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Use of Unconventional Therapies by Children With Cancer at an Urban Medical Center

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Purpose: The aim of this study was to determine the prevalence, modalities, and determinants of use of unconventional therapies among children with cancer receiving conventional treatment at an urban academic medical center in the United States.

Patients and Methods: We interviewed the parents of patients and/or patients who were receiving or had received conventional therapy for treatment of childhood cancer. Of 78 patients/parents asked, 75 consented to the interview, which included demographic factors, life events, and use of unconventional therapies. All participants also consented to the abstraction of chart data for this study.

Results: Overall, 84% of respondents reported the use of one or more unconventional therapies. The most commonly used modalities were changes in diet, nutritional and herbal agents, and mind/body treatments. Most users had tried more than one unconventional modality. No difference in use was seen by cancer diagnosis, race/ethnicity, socio-economic status, or educational attainment of the respondent. Of the therapies used, 50% were not reported to the physicians. Of patients reporting use of an unconventional approach, 85% were concurrently enrolled on clinical trials for primary treatment of their cancer.

Conclusions: The use of unconventional therapies is highly prevalent among children with cancer and is not associated with demographic or clinical factors or participation in clinical trials. The possibility that an unconventional treatment may interact with a protocol treatment underscores the need for more information about the use of such therapies among all patients.

Key Words: Unconventional therapies—Complementary and alternative medicine—Children—Pediatric oncology—Cancer.

Unconventional therapies are health-related practices that are outside the domain of mainstream Western medicine. Interest in such therapies is widespread; two surveys conducted by Eisenberg et al. indicate that 34% to 42% of Americans had used at least one form of unconventional therapy within the previous year, leading to expenditures on such treatments in excess of $13.7 billion (1, 2). Use of such therapies was associated with nonblack race, high educational attainment, and high income.

Surveys have found that a substantial proportion of adult patients with cancer begin to use unconventional therapies after their diagnosis (3). One of the motivations for patients with serious illnesses, such as cancer, is to "leave no stone unturned" (4).

Pediatric patients with cancer also have been found to use unconventional therapies. In the 1970s, 6 of 69 pediatric patients or parents of patients with cancer at the M.D. Anderson Cancer Center reported having tried at least one "unproved remedy" (5). Nearly 20 years later in a similar survey conducted in Australia, parents of 22 of 46 children with cancer reported having used at least one "alternative therapy" (6). A survey performed in Finland with families of 15 children with acute lymphoblastic leukemia and 26 control families found that 6 of 15 patients and 2 of 26 controls had used alternative medicine, and that all the patients and 50% of the controls used vitamins (7). In British Columbia, a mail survey of 584 families of pediatric patients with cancer, of whom 363 responded, found that 141 (41%) had used alternative therapies (8). Use of unconventional therapies was associated with parental postsecondary education but did not appear to be associated with ethnicity or family income. No survey of pediatric oncology patients in an urban area of the United States has been reported since the 1970s. Because ethnic minority group members who adhere to cultural traditions may be underrepresented in population-based surveys, we hypothesized that the use of unconventional medicine may be higher in our ethnically diverse patient population than in others previously

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studied. We therefore initiated a survey of patients treated at our medical center.

PATIENTS AND METHODS

Study Population

The study participants were patients or parents of patients treated for cancer at the Babies and Children's Hospital of New York (Columbia-Presbyterian Medical Center). Participants were interviewed from May 1997 through November 1998. To make sure that the families had the opportunity to consider the use of unconventional therapies for the patient's cancer, we recruited only families of patients who were more than 3 months past their date of diagnosis. Participating patients included those currently receiving active therapy with conventional chemotherapy, radiotherapy, and/or surgery, and those who were being seen for follow-up.

Our medical center is located in northern Manhattan. The population of the neighborhood is predominantly Hispanic, but only 50% of the patients are from the local area; the remainder are largely from midtown and lower Manhattan, the other New York City boroughs, and suburban Westchester, New Jersey, and Connecticut. Therefore, our patient population is culturally and ethnically diverse.

Survey Methods and Interview Content

The study was approved by the Institutional Review Board of Columbia-Presbyterian Medical Center. Informed consent was obtained from the patient, parent, or legal guardian. The interviewer met with either the parents/guardians or the patient to administer a questionnaire in a face-to-face interview during a routine visit of the patient to the pediatric oncology outpatient clinic for treatment or follow-up or administered the questionnaire via the telephone at a convenient time for the patient and/or parent. The interviews lasted 10 to 60 minutes, depending on the extent of the patient's use of unconventional therapies. The interviewers were not involved in the medical care of the patients who participated.

The study data came from two sources. The first was the interview, consisting mainly of questions about categories of self-help measures or efforts made to improve the child's health since diagnosis. An unconventional therapy was defined as an agent or practice initiated since diagnosis and not part of the standard care of a child with cancer. Table 1 lists the categories used in the questionnaire. Respondents who were uncertain about the categorization of therapies were given a list of examples of therapies in each category.

For each self-help measure (unconventional therapy) used, the respondent was asked more specific information, including: dose, schedule, duration of use, source of information about the therapy, original purpose, effectiveness, and whether the treatment was mentioned to the child's physician. We also collected demographic data and information about changes in the child's environment (e.g., home, school) and lifestyle (e.g., physical activity, friends) since diagnosis.

TABLE 1. *Categories of self-help measures as listed in the study questionnaire*

1.	Changes in diet
2.	Nutritional supplements
3.	Herbal, botanical, or other plant-based medications administered orally
4.	Other types of medication or treatment administered orally
5.	Ointments, creams, poultices administered orally or other treatments applied directly to the skin
6.	Other medications administered directly to the child by some other route
7.	Detoxification treatments
8.	Water treatment or hydrotherapy
9.	Aromatherapy or other treatments intended to be inhaled
10.	Touch therapies or manual healing techniques
11.	Bioenergetic treatments
12.	Mind/body programs
13.	Systems or comprehensive approaches to health
14.	Any other self-help measures

The second source of data was the patient's medical chart. The data collected included: type of cancer, stage of disease including presence of metastatic disease, conventional treatment received, and toxicity encountered (maximal grade of mucositis, nutritional supplementation, blood product transfusions, documented infections) and presence of relapse.

Data Analysis

We calculated means and frequencies for the demographic variables for the study participants overall, for users and nonusers of unconventional therapies, and for users of specific modalities. We calculated the percentage distributions of use of the various unconventional modalities and used χ-square techniques to analyze complementary and alternative medicine use/nonuse by respondent's relationship to the patient, ethnicity, income, and educational attainment of the respondent. We used *t*-tests to compare age distributions of users and nonusers of such therapies.

RESULTS

Of the 78 patients initially invited to participate in the study, three refused. The remaining 75 patients are included in this analysis. Fourteen patients age 10 to 26 years were interviewed directly, and 49 mothers of patients age 3 months to 20 years, 11 fathers of patients age

1 to 16 years, and 1 aunt of a 13-year-old patient were interviewed.

Of the 75 respondents, 63 (84%) reported having used at least one unconventional therapy since the time of the diagnosis of the child's cancer (Table 2). Users and nonusers did not differ significantly by age, ethnicity, family income, or (for those patients whose parents were respondents) parental educational attainment. The ethnic diversity of the participants was similar to the overall population treated at our center in which the distribution was: white 47%, Hispanic 30%, black 11%, Asian 6%, and other 5%.

Most users tried more than one therapy. The therapies most commonly reported were changes in diet, nutritional supplements, herbal remedies, and mind/body therapies (Table 3). Table 4 lists specific agents or approaches mentioned by study participants. Many respondents reported having increased intake of fruits and vegetables and/or having added organic foods to the diet, but a few patients reported the use of unorthodox diets, such as the "diet for your blood type" in which one's ABO blood group determines which of several dietary plans one should adhere to. Even excluding dietary modification, which may or may not be considered an unconventional treatment of a child with cancer, 49 (65%) of the respondents were using at least one form of unconventional therapy. Users outnumbered nonusers of unconventional therapies for nearly all childhood cancer diagnoses, including those with good prognosis such as acute lymphoblastic leukemia. Only eight of the respondents had experienced a relapse, and all eight had used one or more unconventional therapies.

TABLE 2. *Demographic characteristics of users and nonusers of unconventional therapies*

	Users (n = 63)		Nonusers (n = 12)	
Characteristics	n	%	n	%
Relationship of respondent to patient				
Self	13	21	1	8
Mother	42	56	6	50
Father	8	67	4	33
Aunt	0	0	1	8
Age				
0–4 yrs	14	22	6	50
5–9 yrs	23	36	2	17
10–14 yrs	9	14	2	17
15–19 yrs	14	22	1	8
20+ yrs	3	5	1	8
Race/ethnicity				
Black	4	6	0	0
Asian	9	14	0	0
White	28	44	5	42
Hispanic	21	33	6	50
Other	1	2	1	8
Income				
<$10,000	9	14	2	17
$10,000–$29,999	8	13	1	8
$30,000–$49,999	10	16	1	8
$50,000–$74,999	9	14	4	33
$75,000–$99,999	8	13	1	8
>$100,000	10	16	1	8
Not disclosed	9	14	2	17
Parental educational attainment				
<8 yrs	1	2	1	8
9–12 yrs	21	33	4	33
>12 yrs	41	65	7	58

TABLE 3. *Distribution of unconventional therapies used by pediatric oncology patients: comparison of all respondents and all patients enrolled on protocol*

	All respondents (n = 75)		Patients enrolled on protocol (n = 55)	
	n	%	n	%
Any use	63	84	47	85
Diet changes	35	47	29	53
Nutritional supplements	27	36	18	33
Herbal agents	20	27	15	27
Other oral therapies	5	7	4	7
Touch therapies	12	16	12	22
Bioenergetic	6	8	5	9
Mind/body therapies	20	27	17	31
Topical therapies	13	17	11	20
Other nonoral therapies	1	1	1	2
Detoxification	1	1	1	2
Hydrotherapy	2	3	2	4
Aromatherapy	1	1	1	2
Comprehensive systems	2	3	2	4
Other	6	8	4	7

Use of unconventional therapies was not found to be associated with the severity of chemotherapy-induced or radiotherapy-induced mucositis, need for blood transfusions or nutritional supplements, or documented infections (data not shown).

All the patients in our study were receiving or had received conventional therapy for their cancer; no patients were using unconventional approaches in lieu of conventional therapy. Of the 55 patients enrolled on clinical protocols for primary treatment, 47 (85%) were concurrently using unconventional therapies. Table 3 lists the numbers of patients enrolled on clinical protocols who reported using specific unconventional modalities: 18 (38%) used nutritional supplements, 15 (32%) used herbal agents, and 4 (8%) used another medication orally (e.g., shark cartilage). All these agents have potential biologic activity that may interact with chemotherapy. Of the various modalities they had tried, respondents had mentioned only 50% to the child's physician.

Information used in choosing unconventional therapies was obtained from a wide variety of sources. The most common source of information was the parent's or patient's knowledge base with 41% self-referred to an

TABLE 4. *Examples of some of the specific therapies used by pediatric oncology patients*

Therapies	Number of users
Changes in diet	
Increase fruit and vegetable intake	15
Switch to organic foods	10
Reduce fat intake	8
Juicing	4
Eliminate red meat	5
Addition of specific foods (for their anticancer or detoxification effects): asparagus, grapes, red dates, maple syrup, fish soup with ginseng, liver, grapefruit	11
Nutritional supplements	
Vitamins: megadose, B-complex, C, E	27
Co-enzyme Q10	3
Grape seed extract, pycnogenol	3
Minerals: selenium, colloidal silver	2
Herbal, botanical, or other plant-based medications administered orally	
Cat's claw	4
Green tea	5
Echinacea	2
Essiac tea	3
Other types of medication or treatment administered orally	
Shark cartilage	4
Mataki mushroom	1
Blue green algae	1
Chem-X	1
Ointments, creams, poultices, or other treatments applied directly to the skin	
Arnica	2
Tea tree oil	2
Vitamin E cream/oil	4
Tiger balm	1
Touch therapies or manual healing techniques	
Chiropractic	3
Massage	9
Bioenergetic treatments	
Laying on of hands	5
Reiki	1
Mind/body programs	
Prayer	10
Visual imagery	4
Psychotherapy	4
Music therapy	4

unconventional modality. The next most common source of referral to unconventional therapies was relatives (16%) or friends (15%). Patients identified the physician or hospital staff as the source of information of referral to 15% of therapies. Only a few patients or parents reported using recommendations from the staff of health food stores or from unconventional medicine practitioners.

The survey also addressed the intended purpose of the unconventional therapies used (Table 5). The purpose most commonly cited, to improve the general health of the child, accounted for 29% of treatments. Relaxation was another frequently mentioned purpose, particularly for mind/body and touch therapies. Only 8% of therapies were initiated to reduce tumor size and 2% to prevent recurrence.

The therapies were largely viewed as serving their purpose. More than 50% were rated as "very effective," and an additional 34% were rated "somewhat effective." Only 3% of unconventional therapies were judged "non-effective."

DISCUSSION

Our study demonstrates the high prevalence of use of unconventional therapies by pediatric patients with cancer receiving care at an urban medical center in the United States. The results are similar to those of Fernandez et al. (8) with regard to types of therapies used, sources of information about them, and reasons cited for use of these therapies. Although the overall prevalence rate of 84% is higher than in previously published surveys of pediatric oncology patients, it may reflect either our interviewers' effectiveness in putting the respondents at ease during the interviews or the ethnic diversity of our patient population.

Our study suggests that the use of unconventional therapies is increasing among pediatric oncology patients also receiving conventional treatment. Data obtained from patients being treated at an academic medical center do not indicate to what extent pediatric patients with cancer are being treated only with unconventional therapies. However, we are not aware of patients who have been withdrawn from therapy in our center so that they can be treated exclusively with unconventional methods, nor have we seen patients with advanced disease who were brought to us after an unconventional therapy failure. Our sample represents only patients receiving and largely, to the best of our knowledge, complying with conventional therapy.

In the past 25 years, the life expectancy of children with cancer diagnosed has dramatically lengthened. Relative 5-year survival rate among children with cancer is now higher than 70% (9). However, the diagnosis and treatment of cancer can still be traumatic for both pediatric patients and their families. Treatment for pediatric

TABLE 5. *Purpose of unconventional therapies used by pediatric oncology patients*

	% Of therapies
Improve general health	29
Relaxation	14
Detoxification	13
Improve immune function	8
Tumor reduction	8
Improve appetite/digestion	7
Wound healing	5
Decrease nausea	4
Prevent recurrence	2
Pain control	2
Other	6

cancers is harsher in some respects than that for adult cancers, and having a child with cancer is highly stressful for families (10). This stress may account for the high prevalence of use of unconventional therapies across all diagnoses of cancer, including those with a favorable prognosis. The most common reason given for using unconventional therapies was not to cure the cancer but to improve the child's general health. Our impression is that the parents viewed what they were doing as simply part of their job as parents: to provide what the child would need to reach adulthood in good condition. Parents derived comfort from the overwhelming impression that these therapies were "very effective" or at least "somewhat effective."

Mind/body therapies were the third most common modality reported by our patients. It is possible that some of these mind/body approaches, such as prayer, were used more often than reported. However, practices initiated before the cancer diagnosis were not included in the survey. Prayer is not ordinarily considered an unconventional therapy. However, when prayer is initiated specifically to improve the health of a patient with cancer, we consider it to be an unconventional therapy, if only because it is not an explicit part of the conventional care for such a patient.

Many children with cancer are treated on cooperative group protocols. More than 85% of such patients interviewed for this survey reported using unconventional therapies. Among the specific modalities used by our patients, dietary changes, nutritional supplements, and herbal remedies were the most common. These findings are similar to those reported for adult patients with cancer (11–13). However, the history of antifolate development suggests that even dietary changes and nutritional supplementation may affect tumor growth and bioavailability of conventional treatment agents (14). Nutritional supplementation and herbal agents may also interfere with the action of antimetabolites (15), which are a major component of therapy for children with acute lymphoblastic leukemia. Most users of unconventional therapies had used more than one, creating the possibility of even more complex interactions. Participants in clinical trials are not routinely asked about the use of such agents, and as our study and others (1,6) demonstrate, 50% of unconventional therapies are not reported to physicians.

Other surveys of pediatric oncology patients have identified factors associated with use of unconventional therapies, including advanced parental education (8) and presence of relapse (16). So few patients in our study were not using unconventional therapies that we were not able to identify any factors predictive of their use. We must therefore inquire about the use of such therapies in all patients, offer parents and patients the best information about them that is currently available, not dismiss the possibility that a treatment that is not evidence-based can have benefit, and encourage parents and patients to report promptly any adverse effects.

Although there are anecdotal reports of benefit or harm from unconventional therapies, there are little solid data to support or discourage their use. Our survey, designed to assess the prevalence of use of these therapies in an urban population, found that such use was widespread. Dietary changes and the use of nutritional supplements were particularly common. Further research on these modalities is needed.

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