

## Use of Complementary and Alternative Medicine in Paediatric Oncology Patients in Singapore

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### Abstract

**Introduction:** Complementary and alternative medicine (CAM) is garnering increasing interest and acceptance among the general population. Although usage is thought to be widespread among paediatric cancer patients, local studies have not been done. We aimed to investigate the prevalence and predictors of CAM usage in paediatric cancer patients in a single institution. **Materials and Methods:** Parents of 73 paediatric cancer patients treated at KK Women's & Children's Hospital completed an interviewer-administered questionnaire. Data about the types of CAM therapies used, motivations for use, adverse effects, costs and discussion of usage with the patient's physician were obtained. General perceptions towards CAM and conventional medicine were explored. A subsequent telephone survey enquired about spirituality, benefits of CAM use and overall satisfaction with the therapies. **Results:** Two-thirds of patients used at least 1 CAM treatment, mainly as supportive adjuncts to conventional cancer treatment. Dietary changes, health supplements, herbal tea and bird's nest were the most common therapies used. Few patients (8.1%) consulted a CAM practitioner. Positive predictors of CAM usage included being of Chinese race, the practice of Buddhism or Taoism, the use of CAM prior to diagnosis, perception of CAM effectiveness and dissatisfaction with conventional treatment. Significantly, 55.1% of the parents had not discussed their CAM usage with their child's physician. **Conclusions:** A substantial proportion of paediatric cancer patients utilises CAM therapies, often without their physician's knowledge. Healthcare providers need to remain cognisant of the potential implications of CAM usage in order to proactively counsel patients. This would ensure that conventional therapy remains uncompromised.

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**Key words:** Childhood cancer, Prevalence, Traditional Chinese Medicine

### Introduction

Complementary and alternative medicine (CAM) has been gaining acceptance throughout the world. The efficacy of CAM is unproven, yet it remains popular with the general public, with many of them utilising it for a whole spectrum of ailments.<sup>1</sup> CAM has even made inroads into the major institutions of conventional western medicine, including medical schools and hospitals.<sup>2</sup>

The National Center for Complementary and Alternative Medicine (NCCAM) in the United States defines CAM as a group of diverse medical and healthcare systems, practices, and products that are not presently considered to be part of

conventional medicine and are yet to be validated by scientific methods.<sup>3</sup> Although the terms are often used interchangeably, alternative medicine describes therapies used in place of conventional medicine whilst complementary medicine is used along with conventional medicine. Table 1 shows the categories of CAM modelled after the classification system of NCCAM.<sup>3</sup>

CAM could be particularly detrimental in cancer, where early treatment is critical for prognosis and survival.<sup>4</sup> Physicians are also concerned about possible drug-CAM interaction, harmful side effects, financial loss to the patient and diversion of important and expensive community

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resources. Patients risk increased emotional distress when they fail to experience a promised cure or even an enhanced quality of life.<sup>5,6</sup>

The frequency of adult usage of CAM therapies for cancer ranges from 7% to 69%, with an average prevalence of 31.4%.<sup>7</sup> Two early studies in the United States by Faw et al<sup>8</sup> and Pendergrass et al<sup>9</sup> reported CAM use by 8.7% and 16% of paediatric oncology patients respectively. A 1994 Australian study<sup>10</sup> in 48 non-brain tumour patients indicated a high frequency of use (46%) of CAM therapies that mainly involved psychological strategies such as positive imagery, hypnotherapy and relaxation exercises. In British Columbia, a retrospective mail survey<sup>11</sup> of 584 families of paediatric oncology patients found that 141 (42%) had used CAM. Eighty-two per cent cited “wanting to do everything possible” as an important motivational factor. In Amsterdam, Grootenhuis<sup>12</sup> noted that about one-third of children with cancer in a clinic-based sample used alternative treatments and Friedman et al<sup>13</sup> reported that 65% of a similar group of patients used CAM in Florida. A recent study<sup>14</sup> showed that 73% of patients in Washington State had used at least 1 CAM therapy, and 21% had consulted an alternative provider. In the Asian context, few studies have been done in paediatric oncology patients. In Malaysia, Ariffin et al<sup>15</sup> conducted a survey among 87 parents of 49 patients. About one-third sought aid from traditional healers, with 13% delaying conventional treatment. All the parents were Malay Muslims, of low socioeconomic class and were living in rural areas. All sought help from the traditional medicine man, who was usually a respected elder of the community. A Taiwan study by Yeh et al<sup>16</sup> interviewed 63 primary caregivers and determined a CAM usage prevalence rate of 73%.

In our study, we aimed to: (1) determine the prevalence of CAM usage before and after cancer diagnosis, (2) assess factors that are associated with CAM usage, (3) describe the reasons for usage or non-usage of CAM therapies, (4) estimate the costs incurred, and (5) assess parental perceptions towards CAM and conventional medicine. Since our study was hospital-based, it was mainly limited to patients who were using CAM concurrently with conventional treatment.

The results were anticipated to provide a profile of the CAM user in Singapore, so that clinicians could identify parents likely to choose CAM therapies for their child, and then assist them to make their decision in an informed way.

## Materials and Methods

Our study population comprised 73 paediatric cancer patients (<15 years old) from the Children’s Cancer Centre of KK Women’s and Children’s Hospital, which treats two-thirds of paediatric oncology patients in Singapore.

Patients who had been diagnosed for less than 3 months were excluded from the study, as there would not have been sufficient time for them to try out CAM. Primary caregivers were enrolled at the specialist outpatient clinic, at the oncology ward or at the day therapy unit. All parents were conversant in English or Chinese; hence, the 2 interviewers (JYFL, MZW) did not encounter any significant language problems. Standardisation of inquiry by each interviewer was enforced to reduce possible bias. A pilot study was done on 10 patients. The questionnaire was then assessed and revised for clarity and easy response. The study proper was performed over 3 weeks in May 2002.

Demographics of the primary caregivers (age, gender, race, religion, total monthly household income and educational level) and the patients (age, gender, diagnosis, conventional treatment modalities used) were collected. The types of CAM used (both before and after diagnosis), frequency of use, cost per month, sources, reasons for usage and non-usage of CAM as well as general perception towards CAM, were also explored. We also assessed if the child’s CAM usage had been discussed with the oncologist-in-charge. We excluded mind-body intervention therapies (Table 1) in our definition of CAM in our study.

A subsequent telephone survey reached 59 of the original 73 caregivers (25 CAM users for cancer, and 34 non-users). This second phase focused on questions relating to spirituality as a treatment modality, benefits of CAM use, and overall satisfaction with the CAM therapy used, which were not sufficiently addressed in the original questionnaire. Although spirituality (as part of mind-body intervention therapies) was not included in our definition of CAM, we wanted to have an idea of its effect on our patients.

## Statistical Analysis

Data collected were analysed using SPSS v11.0 software. Descriptive and univariate analyses were performed to determine the factors associated with CAM usage. Bivariate analysis, including Pearson Chi-square test was performed for categorical variables to determine if differences between each group were statistically significant.

Table 1. Categories of CAM Methods

Category	Examples
Alternative Medical Systems	Traditional Chinese Medicine, Ayurveda, Homeopathic Medicine, Naturopathic Medicine.
Mind-Body Interventions	Meditation, Prayer, Mental Healing.
Biologically Based Therapies	Dietary Supplements, Herbal Products.
Manipulative and Body-based Methods	Massage, Osteopathic Manipulation, “Tui-na”.
Energy Therapies	Reiki, “Qi-gong”, Bioelectromagnetics

**Results**

We interviewed 73 (16 male and 57 female) parents of 42 male children and 31 female children aged 1 to 14 years old. The demographics of the population interviewed were found to be comparable to the Singapore Cancer Registry in terms of gender and race. Seventy-four per cent of the children were undergoing active treatment, with the remaining 26% on follow-up. Seventy-one patients (97.3%) received chemotherapy, 11 (15.0%) received radiotherapy, and 10 (13.7%) received surgery. One received a bone marrow transplant.

*Patterns of CAM Use*

Of the 73 respondents, 49 caregivers (67.1%) reported having used at least 1 CAM therapy since the diagnosis of the child’s cancer. Users outnumbered non-users for nearly all childhood cancer diagnoses, including those with good prognoses such as acute lymphoblastic leukaemia. The therapies most commonly instituted were changes in diet (55.1%), health supplements (44.9%), herbal tea (36.7%) and bird’s nest (36.7%) (Fig. 1). Many respondents reported having increased intake of fruits and vegetables, consuming large amounts of fruit juice or fruit juice concentrate, and avoidance of meat. One patient relied on “mushroom water” (drinking only water boiled with mushrooms). However, no patients reported the adoption of organic, macrobiotic or other unorthodox diets. Even excluding dietary modification, 60.3% used at least 1 form of CAM. About 20 different kinds of health supplements were used, including cactus juice, noni juice, wheatgrass, soybean, plant extracts, pure wild honey, growth factors and enzymes. Herbal teas (like herbal soups, chrysanthemum tea and barley drink), regarded as “cooling” in traditional Chinese medical practice, were believed to decrease the “heatiness”

of the body induced by chemotherapy. Only 6 patients (8.2%) consulted a traditional Chinese physician.

Phase II of the survey found that 25.4% of the 59 telephone respondents had used some form of spirituality, such as formal prayer (8 patients), laying on of hands (3), seeking help from a bomoh (2) or temple medium (1).

*Predictors of CAM Use*

Twenty-six of the 49 CAM users (53.1%) had used 1 or more forms of CAM since birth, whilst 46.9% used CAM for the first time after the diagnosis of cancer was made. The most popular CAM remedies before cancer diagnosis were herbal tea, bird’s nest and multivitamins. A previous CAM user was more likely to use CAM after diagnosis than previous non-CAM users (relative risk, 1.93).

Other than prior use of CAM, being of Chinese race ( $P < 0.001$ ) and the practice of Buddhism/Taoism ( $P < 0.001$ ) were identified as predictors of CAM use. A perception of CAM effectiveness and dissatisfaction with conventional treatment were also positively associated with CAM usage.

*Reasons and Expectations for CAM Use*

We also explored parental expectations about what CAM could achieve. Before cancer diagnosis, the main reason for the use of CAM was to improve general health. After the diagnosis of cancer, most (85.7%) used it to supplement mainstream medicine, as a form of supportive therapy. A quarter (24.5%) used it to control the side effects of conventional treatment, especially chemotherapy. Only 20.4% of respondents hoped the CAM treatment would have curative or anti-cancer effects. Important specific purposes for using CAM were to strengthen the immune system (63.3%) and to improve general health (63.3%). “To do everything possible for the child” was another frequently cited reason (42.9%).

*Sources of Information*

Information used in choosing CAM therapies was obtained from a wide variety of sources. Most (70%) had more than 1 source, the most common being friends (51%).

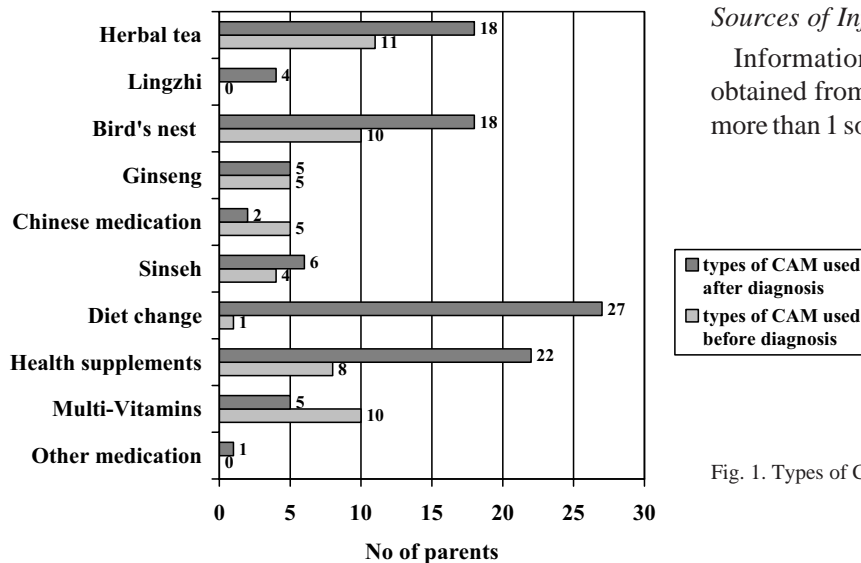


Fig. 1. Types of CAM used.

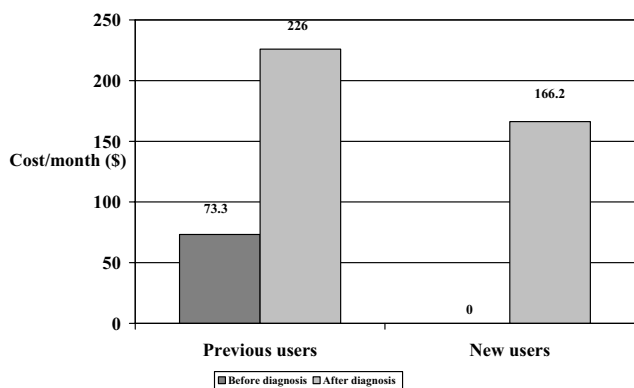


Fig. 2. Average amount spent on CAM.

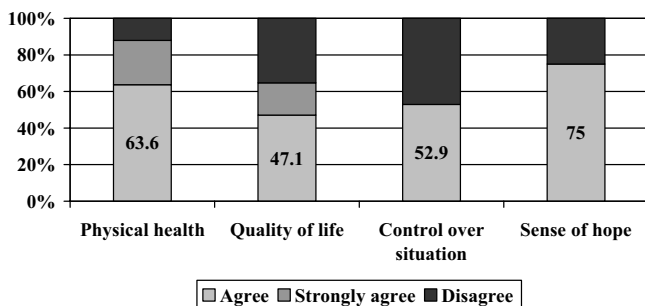


Fig. 3. Benefits of CAM use.

The next most common source was other patients (32.7%) or parent’s knowledge base (self-referral). Two parents (4%) identified the physician or hospital staff as the source of referral to CAM. Eight per cent reported using recommendations from the staff of health food stores, but none sought information from CAM practitioners. Interestingly, before cancer diagnosis, parents turned most often to family (44.4%), their own knowledge base (29.6%) and friends (22.2%) for information about CAM.

*Doctor-Patient Relationship*

The majority of parents (61.2%) felt it was important for the doctor to be aware of their CAM usage. However, only 44.9% actually sought input from or informed the physician. Many parents felt that CAM remedies (especially fruit juices and health supplements) are derived from natural sources and are thus non-toxic. They reasoned that their children could consume these regularly, without detriment to health. Some patients believed that the doctor already knew about their CAM usage, even though the doctor had not been informed. A small percentage of parents believed that the doctor would be unsupportive and would discourage CAM usage. One parent thought that the doctor would stop chemotherapy if he discovered concurrent CAM usage. On a positive note, 41.7% of non-CAM users cited advice from an oncologist as the main reason for non-usage. The majority of non-CAM users (87.5%) were themselves wary

of adverse interactions with conventional therapy. Some perceived CAM to be ineffective with its own side effects, while others felt they did not know the indications for use.

Forty-six CAM users (93.9%) would continue their CAM usage after completion of conventional therapy. Prior CAM users were more likely to continue using CAM as compared to new CAM users (who initiated use only after diagnosis). The majority of CAM users (65.3%) would recommend their CAM therapies to other parents. Even some non-users (12.5%) would advise others to try an unconventional therapy for cancer.

*Expenditure on CAM*

Only 1 prior CAM user discontinued use after cancer diagnosis, and 2 decreased the amount spent. Before cancer diagnosis, parents spent an average of S\$73.30 per month (SD, S\$87; range, S\$6 to S\$300) on CAM for their child. This is compared to S\$226 per month (SD, S\$234; range, S\$0 to S\$1000) after diagnosis. New CAM users spent an average of S\$166.20. Overall, parents spent an average of S\$197.90 per month on CAM for cancer (Fig. 2). Despite the substantial costs incurred, many caregivers deemed it money well spent.

*Satisfaction with CAM and Conventional Treatment*

The majority of CAM users (63.6%) agreed, with 24.2% strongly agreeing, that CAM improved their child’s physical health and well-being. Most (64.7%) felt that CAM had a beneficial effect on their child’s quality of life (Fig. 3). Three-quarters of CAM users acknowledged that CAM conferred a psychological benefit of hope, while half felt that the use of such therapies gave them a sense of control or autonomy over the situation. Only 3 patients had experienced side effects with CAM.

Overall satisfaction with both CAM (76.5% satisfied, 17.6% very satisfied) and conventional treatment (61% satisfied, 27.1% very satisfied) was high. General perceptions of the parents towards CAM and mainstream medicine were also investigated in the survey. Sixty per cent felt that, as compared to conventional medicine, CAM was more easily obtainable, and had fewer side effects. Despite the high prevalence of CAM usage among our study population, only 6 felt it was more effective than conventional medicine. CAM was not deemed to be necessarily safer or cheaper compared to conventional medicine.

**Discussion**

In Singapore, paediatric oncology patients commonly rely on their traditional indigenous medicines. These therapies, like acupuncture, Malay jamu and ayurvedic medicine, are not well-analysed in the surveys conducted overseas. There is also a relative paucity of Asian studies.



Coupled with the intrinsic variability in the sample populations, CAM definitions used, methodologies, analysis and results, it is difficult to make meaningful comparisons of study outcomes.

However, several interesting and consistent trends emerge. The local prevalence rate of 67.1% represents a comparable<sup>14,16</sup> or somewhat higher<sup>11,13,14</sup> use of CAM than was previously reported in the literature. A strong association was found between patients' use of CAM before and after the diagnosis of cancer.<sup>13</sup> Dissatisfaction with conventional therapy was also a predictive factor, as described by Neuhouser et al.<sup>14</sup> Caregivers felt that CAM had both physical and psychological benefits, contributing to high levels of user satisfaction.<sup>17</sup>

It was interesting that despite entirely different socio-cultural backgrounds, the motivations of our parents in using CAM mirrored those of others around the world. Patients utilised CAM mainly for adjunctive reasons;<sup>10,14</sup> from boosting the immune system to countering the toxic effects of chemotherapy. To our parents, CAM remedies represented a natural and thus essentially "harmless" way by which they could help their child's recovery. Nearly half (42.9%) of our parents agreed they wanted to "do everything possible for the child".<sup>16</sup> They were thus open to CAM, provided the effectiveness of conventional treatment is not compromised.

CAM use in Singapore was prevalent across all socio-economic strata and it is regardless of parental educational level. CAM users and non-users did not differ significantly by cancer type or site, age of child at diagnosis, symptom severity, presence of cancer relapse or the type of conventional treatment modality used. Experiencing side effects from allopathic treatment (89% of patients), most commonly chemotherapy, was not found to be associated with CAM usage. We were unable to assess the effect of disease risk status or prognosis on CAM usage, as most parents were unclear about this aspect. The above were all factors identified in other populations<sup>15,18-20</sup> as predictive of CAM usage.

The types of CAM used here were comparable to those found by a Taiwanese study, probably due to the predominance of Chinese among our patients. Yeh et al<sup>16</sup> found that formulated functional food (48% of CAM users), temple worship/shamanism (40%), traditional Chinese medicine (20%), secret recipes and herbs (28%), as well as diet supplements (19%) were popular. In Singapore, parents may be strongly influenced by their cultural roots, hence the popularity of traditional remedies like bird's nest or ginseng. On the other hand, they were willing to try so-called "scientifically proven" products like health supplements. Research could be done online, where they could read about new "evidence-based"

therapies. With the ease provided by the Internet, ordering imported honey from USA at \$200 a bottle, for example, is not difficult at all.

However, therapies such as bioelectromagnetics, crystals and homeopathy<sup>11,17,21</sup> were not popular in our local population. Only 1 parent (a Persian man) utilised energy healing/therapeutic touch (Reiki). The spectrum of CAM used in our patients appears to be relatively narrow, as compared to other published surveys. This could be accounted for by a "herd effect", where parents within this small community mutually influence each other's choice of CAM.

A significant finding was that 55.1% of patients were reluctant to disclose their CAM usage to their doctors. The oncologist needs to be aware of the diversity of therapies used, and be systematic and specific when asking about them. Initiating pre-emptive discussion in a non-judgmental manner may avoid disrupting the doctor-patient relationship. Indeed, when patients perceive an unsatisfactory or alienating relationship with health care providers, it may motivate them to seek treatment elsewhere. Cassileth<sup>22</sup> suggests that physicians should remain open to unconventional ideas but must help their patients understand the need for a scientific approach to CAM practices and products.

Our study also highlighted the significant costs parents were willing to fork out for CAM, confirming the results of previous research.<sup>11</sup> This may constitute an unnecessary financial burden on patients that many can do without. Recent data suggest that including complementary therapies as treatment options increases overall healthcare costs for adults because CAM therapies are used as "add-ons" rather than replacements.<sup>23</sup> Similar studies have not been reported for children.

Finally, although most participants in this study (94%) experienced no ill effects with CAM, reports of serious side effects of CAM have been published. For example, of 260 traditional Chinese patent medicines investigated by Ko,<sup>24</sup> at least 83 (32%) contained undeclared pharmaceuticals or heavy metals, and 23 had more than 1 adulterant. Some herbal remedies, like chaparral tea, can induce severe liver and kidney damage. These reports underscore the fact that natural products are not necessarily safe or harmless. Even dietary changes and nutritional supplementation may affect tumour growth and bioavailability of conventional treatment agents. Antioxidants such as vitamins C and E can reduce the effectiveness of chemotherapy.<sup>14</sup> Most users of unconventional therapies had used more than one, creating the possibility of even more complex interactions. Thus, the oncologist may have to monitor such patients for drug-herb-vitamin interactions.<sup>19</sup>

There were several limitations to our study. Our sample

size of 73 was small, but cancer is a relatively rare disease in children. We managed to survey only 17 Malay and 3 Indian parents, thus our small sample size may have been underpowered to detect use of therapies like Jamu or Ayurvedic medicine. It should be acknowledged that some of these factors, such as sources of information, are associated with recall bias, which would be addressed by a prospective study. Also, we were not able to generalise to the entire paediatric cancer population because we limited the study sample to patients who were still alive and receiving conventional treatment at our centre. Though the data obtained cannot indicate the extent to which parents use CAM exclusively as front-line treatment for their children's cancer, we hope these cases are isolated rarities. However, a national cancer registry-based study would fully describe differences in behaviour that may be linked to specific ethnic or other demographic characteristics.

### Conclusion

Even taking the above limitations into account, we can draw several important conclusions from the results of our study. CAM has a widening impact on every facet of the healthcare system and all specialties of medicine, including paediatric oncology. The reasons proposed for its rise include aggressive marketing by "health-oriented" companies and dissatisfaction with the harsh treatments, such as chemotherapy, that may be needed. In the local context, traditional Chinese medicine (TCM), with its established history and holistic approach, would represent a tempting alternative healing system.

Evidence-based conventional treatments for childhood cancer have brought about a survival rate as high as 80%. Yet, for many parents, the motivation to "leave no stone unturned",<sup>11</sup> would lead them to seek other adjunctive therapies. Having a child with cancer is also highly stressful for families. CAM can bring psychological benefits such as hope, optimism and a sense of control in a formidable hospital environment.<sup>17</sup>

Future research needs to clarify the distinction between potentially harmful alternative "cancer cures" and potentially beneficial complementary therapies employed as adjuncts to cancer treatment. In the meantime, oncologists need to counsel their patients and remain vigilant for any adverse effects or drug interactions.

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