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Alternative Medicine Methods in Children with Cancer: Evaluation of Parents' Views and Knowledge

Kanserli Çocuklarda Alternatif Tıp Yöntemleri: Ebeveyn Görüş ve Bilgilerinin Değerlendirilmesi

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Cite as: Kızmaçoğlu D, İnce D. Alternative Medicine Methods in Children with Cancer: Evaluation of Parents' Views and Knowledge. J Tepecik Educ Res Hosp 2022;32(3):448-53

Abstract

Objective: Childhood cancers are a relatively rare group of diseases. In addition to conventional treatment, the use of alternative medicine methods is increasing. Especially during the diagnostic and treatment process, families ask doctors about alternative medicine practices. In this study, we evaluated the knowledge and opinions of the parents of childhood cancer patients about alternative medicine methods.

Methods: The volunteer parents of patients were interviewed and a questionnaire was applied to them. They were asked about which alternative medicine practices they had information about, where they had information about these practices, and what they thought about.

Results: A total of 135 people participated; the parents of children who were treated at the Dokuz Eylül University and University of Health Sciences Turkey, İzmir Tepecik Education and Research Hospital Pediatric Oncology Clinics in İzmir. They completed a questionnaire about their opinions and knowledge about alternative medicine methods. 80% of the respondents stated that they had heard about alternative medicine before and 60% of them stated that they were recommended alternative methods at any time of treatment. We found that 21.5% of the respondents used alternative methods. The most commonly used methods were herbal cures, propolis, donkey milk, turtle blood, silver water, kefir, reiki mushrooms.

Conclusion: The methods known by the participants were in a wide range. We have seen that parents with a higher education level are more inclined toward alternative medicine methods. We concluded that we should evaluate the tendency of patients to alternative medicine methods and guide them correctly.

Keywords: Alternative medicine methods, pediatric oncology, survey

Öz

Amaç: Çocukluk çağı kanserleri göreceli olarak nadir karşılaşılan bir hastalık grubudur. Tedavide kemoterapi, radyoterapi ve cerrahi uygulamalar multidisipliner bir yaklaşım ile uygulanmaktadır. Konvansiyonel tedavinin yanı sıra alternatif tıp uygulamalarının kullanımı da artmaktadır. Özellikle tanı ve tedavi sürecinde aileler kanser tanısı alan çocukları için doktorlara alternatif tıp uygulamaları hakkında sorular sormaktadır. Bu çalışmada kanser tanısı alan çocuk hastaların ebeveynlerinin alternatif tıp uygulamaları hakkındaki bilgi ve görüşlerinin değerlendirilmesi amaçlanmıştır.



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Received/Geliş tarihi: 08.12.2021

Accepted/Kabul tarihi: 12.01.2022

Öz

Yöntem: Çocukluk çağı kanser hastalarının ebeveynleri ile görüşülüp kendilerine bir anket uygulanarak hangi alternatif tıp uygulamaları hakkında bilgi sahibi oldukları, bu uygulamalar hakkında nereden bilgi sahibi oldukları, bu uygulamalar hakkında neler düşündükleri anket aracılığıyla sorgulandı. Tanımlayıcı ve gruplar arası karşılaştırmalı istatistiksel analizler yapıldı.

Bulgular: Dokuz Eylül Üniversitesi Tıp Fakültesi Hastanesi Çocuk Onkoloji Polikliniği ve Sağlık Bilimleri Üniversitesi, İzmir Tepecik Eğitim ve Araştırma Hastanesi Çocuk Onkoloji Kliniği'nde tedavi gören çocukların ebeveynlerinin alternatif tıp ile ilgili bilgi düzeyleri ve konu hakkındaki düşüncelerini değerlendirmek için yaptığımız ankete 135 kişi katıldı. Anket uygulananların %80'i daha önce alternatif tıptı duyduğunu ve %75'i de alternatif tıp hakkında bilgisi olduğunu, %60'ı ise tedavinin herhangi bir döneminde kendilerine tavsiye edilen alternatif tıp yöntemleri olduğunu belirtti. Anket uygulananların %21,5'inin alternatif tıp yöntemi kullandığını tespit ettik. En sık kullanılan yöntemler; bitkisel kürler, propolis, eşek sütü, kaplumbağa kanı, gümüş suyu, kefir, reiki mantarı idi.

Sonuç: Katılımcıların bildiği yöntemler oldukça geniş bir yelpazedeydi. Eğitim düzeyi yüksek olan katılımcıların, alternatif tıp yöntemlerine daha yatkın olduklarını gördük. Hastaların alternatif tıp yöntemlerine olan eğilimini değerlendirip, onları doğru bir şekilde yönlendirmemiz gerektiği sonucuna vardık.

Anahtar Kelimeler: Alternatif tıp uygulamaları, çocuk onkoloji, anket

Introduction

Cancer is an important health problem worldwide. We observe that number of cases has increased over the years. Cancer in childhood is relatively rare. Only 0.5% of all cancers are detected under the age of 15⁽¹⁾. Unlike adult cancers, children have a longer life expectancy and better response to treatment. Chemotherapy, radiotherapy and surgery are the treatment options, applied with a multidisciplinary approach.

Alternative medicine includes many treatments that are used in addition to or instead of conventional methods such as chemotherapy and radiotherapy. First, Eisenberg defined alternative medicine as medical interventions not usually taught in medical school and not found in a hospital setting⁽²⁾. We can evaluate complementary and alternative medicine (CAM) methods in five groups (Table 1)⁽³⁾. The frequency of tendency to alternative methods in the protection of health, also fighting against chronic diseases and cancer is increasing.

According to the research of the European Partnership on Action Against Cancer, the most preferred methods are acupuncture, homeopathy and herbal products⁽⁴⁾. In our country, especially herbal products are more frequently preferred⁽⁵⁾.

Parents whose children are diagnosed with cancer, ask questions about alternative medicine to healthcare professionals during their treatment period. By researching alternative medicine methods, parents are thinking about and even using these methods for different purposes⁽⁶⁾. We always inform families about our opinion that using alternative medicine methods during multidisciplinary cancer treatment is not appropriate. However, it is within our knowledge that the families have tried or want to try alternative methods at the time of diagnosis, treatment phase or the terminal period.

In this study, we wanted to evaluate the knowledge and opinions of the parents of children with cancer about alternative medicine methods.

Materials and Methods

The volunteer parents of patients whose child diagnosed cancer and continuing active treatment were interviewed, a questionnaire was applied to them. They were asked about which alternative medicine practices they had information about, where they got information about these practices, and what they thought about these practices. A questionnaire consisting of 35 questions was applied to the volunteers (mother, father, older brother/sister or grandparent) of the children who were treated in Dokuz Eylül University Medical

Table 1. Complementary and alternative medicine methods

| | |
|---|--|
| 1- Alternative and medical system | Homeopathy, Ayurveda, Chinese medicine |
| 2- Body - mind therapy | Hypnosis, music, prayer, biofeedback |
| 3- Biologically based treatments | Herbal products, vitamins, special diets |
| 4- Energy treatments | Reiki |
| 5- Manipulative and bodily based treatments | Massage, exercise, hydrotherapy, reflexology |

Faculty Hospital Pediatric Oncology Clinic or University of Health Sciences Turkey, İzmir Tepecik Education and Research Hospital Pediatric Oncology Clinic. Informed consent was obtained from the volunteers before the questionnaire. The study protocol was approved by the local Ethics Committee of University of Health Sciences Turkey, İzmir Tepecik Education and Research Hospital (2021/05-27).

Statistical Analysis

The data obtained from the questionnaires were entered into the SPSS 22.0 program to calculate descriptive statistics. Associations between the demographic and clinical variables were analyzed using chi-square test, t-tests and Mann-Whitney test for independent groups. For statistical significance, $p < 0.05$ was accepted as significant.

Results

A total of 135 people, 61 from Dokuz Eylül University Medical Faculty Hospital Pediatric Oncology Clinic and 74 from University of Health Sciences Turkey, İzmir Tepecik Education and Research Hospital Pediatric Oncology Clinic, participated in the survey.

When we look at the characteristics of patients; 46% were female and 54% male (M/F=1.17). The median age at diagnosis was 8 (1-17 years). While 54% of the children were diagnosed with leukemia and lymphoma, the others were diagnosed with solid tumors. 86% of the patients received chemotherapy and 24% received radiotherapy. Surgery was performed in 41% of the patients.

The median age of the respondents was 35 (20-67 years). The demographic characteristics of the participants are presented in Table 2. While most mothers (79.5%) were homemakers, 40% of the fathers were self-employed, 15% were civil servants, 37% were workers, and 8% were unemployed.

Of those respondents, 80% said they had heard about alternative medicine before, and 75% said they knew alternative medicine. 60% of them stated that they had alternative medicine methods recommended to them at any time of the treatment.

The methods they heard and described as alternative medicine included herbal cures, hiyama, tarhana rub, leech, spring water, bioenergy, propolis, donkey milk, chamomile, donkey grass, fenugreek, bioresonance, centaury oil, breast milk, silver water, turtle blood, olive leaf, royal jelly,

pollen, clove oil, carob molasses, mulberry molasses, cupping, hemp oil, kefir, vitamin pills, blue scorpion venom from Cuba, turmeric, dandelion, reiki mushrooms.

Respondents asked about the ways of accessing information about these methods: 15% said they heard it from their friends, 7% from their relatives, 29% from other patient relatives; 12% said that they reached through internet searching motors, 15% from social media, 18% from television, 4% from books/newspapers/magazines.

21.5% (n=29) of those participants have used at least one type of alternative medicine method. The methods used are summarized in Table 3. While 83% (n=24) of parents have used a single method, 17% (n=5) have used more than one method. The method of application: 80% had taken orally, 20% applied to the skin as rubbing. All the methods were applied by a family member. Respondents who reported the use of alternative medicine were asked if had discussed this with healthcare providers: 30% reported to their doctor, and 20% to any health personnel other than the doctor.

When asked about the reasons for using alternative medicine methods, the following list was provided: Reduce side effects/physical stabilization (40%), strengthening the immune system (24%), increase the effect of treatment (35%) and improving cure chance as a source of hope (12%). Respondents were asked to specify the factors that convinced them to use alternative methods; advice of neighborhood

Table 2. Demographic characteristics of the respondents

| | Number (n) | Percent (%) |
|--|------------|-------------|
| Respondent | 135 | 100 |
| Mother | 86 | 63.7 |
| Father | 36 | 26.7 |
| Sibling | 7 | 5.2 |
| Grandmother/grandfather | 6 | 4.4 |
| Participant's educational level | | |
| Illiterate | 8 | 5.9 |
| Primary school | 42 | 31.1 |
| Secondary school | 20 | 14.8 |
| High school | 39 | 28.9 |
| University graduate | 26 | 19.3 |
| Economic status of the family | | |
| Poor | 34 | 25.2 |
| Moderate | 77 | 57.0 |
| Good | 24 | 17.8 |

50%, positive results in their environment 20%, confidence in alternative medicine 10% and because of desperation 8%.

When we asked the participants to evaluate their level of knowledge about the alternative medicine method they used, 14% answered that they had a lot of knowledge, 55% said that they had moderate knowledge and 31% answered that they had a little knowledge.

While the rate of those who thought that there was a risk in the application of the methods was 28%, the rate of those who thought that they benefited from these methods was 70%. When we asked those who stated that they had knowledge about alternative medicine methods but did not use them; 60% said they had consulted a doctor and it was not considered appropriate, 20% said they did not want to take the risk, 10% said they did not need it, 5% did not find it reliable, and 5% still thought.

Discussion

Today, the use of alternative medicine methods is becoming increasingly common both in general population and in cancer patients. Although studies with adult cancer patients are in the majority, it is also an important and questionable issue for childhood cancers. In the literature review, the frequency of alternative treatment use in Turkey was found to be 22.1-84.1%⁽⁷⁾.

There is a wide variety of alternative medicine methods available. There was no guidance regarding the methods in our survey, the participants stated that they mostly knew

about or used herbal products. The most frequently preferred method in the literature is herbal agents, either⁽⁸⁾.

In a clinical trial evaluating the use of complementary/alternative treatment in patients with breast cancer, it was found that 48.8% of the patients applied at least one method. The most frequently applied method was herbal methods, as in our study⁽⁹⁾.

In a study with lung cancer patients, it was found that low socioeconomic status and low education level were the most important factors affecting the use of alternative medicine methods⁽¹⁰⁾. In our study, there was no statistically significant difference in terms of educational status and socioeconomic status between user/nonusers, respectively ($p=0.067, 0.12$).

Alternative medicine method use rarely discussed with the doctor. Parents tend to hide their use of alternative medicine methods from doctors and other health professionals, and we think that the rate of alternative medicine method use may be higher than our study results, even if the survey was nameless.

Views of the parents on alternative non-medical practices in children, evaluated in a study, the rate of at least one method usage was found to be 26.1%. In this study, it was emphasized that these practices can harm most people and change the effectiveness of conventional treatment⁽¹¹⁾.

Drozdoff et al.⁽¹²⁾, studied about complementary medicine intake during systemic therapy in adult cancer patients, and found that especially herbal products are often used together with systemic cancer therapy. Therefore it would be inevitable to use alternative treatments in the clinical routine in the future.

A population-based retrospective survey conducted in Germany on complementary and alternative treatment methods in children with cancer. The rate of alternative method usage was reported as 35%. The most common reason for use is physical stabilization, strengthening the immune system and increasing the chance of recovery. These results were similar to our study. 70% of respondents not discussed the use of alternative method with their doctor. This rate is surprisingly lower in our study. Our respondents discussed the situation either with their doctor or healthcare professionals, this can be the reason for higher rate⁽¹³⁾.

In another survey study on the use of alternative and complementary therapies in children with cancer, the rate of alternative medicine use was found to be 49%⁽¹⁴⁾. This rate

Table 3. Alternative methods used by parents

| Method | Number (n) | Percent (%) |
|---------------------|------------|-------------|
| Herbal mixtures | 8 | 27.6 |
| Propolis | 4 | 13.8 |
| Kefir | 4 | 13.8 |
| Donkey milk | 3 | 10.3 |
| Vitamin pills | 2 | 6.9 |
| Reishi mushroom | 1 | 3.45 |
| Turtle blood | 1 | 3.45 |
| Silver water | 1 | 3.45 |
| Nettle | 1 | 3.45 |
| St. John's Wort oil | 1 | 3.45 |
| Bioenergy | 1 | 3.45 |
| Prayer | 1 | 3.45 |
| Massage | 1 | 3.45 |

is higher compared to our study, and when we look at the methods used, it was seen that physical and psychological methods were also included in this study, unlike ours.

In an observational study conducted in a pediatric oncology center in Italy, the rate of alternative medicine method usage was found to be 12.4%. They stated that the most common reason for use is to reduce the side effects of chemotherapy drugs⁽¹⁵⁾.

Like our study, the use of CAM in children with cancer investigated in two oncology centers in France. A hundred eleven families answered questionnaire, 48.6% of respondents reported CAM uses, 59.3% reported it to the health worker. The most commonly used method was homeopathy in this study. As we found in our study, the main reason for the using CAM was to control the side effects of conventional treatment⁽¹⁶⁾.

Similarly, in a survey study performed in two clinics in Canada, the prevalence of use of alternative medicine method was determined as 60.5%, and most those who used it did not share this issue with the doctor and other healthcare professionals, as in our study⁽¹⁷⁾.

In a study conducted in our country, a questionnaire was applied to 110 mothers with a child diagnosed with cancer and the rate of use of alternative methods was given as 53.6%. Herbal products were used most frequently, and the diversity was found to be similar to our study⁽¹⁸⁾. Genç et al.⁽¹⁹⁾ determined the prevalence of CAM use as 75% and the rate of sharing this issue with the doctor was 25%.

The use of alternative medicine methods is becoming more and more common. Use is more common in adults and especially in chronic diseases. It is also a popular topic for oncology patients and is a subject that physicians consult. The diversity of the methods and the ease of accessibility necessitated the need to have knowledge about these methods and their possible beneficial/harmful effects. It is used more frequently in adult oncology patients, but the rate decreases in pediatric patients. This may be related to the protective attitudes of parents toward their children and their reluctance to use methods whose effects are unknown.

Due to the wide variety of methods known and used in our study, applying the questionnaire to a larger number of participants may enable us to obtain clearer results.

More studies are needed to evaluate the tendency of patients to alternative medicine methods and to guide

them properly. The possible benefits/harms of alternative medicine methods should be demonstrated based on evidence. Solidarity and cooperation between the healthcare team and families in cancer treatment is critical to best manage the treatment of patients with trust and accurate information.

Study Limitations

This study has some limitations. The small number of participants is the main limitation of our study. Similar studies could be conducted with more than two centers and with more participants. The other limitation is the fact that the questionnaire is administered by the doctor may increase the probability of the family hiding the truth.

Conclusion

As there is a need for prospective studies on the effects and side effects of alternative medicine methods, pediatric oncologists also must have sufficient information about these treatments and inform families professionally.

Ethics

Ethics Committee Approval: This study was approved by the University of Health Sciences Turkey, İzmir Tepecik Education and Research Hospital Ethics Committee (decision no: 2021/05-27, date: 17.05.2021).

Informed Consent: Informed consent was obtained.

Peer-review: Externally peer-reviewed.

Authorship Contributions

Surgical and Medical Practices: D.İ., Concept: D.K., D.İ., Design: D.İ., Data Collection or Processing: D.K., Analysis or Interpretation: D.K., D.İ., Literature Search: D.K., Writing: D.K., D.İ.

Conflict of Interest: No conflict of interest was declared by the authors.

Financial Disclosure: The authors declared that this study received no financial support.

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