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Use of Complementary Medicine in Pediatric Patients With Inflammatory Bowel Disease: Results From a Multicenter Survey

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Abstract

Objectives—We examined the use of complementary and alternative medicine (CAM) at 3 US pediatric medical centers, comparing a group of children with inflammatory bowel disease (IBD) with children presenting with chronic constipation.

Materials and Methods—Surveys were administered by postal mail and at pediatric IBD centers in San Francisco, Houston, and Atlanta from 2001 to 2003. A comparison group consisting of pediatric patients with chronic constipation also was surveyed. Data were analyzed by *t* tests and by exact tests of contingency tables.

Results—In all, 236 surveys were collected from the IBD group; 126 surveys were collected from the chronic constipation comparison group. CAM therapies were used by 50% in the IBD group and 23% in the chronic constipation group. The overall regional breakdown of CAM use in IBD revealed no differences, although the types of CAM therapy used varied by site. The most commonly used CAM therapies in the IBD group were spiritual interventions (25%) and nutritional supplements (25%). Positive predictors for CAM use in IBD include the patient's self-reported overall health, an increase in the number of side effects associated with allopathic medications, white ethnicity, and parental education beyond high school.

Conclusions—This is the first US study to characterize CAM use in pediatric patients with IBD with another chronic gastrointestinal disorder. CAM use was twice as common with the IBD group compared with the chronic constipation group. Regional variations exist with the types of CAM therapy used. Practitioners should know that half of their pediatric patients with IBD may be using CAM in conjunction with or as an alternative to other treatments and that certain predictors can help identify those using CAM therapies.

Keywords

Complementary and alternative medicine; Constipation; Inflammatory bowel disease; Survey study

Inflammatory bowel disease (IBD) is a chronic and relapsing condition characterized by inflammatory infiltrates in the gastrointestinal tract, often requiring repeated exposures to steroids and other immunomodulators and frequent invasive procedures. The prevalence of IBD ranges between 12 and 40/100,000, with approximately 25% of all new patients diagnosed before 20 years of age (1,2). Conventional therapies are associated with significant adverse effects, especially corticosteroids with their common side effects and negative impact on the growing and developing child and adolescent. Considering these factors, coupled with a rising interest in alternative therapies, it is not surprising that the use of complementary and alternative medicine (CAM) in chronic pediatric illnesses is reported to be as high as 30% to 70% (3–5).

The National Institutes of Health define CAM as a group of diverse medical and health care systems, practices, and products that are not presently considered to be part of conventional medicine. When prayer is included specifically for health reasons in the definition of CAM, 62% of US adults have used some form within the past 12 months. This value drops to 36% when prayer is excluded (6). Numerous studies have evaluated the use of CAM in the adult IBD population (7–9); however, the information on CAM in the pediatric population, most of which comes from countries other than the United States, is limited. US studies that used the 1996 Medical Expenditure Panel Survey database showed an overall prevalence of childhood CAM use between 1.8% and 2%, with an annual expenditure of \$149 million on CAM visits and remedies (10,11). It is interesting to note that these percentages were far lower when compared with other non-US estimates (12,13). Yussman et al (11) suggested regional differences within the United States, with the prevalence of CAM being more than 2-fold higher in western compared with northeastern states.

Data on CAM use in the pediatric IBD population are equally sparse. Published national and international pediatric studies report a wide range of use: 7% to 72% of this population have used CAM therapy or seen an alternative medicine practitioner (14–17). Of these studies, 2 included patients from the United States, and only 1, Markowitz et al (16), exclusively investigated US subjects but was limited specifically to the greater Philadelphia area and the surrounding counties in Delaware, New Jersey, and Pennsylvania. In the Markowitz et al study, patients were included based on census data from the 2000 US Census identifying the total number of children living in the surveyed area (16). They estimated that the prevalence of CAM was 50.8% within the previous 12 months. The most common types of CAM used were identified as nutritional supplements, followed by special diets (milk-/dairy-free, low carbohydrates, gluten-free), and only a small percentage used herbal remedies (5.1%). Prayer was not included as an alternative therapy. The perceived benefits of CAM were not outlined. In their analysis, a diagnosis of Crohn disease, frequent school absences, and the use of corticosteroids, antibiotics, immunomodulators, and biological therapies were associated with increased prevalence of CAM use.

Heuschkel et al (15) conducted a similar study and included children and young adults with IBD living in the United Kingdom, Michigan, and Massachusetts. The frequency of CAM use was 41%, and the most commonly reported treatments were megavitamins, dietary supplements, and herbal remedies. Prayer, included in a larger category of “environmental and lifestyle changes,” accounted for 10%. Dietary supplementation was not categorized as a CAM therapy. Overall perceived benefit was “a little” on a 3-point Likert scale. Variables increasing the likelihood of using alternative therapies included parental CAM usage and number of adverse effects from conventional therapies.

Our aim was to further characterize CAM use in an exclusively US pediatric IBD population. We sought to identify whether regional differences exist with CAM therapies in this patient group and to define any predictors to help identify patients who may use CAM.

Additionally, we included a comparison group to establish whether differences exist in CAM use between pediatric patients with IBD and those with constipation, representing another group of children with a chronic gastrointestinal condition.

MATERIALS AND METHODS

Complementary and alternative medicine use was evaluated using a cross-sectional survey administered at pediatric IBD centers in San Francisco, Houston, and Atlanta during regular clinic visits and by postal mail from 2001 to 2003. Those taking the survey were categorized into 1 of 2 groups: patients with IBD or with chronic constipation. The IBD group consisted of subjects diagnosed with Crohn disease, ulcerative colitis, or indeterminate colitis. Potential subjects were identified using patient databases maintained at each pediatric IBD center. The comparison group included pediatric subjects with chronic constipation for greater than 6 months and who were followed up by a pediatric gastroenterologist at 1 of the centers. We specifically limited our survey to pediatric subjects under 21 years of age who were diagnosed as having either IBD or chronic constipation. Surveys were coded with an identification number to ensure confidentiality.

The IBD and constipation groups received the same instrument, which was completed by the subject's primary caregiver (eg, parent, guardian) or the patient. The survey consisted of 12 questions addressing demographics, disease history, allopathic medications used, reasons for using CAM, the child's overall health, and lifestyle limitations due to disease. It included 26 specific therapies, in addition to 5 general categories of alternative therapies and practitioners. We included prayer and religious help used specifically to address illness. Nutritional supplements, excluding prescribed therapies such as amino acid-based formulas, also were included, but dietary modifications were omitted because the spectrum of treatment made it difficult to define them as allopathic or alternative. Detailed descriptions of dietary modifications were not requested on the survey. Survey takers indicated whether certain general and specific therapies were ever used by the subject as a treatment for the clinical diagnosis. They were able to write in specific CAM therapies used that were not indicated explicitly on the survey. Survey takers were asked to rate the perceived effectiveness of the treatment using a 4-point Likert scale. The instrument took approximately 10 minutes to complete.

Surveys were distributed to 300 patients with IBD and 150 patients treated for constipation. All 3 centers surveyed 100 patients with IBD. The Houston center distributed surveys to 100 patients with constipation, and the San Francisco and Atlanta centers each distributed surveys to 25 patients with constipation.

Data were analyzed by *t* tests and by exact tests of contingency tables. Analyses concentrated on positive predictors for the use of CAM, how specific CAM treatments varied by region, and perceived benefits of therapies. Tests were considered statistically significant at $P < 0.05$. The institutional review boards of the University of California, San Francisco, Children's Hospital, Texas Children's Hospital, Houston, and the Children's Center for Digestive Health Care, Atlanta, approved the study.

RESULTS

Of the 450 distributed surveys, 362 surveys were collected (Atlanta = 72, Houston = 197, San Francisco = 93). The response rate for the IBD group was 78.7%, whereas the response rate for the constipation group was 84.0%. The response rate also differed by center (Atlanta = 57.6%, Houston = 98.5%, San Francisco = 74.4%). All of the surveys distributed in the clinics were completed (100% response rate), and approximately half of the mailed surveys

were completed and returned (48.4% response rate). Of the surveys analyzed, 236 were collected from the IBD group (146 Crohn disease, 88 ulcerative colitis, and 2 indeterminate colitis), and 126 were collected from the chronic constipation group. Demographic characteristics of the responders are presented in Table 1.

The overall reported use of at least 1 type of CAM was 49.6% in the IBD group and 23.0% in the constipation group. About one third of CAM users reported using more than 3 different therapies, evident in both the IBD and constipation populations. The average age of those using 1 or 2 CAM therapies was not different from those using 3 or more CAM therapies. Regional breakdown of overall CAM use in IBD revealed no differences (52.0% in Houston, 50.7% in San Francisco, and 44.8% in Atlanta; $P = 0.641$). In the San Francisco area, 64% used more than 3 CAM therapies compared with 49% in Houston and 47% in Atlanta.

Responders specified more than 45 different CAM therapies (Table 2). These different types of CAM were classified into 4 categories: spiritual interventions, nutritional supplements, herbal remedies, and alternative practices. Overall, the most commonly used CAM in the treatment of IBD was spiritual intervention, followed closely by nutritional supplements. The type of CAM treatments within the IBD group varied by site: Houston patients used more spiritual interventions ($P = 0.046$) and San Francisco patients used more alternative practices ($P = 0.001$) (Fig. 1).

Survey takers were asked to list subjects' current prescription medications. These data revealed that 43.6% of all patients with IBD used both prescription medications and CAM therapies in the treatment of their disease. The results also showed that in both the constipation and IBD groups, some patients did not use any prescribed therapies, opting for either CAM only or no therapy (Fig. 2).

Several positive predictors for CAM use in IBD were identified. These included the patients' self-reported overall health ($P = 0.012$), an increase in the number of side effects associated with allopathic medications ($P = 0.004$), being of white ethnicity ($P = 0.039$), and parental education beyond high school ($P = 0.044$). The perceived effectiveness of CAM therapies was examined and this suggested that patients with IBD perceive greater benefit from CAM usage compared with the constipation group (Table 3). The majority of standard therapy users in both the IBD and constipation groups believe that their treatments improve their condition (Table 4).

DISCUSSION

Our report is the second study to detail CAM use exclusively in US pediatric IBD patients and is the first study to analyze regional differences of CAM use and characterize its use against a comparison group. Although the constipation comparison group used far more CAM than the general pediatric population, CAM use was only half as prevalent in this group compared with the IBD population (10,11).

The overall prevalence of CAM use in pediatric patients with IBD was similar to previous studies, including a US population, at 40% to 50% (15,16). If we exclude prayer, as have some other studies, then the percentage that used CAM would be 36.4%; however, the perceived degree of benefit from this therapy supports its inclusion (Table 3). The use of herbal remedies by our population was 4 times more prevalent than in the study surveying the greater Philadelphia area (16). This could reflect true regional variations of herbal use, differences in the survey instrument used, or possibly a sampling issue because the latter study included a number of private pediatric gastroenterology practices. The regional breakdown of CAM use revealed almost twice as much spiritual intervention at the Houston

center compared with the San Francisco center. Conversely, nearly twice as many nutritional supplement users were found at the San Francisco center compared with the Houston center.

Several predictors of CAM use in the IBD population were identified. Positive predictors included the patient's self-reported overall health as "poor," an increase in the number of side effects associated with allopathic medications, being of white ethnicity, and parental education beyond high school. If we categorized spiritual intervention separately as a "noninvasive" alternative therapy, then it would be the only negative predictor of CAM use. This may indicate that patients choose spiritual interventions over other types of CAM because of concerns about medication side effects or drug interactions.

Our data on perceived benefits of CAM therapy revealed differences from pediatric populations previously studied in Australia, the United Kingdom, and the United States. Direct comparisons may be difficult, however, because the Likert scales were not uniform between the surveys (14,15). On average, 70% and 66% of patients with IBD who used spiritual interventions and nutritional supplements, respectively, reported that these therapies "improved" their condition. The strong belief that CAM agents are providing improvement is a clear indicator that CAM use will not only continue but also is likely to increase in the future. In fact, the perceived benefit of CAM therapy was relatively close to the average perceived benefit of standard therapies, which was 80% (Table 4).

Our study has several limitations. We had a discordant survey response among the 3 centers and between the 2 comparison groups. We lacked representation from a northern US geographic location, making direct comparison with the Markowitz study difficult (16). The average age of the constipation group was significantly younger than that of the IBD group, potentially influencing the likelihood of using alternative therapies. Finally, when considering the perceived effectiveness of CAM therapies, only probiotics were confirmed to have reached statistical significance ($P = 0.02$). Both low power and dependence between tests make further individual tests dubious, and the sparseness of the data makes a multivariate test impossible.

As the definition of CAM evolves, consensus as to what therapies should be included becomes difficult. Centers for Disease Control and Prevention data on adult CAM use clearly show that CAM definitions can account for a large difference in reported usage (6). Even so, clinicians should know that approximately half of their pediatric patients with IBD and a significant portion of their patients with chronic constipation may be using CAM in conjunction with or as an alternative to other treatments. Further understanding of the interaction of these alternative treatments with the standard prescribed therapies is warranted.

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FIG. 1.

Specific complementary and alternative medicine therapies were categorized as spiritual interventions, nutritional supplements, herbal remedies, and alternative practices, and the mean percentage of use in inflammatory bowel disease subjects is shown for each category at each of the 3 sites.

FIG. 2.

Treatment choices were determined for both the inflammatory bowel disease (IBD) and constipation groups and reported as mean percentages, categorized as prescription (RX) only, complementary and alternative medicine (CAM) only, both RX and CAM, or neither RX nor CAM.

Table 1

Demographic characteristics of subjects who responded to the survey

	IBD, n = 236	Constipation, n = 126
Age, y		
Mean	13.6 ±9.6	6.6 ±12.4
Range	2–21	1–19
Location (%)		
Houston	100 (42.4)	97 (77.0)
San Francisco	69 (29.2)	24 (19.0)
Atlanta	67 (28.4)	5 (4.0)
Diagnosis (%)		
Crohn disease	146 (61.9)	-
Ulcerative colitis	88 (37.3)	-
Indeterminate colitis	2 (0.8)	-
Race (%)		
White	203 (86.0)	104 (82.5)
African American	24 (10.2)	15 (11.9)
Native American	1 (0.4)	1 (0.8)
Asian	4 (1.7)	2 (1.6)
Other/unknown	4 (1.7)	4 (3.2)
Survey taker (%)		
Mother	182 (77.1)	110 (87.3)
Father	27 (11.4)	10 (7.9)
Self	24 (10.2)	2 (1.6)
Other/unknown	3 (1.3)	4 (3.2)
Survey taker education level (%)		
High school	58 (24.6)	37 (29.4)
College	115 (48.7)	68 (53.9)
Graduate school	60 (25.4)	20 (15.9)
Other/unknown	3 (1.3)	1 (0.8)

IBD = inflammatory bowel disease.

Table 2

Types of complementary and alternative medicine therapies used

	IBD, n = 236	Constipation, n = 126
Spiritual interventions (%)	59 (25.0)	12 (9.5)
Religious help (unspecified)	57 (24.6)	12 (9.5)
Prayer (%)	38 (16.1)	8 (6.3)
Nutritional supplements (%)	57 (24.6)	12 (9.5)
Probiotics (%)	52 (22.0)	8 (6.3)
Omega-3 fatty acids	20 (8.5)	7 (5.6)
Butyrate (Cal-Mag)	6 (2.5)	0 (0.0)
Macaroons	3 (1.3)	0 (0.0)
Other	4 (1.7)	1 (0.8)
Herbal remedies (%)	46 (19.5)	14 (11.1)
Herbal preparations (unspecified)	27 (11.4)	9 (7.1)
Aloe	24 (10.2)	3 (2.4)
Chamomile	9 (3.8)	4 (3.2)
Echinacea	9 (3.8)	4 (3.2)
Licorice root	5 (2.1)	0 (0.0)
Slippery elm	4 (1.7)	2 (1.6)
Milk thistle	4 (1.7)	0 (0.0)
Other	18 (7.6)	0 (0.0)
Alternative practices (%)	33 (14.0)	13 (10.3)
Nonmedical practitioners (unspecified)	23 (9.7)	6 (4.8)
Homeopathy	9 (3.8)	0 (0.0)
Acupuncture	6 (2.5)	2 (1.6)
Chiropractor	5 (2.1)	3 (2.4)
Massage	3 (1.3)	2 (1.6)
Other	11 (4.7)	4 (3.2)

IBD = inflammatory bowel disease.

Table 3

Perceived effectiveness of particular complementary and alternative medicine therapies

	IBD					Constipation				
	n	Improved,%	No change, %	Worsened,%	Hard to tell, %	n	Improved,%	No change, %	Worsened,%	Hard to tell, %
Spiritual interventions										
Religious help (unspecified)	57	68.4	15.8	0.0	15.8	12	50.0	33.3	0.0	16.7
Prayer	38	71.1	10.5	0.0	18.4	8	50.0	25.5	0.0	25.0
Nutritional supplements										
Probiotics	52	61.6	11.5	0.0	26.9	8	12.5	37.5	12.5	37.5
Omega-3 fatty acids	20	35.0	10.0	5.0	50.0	7	42.8	28.6	0.0	28.6
Butyrate (Cal-Mag)	6	66.6	16.7	0.0	16.7	0	0.0	0.0	0.0	0.0
Macarons	3	100.0	0.0	0.0	0.0	0	0.0	0.0	0.0	0.0
Herbal remedies										
Herbal preparations (unspecified)	27	51.9	22.2	0.0	25.9	9	33.3	44.4	11.1	11.1
Aloe	24	54.2	16.6	0.0	29.2	3	0.0	100.00	0.0	0.0
Chamomile	9	55.6	11.1	0.0	33.3	4	25.0	75.0	0.0	0.0
Echinacea	9	66.7	0.0	0.0	33.3	4	25.0	25.0	0.0	50.0
Licorice root	5	20.0	20.0	0.0	60.0	0	0.0	0.0	0.0	0.0
Slippery elm	4	50.0	25.0	0.0	25.0	2	0.0	50.0	50.0	0.0
Milk thistle	4	75.0	0.0	0.0	25.0	0	0.0	0.0	0.0	0.0
Alternative practices										
Nonmedical practitioners (unspecified)	23	43.5	34.8	0.0	21.7	6	16.7	83.3	0.0	0.0
Homeopathy	9	66.7	22.2	0.0	11.1	0	0.0	0.0	0.0	0.0
Acupuncture	6	50.0	33.3	0.0	16.7	2	0.0	100.00	0.0	0.0
Chiropractor	5	20.0	60.0	0.0	20.0	3	0.0	33.3	0.0	66.7
Massage	3	66.7	0.0	0.0	33.3	2	50.0	50.0	0.0	0.0

IBD = inflammatory bowel disease.

Table 4

Perceived effectiveness of particular standard therapies

	n	Improved, %	Nochange, %	Worsened, %	Hard to tell, %
IBD					
5-ASAs	136	79.4	6.6	0.0	14.0
Immunomodulators	106	69.8	5.7	0.0	24.5
PPIs/H ₂ blockers	52	82.7	3.8	0.0	13.5
Corticosteroids	47	87.2	2.1	0.0	10.6
Folic acid	29	58.6	6.9	0.0	34.5
Antibiotics	25	64.0	4.0	4.0	28.0
Infliximab	18	94.4	0.0	0.0	5.6
Methotrexate	7	85.7	0.0	0.0	14.3
Elemental/TPN/GH	4	100.0	0.0	0.0	0.0
Constipation					
Polyethylene glycol 3350	81	84.0	3.7	2.5	8.6
Other	15	46.7	20.0	6.7	26.7

IBD = inflammatory bowel disease; ASA = aminosalicylates; PPIs = proton pump inhibitors; TPN = total parenteral nutrition; GH = growth hormone.