path with him. We could if we had some instruction and support” and “I just focus on checking his sugar and giving his insulin and hopefully one day they will come up with a cure or something better than what they have now.”

4. Discussion

We confirmed that CAM use is prevalent in children with DM (33%) and found that it does not correlate with control of diabetes. Child CAM use was associated with parental CAM use in univariate analysis and with CAM use in the child's healthy siblings in both univariate and multiple variable models. Child CAM users reported more problems with adherence to the DM

plan than non-users in univariate analysis, with a small, but statistically significant difference. This might lead one to speculate reasons for CAM use, such as frustration with DM care, but only three respondents reported this as a reason for CAM use in their child. In addition, although CAM users had more problems with adherence, they still had a high score in this area (80/100).

As in McCurdy's study of pediatric cancer patients, the respondents in this study were more likely to use CAM if they reported being more religious in univariate and multiple variable models [12]. However, when asked further about how important religion, spiritual beliefs, or cultural beliefs were in the family's health decisions, there was no relationship with child CAM use. Prayer was the most common CAM used by children in this sample (22/35 CAM users) (Fig. 2), but using prayer was not specifically related to religiosity and all but one family used prayer as an adjunct to insulin treatment.

CAM use prevalence in children with DM varies, depending on the definition of CAM and the locale of the study. In Arykan's study in Turkey, the National Institutes of Health definition of CAM was used; prevalence of CAM was higher, 52%, and herbal therapies such as aloe vera and stinging nettle were the most common herbs tried [23]. In Dannemann's German study, only 18.4% of children had tried CAM, and homeopathy was the most common therapy tried [24]. The German study also included vitamin use in the definition of CAM [24]. It is clear that different countries and cultures have different CAM preferences and this is shown with our US sample, where prayer was most commonly used. A pilot study examined 86 families of children with type 1 DM in Chicago [25]. CAM prevalence in this sample was 19%, and child CAM use was associated with parent CAM use and with foreign-born

parents [25]. The current study used the same CAM definition; it is possible that prevalence was lower in the prior study because of poor response rate (35%) in that study. Wilson et al. examined CAM use in 50 healthy children and 50 children with DM in New Zealand, and found prevalence of lifetime CAM use to be 70% in both samples [33]. The definition of CAM included oral or topical supplements, including multivitamins [33]. CAM use was associated with parental CAM use and most families did not discuss CAM use with their practitioner [33]. Another study examining pediatric chronic diseases (Duchenne muscular dystrophy, cystic fibrosis, DM, spina bifida, and cerebral palsy (CP)), had the highest rate of CAM use (35%) in children with CP ($n=22$) and the lowest rate (6%) in patients with DM ($n=49$) [34].

It is interesting to note that there were no significant associations between CAM use and demographic variables or clinical DM characteristics in this study. Specifically, child CAM use was not related to HgbA1c, number of hospitalizations, or number of missed insulin doses. Practitioners should remember that any of their patients might be experimenting with treatments that have not been recommended, and every family should be asked about CAM use, including prayer. Also, this study examined family health care belief systems, psychosocial variables, stress, and quality of life in detail with validated questionnaires [26–31] and did not find any differences between CAM users and non-users in these areas with the exception of reported difficulty adhering to DM treatment plan.

Greene et al. examined cultural differences in family and community involvement in adolescent DM management in two Scottish populations [35]. Sudhir and Kumaraiah explored the role of family in a case study of an Indian girl with type 1 DM [36]. In both studies, more support from the family and surrounding community was associated with improved DM control. This study did not demonstrate correlation between family or community support and DM control.

Families were trying fewer supplements (teas, nutritional supplements, vitamins, herbs, or special diets) than activities, for their child. These could be thought to have more potential for harm than activities such as prayer, yoga, or massage therapy, which might be considered safe when used in conjunction with prescribed therapies. However, most of the supplements tried, such as flax seed oil or fish oils, though not specifically recommended by these families' health care teams, could be considered healthy, reasonable, and perhaps mainstream. Several children had tried cinnamon; doses were not specified, but some families stated they added it to their child's food. A recent study by Altschuler et al. examined the effect of cinnamon on HgbA1c in adolescents with type 1 DM and did not find any improvement in DM control [37]. No adverse effects were reported in this study [37], suggesting that, while cinnamon is not an effective way to improve DM control in adolescents with type 1 DM, it is likely not harmful either.

It is important to note that many mainstream practitioners have been resistant to CAM use for several reasons: (1) they are not familiar with these modalities and do not know how different supplements or activities might interfere with current mainstream therapies such as insulin; (2) they are fearful that if families are given an "OK" for CAM treatments than they will become less adherent to the conventional DM plan;

(3) they might not approve of adding therapies to the treatment plan that might not be helpful, as the treatment plans are already tedious.

The results of this study address some of these issues. Most complementary activities reported by these participants are relatively safe. For example, yoga, massage, relaxation techniques, and chiropractic treatments in experienced hands, will not incur a greater risk than the regular exercise that is routinely prescribed for children with DM. Prayer and spirituality used adjunctively should not impart harm to the patient. If these therapies help families to cope with their child's DM, practitioners should not categorically oppose the use of CAM. It should be noted that there were no differences in stress and ability to cope in this sample. It may be that some families cope well without these adjuncts, and other families feel the need to use all of their available options to optimize their child's DM care.

One caveat is that one of the 106 families reported that they had substituted prayer as an alternative to insulin, a practice that could have quickly become life threatening. This underlines the importance of health care teams being aware of CAM and maintaining open communication between families and the DM health care team. With proper education, more support, and open minds about the use of prayer as an adjunct to insulin therapy from the DM team, this family may not have attempted to do without insulin. Only five families reported that they would be uncomfortable discussing CAM with the DM team, but only 13 families actually discussed it. Of those who did not discuss CAM use with their practitioners, 27 (29%) reported trying CAM for their child. It behooves the practitioner to bring up the subject of CAM, including prayer, and engage with families in open discussion. Practitioners need to learn about what CAM therapies are available, and what is being tried, to be able to help these families. Specifically, it is most important to learn about what therapies may be used which can be harmful or dangerous and to engage patients and families in open discussions about these therapies.

4.1. Limitations

This study was limited by possible bias in having the same person (JM) design the study, interview the families, enter data, and analyze data. Although the sample size was large enough to detect clinically significant differences in HgbA1c (1%), a larger sample size may have been beneficial to detect smaller differences in family characteristics or beliefs and CAM use. This sample was also limited by a single geographic area and the ability to include only families who were fluent in English. There may be regional or cultural differences in prevalence and types of CAM use which this study was not powered or designed to decipher. Families were asked to report CAM use only if it had been tried in the previous year specifically for the child's DM. It is possible that families are trying additional or different CAM therapies for their children's overall health, which was not assessed by this study.

Prevalence of CAM use in children with type 1 DM is significant, but is not related to HgbA1c, or other characteristics of overall DM control. As the response rate of 89% shows, families are willing to discuss CAM with their practitioners. Many families stressed their reliance on the DM team for guidance in

the area of CAM use. It is important that practitioners educate themselves and their patients on safe complements to traditional DM care. The use of low dose nutritional supplements is likely to be harmless. Might yoga, pilates, and relaxation techniques help a young child deal with anxiety about DM or overall stress, which may in turn, lead to improved glycemic control? This study suggests that multidisciplinary pediatric DM health care teams should openly communicate with families about CAM therapies to learn about the modalities families employ for their children and what their rationale for doing so may be. Practitioners need to broach the subject of CAM with their patients and engage in a mutual learning experience; in doing so, they should consider one of the most important mantras of medicine, "Primum non nocere", or "First, do no harm."

Conflict of interest statement

Jennifer Miller received a speaking honorarium from Advocate Christ/Hope Children's Hospital, Oak Lawn, IL, USA.

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