

Non-Conventional Therapies in Childhood Cancer: Guidelines for Distinguishing Non-Harmful From Harmful Therapies: A Report of the SIOP Working Committee on Psychosocial Issues in Pediatric Oncology[†]

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This is the 11th official document of the SIOP Working Committee on Psychosocial Issues in Pediatric Oncology, instituted in 1991. There is a tendency for some physicians to make blanket statements against the use of non-proven, non-conventional therapies, even when these therapies are not harmful. There is an equal and opposite tendency on the part of many parents to do all that they possibly can for their children,

including using any non-conventional therapy they feel might do some good. The health care team must open a healthy dialogue with parents that will lead to a clear distinction between those complementary therapies that are harmful and those that are not, indeed, might even be helpful psychologically if not therapeutically. *Pediatr Blood Cancer* 2004;42:106–108.

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INTRODUCTION

These guidelines will outline key issues in distinguishing childhood cancer therapies that are not harmful from those that are partially and/or definitively harmful. Inherent in this discussion is the presumption that the parents—and the children/adolescents themselves as fully as their level of development allows—participate actively in the decision-making process regarding the use of conventional medical treatment. Inherent as well in the discussion is that the physicians and other members of the extended health care team will encourage dialogue, offer advice, and listen to the concerns of the patients and their parents regarding the use of non-conventional therapies.

Conventional medical therapy in childhood cancer includes both proven treatments (tested therapies that are evidence-based and found to be effective) and investigational treatments (therapies that are being studied in a clinical trial). Conventional therapy thus refers to forms of medical treatment (a) that are widely practiced and accepted by medical practitioners as the most effective, (b) for which there typically is scientific evidence of efficacy, and (c) with supportive data and conclusions published in journals of high scientific reputation [1]. We underscore the fact that conventional therapies are based on clinical research.

Non-conventional medical therapy in childhood cancer encompasses two concepts that differ both in meaning and in medical practice: complementary therapies (those that

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are used along with conventional medicine) and alternative therapies (those that are used in place of conventional therapy) [1–4]. What follows is an elaboration of the distinction in the term non-conventional therapy between those therapies that are used in the place of conventional medicine (alternative therapies) and those therapies that are used along with conventional medicine (complementary therapies). While these guidelines are written for pediatric oncology, much of the early work in this field has been done in adult medicine [5–10] and is generally applicable to children as well.

ALTERNATIVE THERAPIES

Alternative therapies are unproven treatments that are substituted for and used instead of conventional medicine [1]. In doing so, they lead to discontinuation of therapy shown to be medically effective. That treatment, recommended for that particular child/adolescent by physicians expert in that form of pediatric cancer, typically is substituted by an unproven non-conventional medical and/or non-medical treatment. Such a substitution can lead to the loss of the patient's right to the best available treatment and thus the loss of the child/adolescent's best hope for survival. This particular use of alternative medicine should be forcefully discouraged, with full and adequate explanation given to the children/adolescents and their parents so that they understand the reasons for such advice.

COMPLEMENTARY THERAPIES

Complementary therapies are those that are used along with conventional medicine, to help relieve symptoms, lessen side effects, or provide psychological benefit [1]. There is an ever-increasing use of such complementary treatments with about half of all adult cancer patients using some form of complementary therapy, and an increasing number of parents of children with cancer supporting its use [2]. These non-harmful therapies include interventions such as biofeedback, relaxation and meditation, hypnosis, imaging, massage, aromatherapy, a variety of culturally dependent and culturally sensitive spiritual healing therapies, and in-depth religious beliefs and practices. Such non-harmful complementary therapies (a) often make the child/adolescent patients and their parents feel better, (b) give them a sense of having a wider control over the decision-making process regarding the child's health, (c) can help reduce psychological as well as physical pain, (d) can improve the quality of life, (e) might offer some relief from the side effects of conventional therapies, and (f) can boost the immune system. Both hard and soft data from pediatric cancer clinics verify the value, usefulness, and extensive participation by families in such complementary therapies [2]. Those that are not harmful and provide psychological support for the children and

their families should not be discouraged by the medical health care team.

In summary, physicians and the other members of the health care team should discourage discontinuation of proven conventional therapies and the substitution of unproven alternative therapies. At the same time, physicians should not discourage parental discussion of and controlled use of non-harmful complementary therapies, with the following caveat.

HARMFUL VERSUS NON-HARMFUL COMPLEMENTARY THERAPIES

The serious problem in the use of complementary therapies is that when taken to excess some of the therapies can induce complications, cause serious side effects, be physically harmful to the child, and even lead to death. Herbal toxicity is a prime example of supposedly non-harmful therapies that can actual become very harmful. Herbs, vitamins, and minerals fall within this category. A mixture of Chinese herbs called *Aristolochia fangchi* can cause progressive renal failure and consequently bladder cancer. *Borrago officinalis* can lead to veno-occlusive disease. *Tussilago farfara* can lead to liver necrosis, *Eucalyptus globulus* to ataxia, Camphora to convulsions, Gingseng to hypertension, and high doses of vitamin A to liver failure. Other complementary therapies can be very harmful as well—for example: excessive use of enemas, application of magnetic fields, and/or electrical energy from outside the body, and the use of pharmacologic agents derived from such sources as apricot kernels and shark cartilage. Eyre and associates give an excellent and detailed overview of this issue [1].

It is not the goal of these guidelines to list all the harmful non-conventional therapies. Rather it is to urge parents, to discuss with their physician and other health care team members whether or not a particular alternative approach might be harmful to their child. Parents should be very cautious about applying non-conventional therapies when (a) the proposed non-conventional therapy is a "secret" that only specific individuals can provide, (b) when the therapy promises a cure for almost all cancers or medical conditions, (c) when the promoters claim to be persecuted by the medical establishment, (d) when the promoters attack the medical community, or especially, (e) when the promoters demand a large amount of money up front.

Harm can be psychological as well as physical. Even if there is no actual physical harm done, giving a false hope to parents can set them up for a severe psychological setback when the non-conventional complementary therapies prove ineffective. Further, when used during the palliative phase of treatment, non-conventional therapies can distract the parents from the very real, emotionally painful, and challenging role of helping each other, the

patient and the siblings to prepare realistically for the patient's last days.

GUIDELINES FOR THE USE OF NON-CONVENTIONAL THERAPY

The following general guidelines apply.

- 1 The health care team members should accept that children/adolescents and their parents use whatever supportive mechanisms they have at their disposal, including non-harmful complementary therapies, even if useful only from a psychological point of view. Specifically, the health care team should not automatically and dismissively discourage the use of non-harmful complementary therapies.
- 2 The health care team should be attentive to non-conventional complementary therapies that may be physically or psychologically harmful to the children/adolescents and/or to their parents.

All family members concerned should be encouraged to discuss openly these harmful treatments with knowledgeable and expert advisers. Through an open dialogue, the children/adolescents, at their own developmental level, and their parents should gain a clear understanding of why the recommendation is made against the use of the non-conventional treatment known to have adverse or toxic effects or interactions.

CONCLUSIONS

There is a tendency for some physicians to make blanket statements against the use of non-proven, non-conventional therapies, even when these therapies are not harmful. There is an equal and opposite tendency on the part of many parents who wish to do all that they possibly can for their child, to search for non-conventional therapies they feel might do the child some good. The health care team must open a healthy dialogue that will lead to a clear distinction between harmful and possibly helpful complementary therapies. A failure to open such a dialogue will keep the children/adolescents and their parents from talking about their interest in complementary therapies, and could eventually lead them to abandon traditional therapies altogether. Full discussion not only

will protect and promote the best health interests of the specific child, but also could promote inquiry regarding the unconventional therapy in question and even broader research in this field.

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