

# The use of alternative or complementary treatment in pediatric oncologic patients: Survey of 100 cases in a level III attention institute

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## Abstract

**Introduction:** Alternative medicine is well accepted and widely used in Mexico, so we researched the frequency and causes of the use of alternative or complementary treatment (ACT) in pediatric oncologic patients at the Instituto Nacional de Pediatría (INP). **Methods:** One hundred questionnaires were applied to caregivers of children with cancer in a course of 100 hundred consecutive patients. **Results:** Fifty-one percent of caregivers interviewed accepted the use of some kind of ACT; biologic therapies were the most frequent treatments used, and 73% felt satisfied with the results. Caregivers told their physicians they were using ACT in 35% of the questionnaires analyzed, and only 2% of the physicians asked directly about its use. None of the caregivers substituted or stopped allopathic treatment. **Analysis:** These questionnaires reveal that more than a half of the caregivers use ACT. We believe superstitious and cultural beliefs, as well as the desire of the caregivers to participate actively in their patient's treatment, are the main causes of the use of ACT; nevertheless not notify their physicians and this may affect chemotherapy treatment in ways not investigated yet. **Conclusions:** The wide use of ACT in Mexico obliges every physician to enquire into it intentionally; it is therefore necessary to establish a stratification risk according to the combination of ACT and allopathic treatment used. (Gac Med Mex. 2016;152:5-9)

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**KEY WORDS:** Alternative medicine. Complementary medicine. Childhood cancer

## Introduction

The use of alternative and complementary therapy (ACT) is an ancestral practice that remains current in this day and age. It occurs in all regions of the world and it is not exclusive of Middle American cultures<sup>1-4</sup>.

The reasons that lead a family to administer alternative and complementary therapies to a sick person are varied, but in the face of a disease such as cancer,

which is a synonym of death for the common population, the need to actively participate in the treatment becomes imperative.

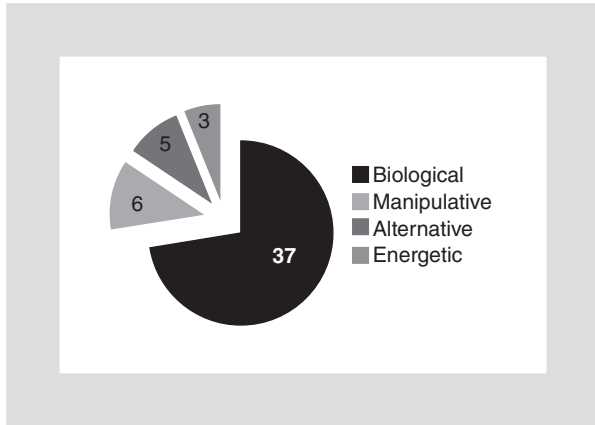
Complementary medicine is understood as the use of substances intended to coadjuvate with allopathic medications by using them concomitantly without pretending to substitute the effect of the latter, whereas alternative medicine is considered as practices that are intended to cure the sick person by themselves, rejecting the allopathic treatment, thereby being used independently<sup>5</sup>.

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Modified version date of reception: 15-08-2015

Date of acceptance: 17-08-2015



**Figure 1.** Distribution of the type of ACT administered in the 51 patients who stated using it.

In Mexico, the frequency of the use of ACT in the oncologic population has been studied twice, one of them in pediatric patients<sup>6,7</sup>. In 2006, Gerson-Cwilich et al. described their experience with ACT-user adult patients and found a higher tendency to use it in young women with advanced disease, who reported improvements in 78% of the cases<sup>7</sup>.

In 2007, Gómez-Martínez et al. published the results of a survey conducted in 110 parents of pediatric cancer patients: 70% recognized administering some type of ACT to their children, and in 69% of the cases the therapies were herbal. Improvement of the child's state with the administration of ACT was reported by 80%, but the treating physician was not informed about the complementary treatment<sup>6</sup>.

The purpose of this study was to determine the frequency of the use of ACT, as well as the reasons for its use, in 100 cancer-diagnosed patients at the National Institute of Pediatrics (INP - *Instituto Nacional de Pediatría*) of México.

## Methods

Primary caregivers of patients treated by the Oncology Department of the INP of Mexico over the period from January through August 2013 were interviewed. A convenience sampling was performed and only those caregivers unwilling to participate were excluded. A total sample of 100 patients was obtained.

For the data collection, a caregiver questionnaire was created *ex profeso* for the investigation, based on the one developed by Molassiotis et al.<sup>8</sup>. It comprised 17 semi-structured items that were adapted to describe the study variables, which were the following: use of complementary and alternative medication, type of ACT taking into account only products regarded as biological

**Table 1. Beneficial effects perceived with the use of ACT**

Perceived benefit	No.
Improves physical status	19
Prevents toxicity	5
Stops cancer growth	5
Raises body defenses	4
Relieved the pain	3
Relaxation	1
None	14
Total	51

therapies by the National Center for Complementary and Alternative Medicine (NCCM)<sup>9</sup> (herbs, vitamins, macrobiotic food and nutritional supplements), parental motivation to administer their children some type of ACT and expected effects following the use of ACT.

In addition, the place of acquisition, who recommended the use of ACT, if the interviewed had referred its use to the treating physician, and the monthly expenditure (in US dollars) generated by their use was recorded.

Prior to administration of the questionnaire, the caregiver was informed on the purpose of the study and signed an informed consent letter. All the interviews were carried out by the main investigator and the provided answers were literally written down. Average duration of the survey was 30 min.

The data were analyzed with the statistical pack SPSS, version 11.0. An analysis of quantitative contents was carried out and the answers were categorized by frequency.

## Results

One hundred consecutive surveys were administered to 100 parents/legal guardians whose children were alive, 68% on treatment phase, 15% on relapse or with no response to the treatment, 7% on diagnostic phase, 6% on surveillance, 3% post-transplantation and 1% with a second, active malignant neoplasm.

Mean age of the patients was 4 years, and the distribution by sex was as follows: 56 females and 44 males. In the case of the caregivers, mean age was 27 years and distribution by sex, 89 females and 11 males. Eighty-nine percent of the population had a low socioeconomic status and the education level was complete secondary school in 79% of the cases.

The distribution of diagnoses was the following: 36 cases of leukemia (34 acute lymphoblastic and 2 acute non-lymphoblastic) and 64 solid tumors (14 retinoblastomas, 13 sarcomas, 11 central nervous system tumors, 8 germ-cell tumors, 7 lymphomas, 6 neuroblastomas and 3 hepatoblastomas).

Of the surveyed subjects, 87% referred having been recommended the use of complementary therapies sometime: in 36% (n = 32) of the cases it was another user with a cancer diagnosis who made the recommendation and in 43% (n = 38) an acquaintance or relative; 9.1% (n = 8) had previous experience with ACT, 5.7% (n = 5) received the recommendation through the media, 3.4% (n = 3) consulted with an alternative doctor and 1% received the indication from an allopathic physician.

Of the caregivers, 51% recognized using some type of ACT; of them, 70% reported having employed it at least once before the cancer diagnosis as a curative habit.

With regard to medical treatment prohibition, 18 patients out of 100 reported having been recommended to drop the orthodox treatment for being detrimental to the child. There were no reports of total or partial discontinuation of the treatment established by the INP because of the use of ACT.

The most requested types of ACT, according to the NCMAC classification<sup>9</sup>, were biological. The distribution of the use of each type among the surveyed subjects is shown in figure 1. Herbal medicine and juice therapy were the types of biological therapy most frequently resorted to, with 25% of the times on both cases. Five cases were found to use 2 or more alternative treatments in combination.

When the reason for the decision to use ACT was asked, the answers were the following: due to a lack of accurate diagnosis (n = 11), to improve the physical status (n = 7), to raise the body defenses (n = 7), to try everything (n = 7), because it is not harmful (n = 4), because of having had a previous positive experience with its use (n = 5), out of desperation (n = 3), to reduce chemotherapy side effects of (n = 2), due to treatment failure (n = 2), because it cures cancer (n = 2) and out of habit (n = 1).

With regard to where the ACT was acquired, the patients obtained their products mainly at stores (19 cases [38%]), through direct contacts (1 case [2%]) and in personal properties (12 cases [24%]); 3 caregivers (6%) obtained them purchasing them through the media and 3 (6%) thanks to the help provided by some member of the healthcare team. In 50% (n = 25) of the patients who used ACT, the product was presented by somebody or obtained on free-access properties, such as plots, thereby not having to spend to obtain it.

Of the interviewed subjects, 30% (n = 15) spent an average of 50 US dollars each month, whereas in the remaining 20% (n = 10), monthly expenditure ranged from 50 to 200 US dollars.

Self-administration occurred in 76% of 51 cases; the remaining 24% resorted to an alternative healthcare team, especially when there were body manipulation therapies and alternative medicine systems involved.

Of the patients who stated using alternative medicine, 18 started using it before the final diagnosis, 28 used it for periods throughout the treatment once surveillance was started; 4 surveyed subjects referred using it frequently since the diagnosis and until treatment completion.

In 29 patients, the administration of ACT was inconsistent and ended up in discontinuation. The causes for discontinuation were the following: discipline with the treating physician in 8 cases, because the child rejected its use in 7 and for not perceiving any improvement in 5. Other 3 caregivers expressed having discontinued the administration of ACT for not being able to do it due the child's hospitalization and, in 4 patients, owing to information obtained on its risks and side effects. Two cases discontinued its use due to unpleasant effects.

When questioned about the benefit attributed to the intake of ACT, 37 patients reported a subjective improvement. The answers referred by the caregivers as beneficial effects attributable to complementary therapies are textually quoted in table 1. In 14 patients, the caregiver did not notice any improvement at all.

Among the surveyed subjects who administered ACT, 80% (n = 40) claimed that the product didn't cause any side effects; the remaining 20% (n = 11) reported effects such as fever, hyporexia, diarrhea, vomiting, non-specified skin reactions, etc.

Only 13 out of 51 users informed the treating physician about the use of complementary therapy; 5 of them did it in order for the allopathic treatment not to be obstructed, 4 requested medical approval for its use, 3 felt confident to comment on it and, in the case of 1 patient, it was the physician who enquired the caregiver on the subject.

Of the 38 patients who did not inform their treating physician on the use of ACT, 11 failed to do it for not considering it necessary, 12 because nobody asked them and 13 referred fear of scolding or negative consequences; 2 caregivers couldn't find the right moment to comment on the subject, according to their own words.

In the group of patients who did not use any type of ACT, the reason for it was enquired: 20 out of 49 patients

did not use out of fear of side effects, 12 for adherence to the orthodox therapy, 11 due to lack of information, 4 due to lack of opportunity because of hospital admission and 2 due to patient refusal.

## Discussion

It is a common belief that Middle American-origin countries are the leaders in the use of alternative or complementary methods for the treatment of childhood cancer; however, this claim is inaccurate: American, Dutch and Pan-european series show 50-80% use of ACT in children with cancer<sup>10-13</sup>, and the figures reported in series of Mexican adults do not differ significantly from those percentages<sup>14,15</sup>.

Neither is the type of used therapies different: herbal medicine occupies the first place<sup>8,16</sup>, followed by manipulative techniques and aromatherapy<sup>15,17</sup>.

With regard to the reasons for using ACT reported by the patients in this series, the lack of an accurate medical diagnosis in light of the child's symptoms was predominant; in other series, the use of ACT has been described as resulting from dissatisfaction with allopathic treatment<sup>18</sup>. The surveyed subjects also referred having used ACT to mitigate unpleasant effects of the treatment and to increase the body defenses and the healing range, which is consistent with reports in the literature<sup>8,11,13,17,19,20</sup>.

The decision to administer ACT was made upon the recommendation of a user and with no medical prescription in most our patients. The recommendation and specification are made only based on anecdotic or empirical knowledge of the product; this way, patients medicate the children without knowing the dose and the exact schedule of administration<sup>21</sup>.

The problem with the use of ACT is that efficacy and safety of the compounds have actually not been demonstrated. In 1994, in the USA, it was determined that the regulations and regimens of the federal agency that regulates food and drugs, the Food and Drug Administration (FDA), should not affect remedies manufactured based on herbs<sup>16</sup>; consequently, these do not have to pass through extensive laboratory clinical tests prior to being introduced into the market and are not forced to comply with the quality standards that are characteristic of patent pharmaceuticals<sup>22</sup>.

In the case of Mexico, the law doesn't endorse the practice of traditional medicine, but neither does sanction it, thus leaving the patient unprotected in case of fraud or negligence.

In a survey made to 16 Mexican traditional doctors, only 3 were found to have some academic degree, and not specifically related to the field of healthcare<sup>23,24</sup>.

In Mexico, traditional therapists don't have an adequate academic preparation and the law does not regulate their activities<sup>22,24</sup>. People use ACT under the common belief that what's natural is harmless and, as detected in this study, they have it within reach with no need for a medical prescription<sup>22</sup>.

An important finding is that 18% of the surveyed sample received the indication to discontinue the orthodox treatment in order to start the ACT, but no one did; i.e., patients who use ACT do not abandon the allopathic treatment, which means there is good compliance with conventional treatment.

As for the acquisition cost of the ACT, in this series only 20% of the surveyed individuals spent an amount higher than 50 dollars per month, since most patients had free access to the ACT or it was given as present by some acquaintance/relative.

Previous reports on the use of ACT in Mexican cancer patients reveal a wide acceptance, as well as a perception of improvement when combined with the allopathic treatment.

In the case of adults, it is young women with advanced stage cancer who are more inclined to use ACT. Noteworthy, there are no significant differences with regard to the academic degree of the users of this type of treatments, as reported by Gerson-Cwilich et al.<sup>7</sup>.

In pediatric patients of western Mexico, 70% of primary caregivers accept using ACT as part of the child's treatment, and nearly 80% of them reported satisfaction with the administration of complementary therapy<sup>6</sup>.

In our series, as in that of the west, satisfaction with the used therapies is large; caregivers describe benefits that for them are tangible, but not for the medical team.

Few patients report any side effects such as nausea vomiting, diarrhea, cough, weight loss, weakness, etc. when using ACT, and the majority do not perceive any specific benefit, or what they perceive is merely subjective<sup>12,17,20</sup>. Some patients that sometime have used some type of ACT even report that they wouldn't do it again and neither would they recommend it to other patients due to the harm it might cause them<sup>15</sup>.

Most patients fail to inform their physician on the consumption of these treatments, which is consistent with observations reported by other studies<sup>11,12,25,26</sup>. The reluctant attitude with regard to this matter, both by the physician and the caregiver, makes it difficult to prevent ACT-derived comorbidities or complications.

The main reasons whereby the patients justify the fact of not communicating their physician on the use of ACT are the following: because the physician doesn't directly ask and out of fear of being judged or eliciting some negative reaction and loose the healthcare service, in addition to the belief that allopathic physicians ignore the effects of traditional medicines and their healing effect<sup>11,12,25,26</sup>.

Nevertheless, most allopathic physicians (75-92%) have been found to possess good knowledge on ACT terminology and main methods and products, although they ignore their mechanism of action and potential adverse effects<sup>27</sup>.

It has been detected that when ACT methods are not intrusive for the body, as in the case of massage or meditation, they are tolerated by allopathic physicians, who even support their use thinking that, indeed, they can improve the patients' quality of life.

Among physicians, 99% consider highly important to know if their patients use ATC, and in case they do, what type of ATC, but less than 50% enquire on the subject in the routine interview. Physicians report that the reduced time to see patients, the priority of the disease and the lack of tools to enquire the patients on the subject, limit its inclusion in the interview and, consequently, they also fail to offer recommendations about the risks and drug interactions that might seriously affect the patient<sup>28,29</sup>.

## Conclusions

In Mexico, complementary therapies are widely used. Only in this series, 50% of the patients recognized having resorted at least once to agents other than those prescribed by the physician and/or healthcare institution. For this reason, the oncologist should intentionally enquire on the use of alternative or complementary therapies, something that currently does not occur on a regular basis. Adequate doctor-patient communication favors the control of therapies administered to these patients, this way preventing adverse effects and drug interactions that might end up being fatal.

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