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Complementary and alternative medicine use in children with cystic fibrosis

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ABSTRACT

Purpose: To estimate the overall prevalence of complementary and alternative medicine use among children with cystic fibrosis, determine specific modalities used, predictors of use and subjective helpfulness or harm from individual modalities.
Results: Of 53 children attending the cystic fibrosis clinic in London, Ontario (100% recruitment), 79% had used complementary and alternative medicine. The most commonly used modalities were air purifiers, humidifiers, probiotics, and omega-3 fatty acids. Family complementary and alternative medicine use was the only independent predictor of overall use. The majority of patients perceived benefit from specific modalities for cystic fibrosis symptoms.
Conclusions: Given the high frequency and number of modalities used and lack of patient and disease characteristics predicting use, we recommend that health care providers should routinely ask about complementary and alternative medicine among all pediatric cystic fibrosis patients and assist patients in understanding the potential benefits and risks to make informed decisions about its use.

1. Introduction

Complementary and alternative medicine (CAM) is defined by the National Centre for Complementary and Alternative Medicine as "health care approaches developed outside of mainstream Western, or conventional medicine for specific conditions or overall well-being" [1]. Many people use CAM for the treatment and prevention of illness. In 2007, 38% of American adults and 12% of children had used some type of CAM in the previous year [2] and spent $33.9 billion on various CAM modalities [3].

The prevalence of CAM use is reported to be higher among children with chronic illnesses [4–8]. In adults (ages 16–44 years) with cystic fibrosis (CF) in Australia, 70% report ever using CAM and 45% report currently using CAM for their condition [9]. The limited number of studies of CAM use in children with CF show prevalence rates of 45%–75% [6,10,11]. A variety of different CAM modalities are reported in these studies ranging from prayer and religious methods, to homeopathy, physical therapies such as massage and chiropractic, and nutritional therapies [6,10,11].

For most CAM modalities, efficacy data in individuals with CF is limited or contradictory [12–14]. A few studies with small sample sizes show some reduction in disease burden with acupuncture, beta-carotene, zinc and probiotics [12,15–17]. A newer CAM modality in North American markets, namely salt therapy, or halotherapy, involves breathing in salt particles, either from rooms built with salt or salt emitted from salt lamps. In one small study, the use of salt therapy was associated with modest improvements in lung function in individuals with CF [18].

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While the current literature reports a high prevalence of CAM use in children with CF, previous studies have not rigorously examined potential correlations between patient specific characteristics (e.g. age, income) or disease severity and the likelihood of CAM use [6]. There is also a paucity of studies that examine the perceived benefit or harm of specific CAM therapies according to patients or caregivers [11]. Such studies could allow identification of specific attributes of children with CF that predict a higher prevalence of all CAM or specific types of CAM use, and which specific CAM therapies are felt to be helpful or harmful. This would provide conventional health care providers valuable information on which patients may be CAM users and the subjective helpfulness of CAM modalities, an area where evidence is lacking. It would also aid families in making informed decisions about CAM use, as well as direct future efficacy studies.

In this study, our objective is to identify the prevalence of CAM use among children with CF treated at a Canadian centre, and to further characterize the most frequently used CAM modalities. We are particularly interested in the use of salt therapy, based on anecdotal reports of its use within the local CF population. We additionally aim to determine the perceived benefit or negative effects of specific CAM therapies used in this population, the frequency of communication between families and healthcare teams about CAM use, as well as any relationship between caregiver demographics, disease severity or other patient factors and CAM use. We hypothesize that rates of CAM use would be higher within more affluent families, and in patients whose family members also use CAM. We further hypothesize that older children with more severe CF disease would be more likely to use CAM as an adjuvant treatment for progressive symptoms.

2. Materials and methods

2.1. Patient recruitment

We developed, pilot tested, then administered a questionnaire about current (within the last 6 months) and ever- CAM use to parents or primary caregivers of children aged 1–18 years who attended the multi-disciplinary CF clinic at the tertiary care Children's Hospital, London Health Sciences Centre in London, Ontario, Canada. All patients who had been diagnosed with CF for more than one year were eligible for inclusion in the study. For ethical reasons, patients who had been diagnosed with CF for less than one year were excluded from the study to allow time to adjust to conventional CF treatments before introducing information about CAM methods through this questionnaire. All eligible participant families received a letter of information describing the purpose and content of the study during their routine CF clinic visit. Those who agreed to participate signed a written informed consent form prior to questionnaire completion. There was no stipend for questionnaire completion.

2.2. Questionnaire development and validation

We developed the study questionnaire after performing an extensive literature review to identify previously published questionnaires with some evidence of validity. We incorporated content and design elements from these questionnaires as a framework for our study questionnaire [19]. We then assessed the study questionnaire for face and content validity with a group of 7 pediatricians and CF allied health professionals, including pharmacists, nurses, physiotherapists, dieticians and social workers. After making minor content revisions, we pilot tested the questionnaire with 10 families of children with CF and made further revisions to improve formatting, clarify instructions and emphasize sections of the questionnaire that had been overlooked by some participants.

When administering the questionnaire, study investigators used a script that defined CAM as “any treatment used specifically for CF excluding what was prescribed by their physicians and CF team”. We included sixty-two specific examples of CAM in the questionnaire, as identified through review of the published literature of CAM use in adults with CF and children with other chronic diseases such as asthma and juvenile arthritis. Caregivers indicated whether the CAM method was used currently (within the past 6 months), in the past (more than 6 months ago), whether it was helpful for breathing symptoms, other symptoms, or not helpful (see eFig. 1 in the Supplement). We included the following categories of CAM in the questionnaire: natural health products (herbal remedies, homeopathy), nutrition (vitamins, minerals, special diets), spiritual/mental treatments (biofeedback, relaxation), physical treatments (acupuncture, massage, chiropractic), and other (biofield, salt therapy, humidifiers). The questionnaire allowed participants to provide free text descriptions of additional CAM treatments that may have been used by the child, though not specifically listed in the questionnaire.

We collected information regarding parent/caregiver demographics such as age, sex, education, family income, and ethnic background, along with patient demographics such as age and sex. The questionnaire further explored the reasons for CAM use, potential negative side effects, whether caregivers spoke to their child's healthcare team about CAM use, prevalence of CAM use among other family members, the amount of money spent on CAM per month, and consultation of alternative health care practitioners (i.e. outside their CF or conventional medical care team) regarding CAM use.

We assessed ethnicity of the children participating in the study to look for associations between ethnicity and CAM use. Research investigators defined the options for ethnic background, which included an “Other” option for the caregiver or child to provide free text. Participants classified the ethnic background of the child. Research investigators did not judge the ethnic background of any participant.

2.3. Additional data collection

Through review of clinical notes and other patient records, we collected information regarding markers of disease severity and CF characteristics, such as body mass index (BMI), pulmonary function (forced expiratory volume in once second-FEV_1), emergency room visits and hospitalizations for pulmonary exacerbations in the preceding year, current use of inhaled antibiotics, dornase alpha or hypertonic saline, colonization of respiratory secretions with *Pseudomonas aeruginosa*, *Aspergillus species,* Methicillin-resistant *Staphylococcus aureus* (MRSA), or *Burkholderia cepacia,* CF genotype, and pancreatic sufficiency.

Data was collected from June 2013 to October 2015.

2.4. Analysis

We used descriptive statistics to identify the prevalence of CAM use and the most frequently used methods of CAM, Fisher exact tests and chi square tests to identify differences in categorical baseline demographics and disease indices between those children who did or did not use CAM, Wilcoxon rank sum tests for continuous variables and the Mantel-Haenszel chi square test to identify significant differences in gross annual family income levels between CAM users and non-users. For all comparisons, we considered a p value of less than 0.05 as statistically significant. The software used for the analysis was SAS 9.3.

We performed univariable logistic regression to identify