



ARAŞTIRMA / RESEARCH

Beliefs and experiences of breast cancer patients about the use of complementary therapies: A qualitative study

Meme kanseri hastalarının tamamlayıcı tedavilerin kullanımına ilişkin inanç ve deneyimleri: Kalitatif bir çalışma

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Abstract

Purpose: Breast cancer patients prefer to use complementary therapies (CT) along with medical treatment to improve their health. However, patients don't share detailed information regarding the use of CT with healthcare professionals. The aim of this study is to examine the beliefs and experiences of breast cancer patients receiving chemotherapy regarding the use of CT.

Materials and Methods: Individual interviews were conducted with 11 breast cancer patients through a semi-structured interview form in June-July 2019. Six-phase thematic analysis was used to analyze the data.

Results: Three main themes were identified in the study: Types of CT used, CT preferences, and positive experiences. In terms of CT types, patients use natural products, and mind and body practices. Patients prefer these methods to prevent the progression of the disease, not to use medical drugs, reduce the side effects of the treatment, or because they don't believe in the therapeutic effect of chemotherapy. Physiological recovery and immunity enhancement are among the positive experiences after the use of CT. Patients continue to use these methods because they have positive experiences related to the use of CT.

Conclusion: Breast cancer patients mostly prefer natural products followed by mind and body practices. Patients receive very little guidance from healthcare professionals regarding the use of CT and prefer to use social communication resources for such information. Advices given by oncology physicians and nurses to the patients in the light of the current evidence-based literature whether to continue using CT are crucial for the health of the patient.

Keywords: Breast cancer, complementary therapies, natural products.

Öz

Amaç: Meme kanseri hastaları sağlıklarını ve refahlarını geliştirmek için tıbbi tedavi ile birlikte tamamlayıcı tedavileri (TT) kullanmayı tercih etmektedir. Ancak TT kullandıklarını sağlık profesyonelleri ile ayrıntılı konuşmamaktadırlar. Bu çalışmanın amacı, kemoterapi alan meme kanseri hastalarının TT kullanımına ilişkin inanç ve deneyimlerini ayrıntılı olarak açıklamaktır.

Gereç ve Yöntem: Yarı yapılandırılmış görüşme formuyla, Haziran-Temmuz 2019'da 11 meme kanseri hasta ile bireysel görüşmeler yürütülmüştür. Verilerin analizi için 6 aşamalı tematik analiz kullanılmıştır.

Bulgular: Çalışmada üç ana tema belirlenmiştir: kullanılan TT çeşitleri; TT tercih ve olumlu deneyimler. Hastalar TT türlerinden doğal ürünleri, zihin ve vücut uygulamalarını kullanmaktadır. Hastalar bu yöntemleri tercih etmelerinin nedenleri; hastalığın ilerlemesini engellemek, tıbbi ilaç kullanmamak, kemoterapinin iyileştiriciliğine inanmamak ve tedavinin yan etkilerini azaltmaktır. TT kullanımı sonucunda fizyolojik iyileşme ve bağışıklığı güçlendirme olumlu deneyimler arasındadır. Hastalar TT kullanımına bağlı olumlu deneyimler yaşadıkları için bu yöntemleri kullanmayı sürdürmektedir.

Sonuç: Meme kanseri hastaları TT türlerinden çoğunlukla doğal ürünleri, daha sonra zihin ve vücut uygulamalarını tercih etmektedirler. Hastalar TT kullanımında, sağlık ekibinden çok az rehberlik ve eğitim almakta, bilgi için sosyal iletişim kaynaklarını kullanmayı tercih etmektedir. Onkoloji hekim ve hemşirelerinin kanıta dayalı mevcut literatür ışığında, hastaların TT kullanımına devam etmeleri veya bırakmaları konusunda tavsiyede bulunmaları hasta güvenliği ve sağlık sonuçları açısından oldukça önemlidir.

Anahtar kelimeler: Meme kanseri, tamamlayıcı tedaviler, doğal ürünler

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INTRODUCTION

Breast cancer which is the most common malignant tumor in females in the world is the second most common cause of cancer-related mortality¹. Breast cancer mortality rate has decreased significantly compared to that of last decade with the advances in screening and treatment². Medical treatment methods such as surgery, radiotherapy, chemotherapy and hormone therapy can be used separately or in combination for breast cancer^{3,4}. Additionally, patients can also receive Complementary Therapies (CT) in addition to these treatments.

The National Center for Complementary and Integrative Health (NCCIH) defines CM as non-mainstream practice used together with conventional medical treatment⁵. According to another definition, CTs are various healthcare practices used for improving health and prevention and treatment of diseases. These practices can be used independently or in combination with conventional medical approaches⁶. Studies in Turkey and the world have found that the use of CT is quite common among breast cancer patients⁷⁻⁹. These patients may refer to CT for reasons such as eliminating disease symptoms, reducing the side effects of cancer treatment modalities, strengthening the immune system, and improving emotional well-being^{8,10-12}.

NCCIH has classified complementary health practices under three headings: Natural products, mind and body practices, and other complementary health approaches⁵. A study stated that the most preferred methods among breast cancer patients were biological practices and mind-body medication, respectively¹³. A study conducted in Malaysia reported that biological treatments (75.9%), mind-body treatments (38.6%) and holistic medical systems (35.4%) were CT methods used by breast cancer patients¹⁴. Another study reported that 71% of breast cancer patients were using CT. In the same study, it was emphasized that prayer, massage and meditation were CT methods perceived as useful by the patients⁷.

The use of CT in Turkey is quite common among cancer patients. It has been determined that patients frequently use natural products, one of the CT types, and do not share adequate information with the healthcare professionals^{8,15}. These products may pose severe risks for patients due to the likelihood of undesired toxic effects during active chemotherapy

and contraindication with other drugs¹⁶⁻¹⁸. Explanation of the CT methods used by breast cancer patients and patient experiences in this regard can provide important and critical information for healthcare professionals working in oncology clinics. The aim of this study is to elaborately examine and describe the beliefs and experiences of breast cancer patients receiving chemotherapy about the use of CT.

MATERIALS AND METHODS

This study was planned as a qualitative study to understand the beliefs and experiences of breast cancer patients about using CT via a semi-structured interview form¹⁹.

Maximum diversity sampling method –one of the purposeful sampling methods–was used in this study. This sampling method was preferred to select a breast cancer patients registered and receiving treatment in the oncology clinic of a tertiary university hospital in Turkey that best fitted the objectives of the study^{20,21}. Maximum diversity sampling was used to increase the diversity of interview data and to include patients with various CT experience in the study^{19,20}. Women over the age of 18, diagnosed with breast cancer, received cancer treatment at least three times, and being able to speak and understand Turkish were included in the study. Patients with a chronic psychiatric diagnosis and patients with a score greater than three on the Eastern Cooperative Oncology Groups (ECOG) performance status (PS) scale were excluded from the study.

Before starting the study, ethical approval was obtained from Akdeniz University Faculty of Medicine Clinical Research Ethics Committee (protocol no: 2019/592) and official permission was obtained from Akdeniz University Hospital Chief Physician. The purpose, plan and benefits of the study were explained to the individuals and the participants were informed that the data obtained in the study would not be disclosed to third parties and informed consent was obtained from each patient. Data for each individual were identified by a code to ensure privacy and confidentiality.

Data collection

The patients who met the inclusion criteria were given information about the study by the researchers and an individual interview was held with 11 patients who volunteered to participate in the research in the

rest room of the chemotherapy department in June-July 2019. The interviews were recorded with a voice recorder after the participant's permission was obtained. All interviews were conducted using a semi-structured interview form after obtaining consent from the participants. Each interview lasted approximately 40-90 minutes. In the interviews, a semi-structured interview form containing seven questions was used to investigate the beliefs and experiences of the patients about CT use. Expert opinion for the interview form was received from two faculty members conducting qualitative research.

The interview form consisted of the following main questions: What do you think about what you need to do to be healthy as a breast cancer patient?; What are your experiences about using CT after the diagnosis?; Could you please tell us?; What is your reason for choosing CT?; Did CT contribute to your health, recovery and well-being? If yes, how so?; What are your thoughts on the use of CT?; Do you have any experiences affecting your use of CT?; Thinking about the past, what did you learn from these experiences?.

At the end of the interviews, a descriptive characteristics form questioning socio-demographic characteristics and health history was filled by the participants. Based on literature data^{9,19}, several characteristics that may affect participants' beliefs and experiences about CT use such as age, education level, marital status and perceived income status were questioned. In the disease history form, time of diagnosis, stage of cancer, type of treatment received for breast cancer, cancer history, and patient's ECOG PS scale score were questioned and ECOG PS score scale for evaluating the performance status of the patient were questioned. After each interview, observations about the characteristics of the interview environment, non-verbal communication and the participant's body language were noted down within 48 hours.

Statistical analysis

The management of all qualitative data was carried out in the NVivo 10 computer program and a 6-step thematic analysis was used to analyze the data: (1) researchers reading the recorded transcripts several times, (2) generating initial codes by considering the research objective and question, (3) searching for themes, (4) reviewing themes and deciding which to combine, refine or separate, (5) defining and naming themes, (6) preparing the report. All analyses and

reporting were carried out by researchers. Sociodemographic and health history variables were calculated and presented as number and percentage distribution.

RESULTS

Mean age of the patients was 50.09 ± 4.63 (range 42-59). More than half of the patients were Grade III cancer patients (Table 1). Table 2 shows the types of CT that patients have been using since the diagnosis of cancer. CT types cover the practices among the three groups defined by NCCIH.

Based on the results of qualitative data analysis, three main themes emerged to understand the beliefs and experiences of breast cancer patients on CT use (Figure 1).

Theme 1. Types of CT used by patients: It was determined that almost all of the participants were using natural products and approximately half were using mind and body therapies.

Herbs were the most commonly used Natural Products. Eleven participants preferred to use herbs, and the most preferred herbs were garlic, turmeric, ginger and Iranian saffron. It was found that apitherapy products were preferred (royal jelly, propolis, pollen, honey or a mixture of these) after natural methods. Two participants were using rock salt in the class of vitamins and minerals. In terms of probiotics, participants preferred mostly yogurt and kefir.

'My friend made a spice mix with turmeric, ginger, etc. She mixed fifty grams of all and put them in a jar. She then gave it to me. I put that special spice mix on food. But I cannot use it these days because of my treatment. I can't use it because turmeric may affect the treatment. Otherwise I love it.' (EY, 50 years old)

'I use a mixture of royal jelly, pollen and honey. I guess this is apitherapy. I used it regularly when I had breast cancer. I use it occasionally so that my blood sugar does not rise. I use it because I think it strengthens the immune system.... I try to use it occasionally.' (Ç, 59 years old)

'You can brew St. John's Wort as a kind of tea. It helps with flatulence. But you should not drink too much. You drink it for three days and then take ten days off. Then you drink it again for three days. You will take a break for ten days. It is very beneficial to the stomach.' (ED, 51 years old)

In terms of mind and body practices, the most commonly preferred methods by the participants

were massage, exercise, reiki, and music therapy, respectively. Two participants used spiritual practices (reading the Quran, prayer beads, prayer). Only one participant did Pilates and Yoga.

'I rubbed my knees with St. John's Wort oil. This really helped with the pain. I had a lot of abdominal pain after chemotherapy. I used to have my stomach massaged with St. John's Wort oil all the time.' (ED, 51 years old)

'I did not have good night sleep for a month because of my pain. My friend would apply reiki to me, I would feel a hot sensation like fire, and all my pain would go away. I would sleep well.' (L, 48 years old)

'I am listening to the Quran and I am praying with my prayer beads reliving me spiritually.' (M, 49 years old)

Theme 2. CT preference: The majority of the participants preferred to use CT for they received information and advice about CT, approximately one third preferred to use CT not to use medical drugs, and few people preferred to use CT because they did

not believe in the efficacy of chemotherapy and to reduce the side effects of chemotherapy.

More than half of the participants received information or advice from other individuals around them (relatives, neighbors, friends, other cancer patients), about half from television, a third from the internet, and the certified doctor on mind and body practices.

'My wife had friends who sold apitherapy products. I heard that some other people having breast cancer used this product.' (Ç, 59 years old)

'Many people with cancer know about alant. There is a lot of information about it online. I find this herb in the Aegean region. It is coming from the mountains. But it has to be picked without any flowers. You dry the herb, soak it in boiled water for 5 minutes and drink it like a cup of tea.' (L, 48 years old)

It was determined that the participants used CT methods in order not to take medication other than chemotherapy and to reduce the side effects of chemotherapy.

Table 1. Sociodemographic characteristics, disease history and treatment information of the patients (n=11).

Variables	n	%
Age (median) 49, (mean \pm SD) 50.09 \pm 4.63		
Marital Status		
Single	1	9.1
Married/Partner	9	81.8
Separated/Divorced/Widowed	1	9.1
Education level		
Illiterate	1	9.1
Primary school	3	27.3
Secondary school	1	9.1
High school	5	18.2
Associate degree	3	27.3
Bachelor	1	9.1
Perceived income status		
Income is less than expenditure	6	54.5
Income is equal to expenditure	3	27.3
Income more than expenditure	2	18.2
Cancer history in the past		
Yes	1	9.1
No	10	90.9
Grade of cancer		
Grade II	3	27.3
Grade III	6	54.5
Grade IV	2	18.2
Type of treatment received for breast cancer		
Chemotherapy	4	36.4
Chemotherapy and Radiotherapy	2	18.2
Surgery and Chemotherapy	4	36.4
Surgery, Chemotherapy, and Radiotherapy	1	9.1

Table 2. Complementary Therapies (CT) used by patients

Code	Age	Used CT method
P	47	NP: Iranian saffron, black seed, ginger, turmeric, apricot kernel
M	49	MBP: Prayer, prayer beads, reading the Quran
H	57	NP: Garlic, a mixture of black seed and honey
K	51	NP: Homemade yogurt, kefir, Bergamot tea, rock salt MBP: Prayer (spiritual practices), reiki
L	48	NP: Propolis, elecampane MBP: Reiki, meditation,
T	42	NP: Propolis, royal jelly, a mixture of ginger and honey, turmeric
Ç	59	NP: Apitherapy MBP: Yoga, exercise,
N	49	NP: Propolis, pollen, apricot kernel, homemade vinegar, natural olive oil, ginger, turmeric, curry, sage, rock salt MBP: Exercise
EY	50	NP: A mixture of apricot kernel and honey, propolis, yogurt, turmeric, ginger, St. John's Wort oil, honey, raw garlic, lemon and lemon peel MBP: Music therapy, deep breathing
G	48	NP: Asphodel, lavandula stoechas, a mixture of molasses and honey, garlic,
ED	51	NP: St. John's Wort oil, olive oil, a mixture of bilberry and thyme, cherry stalk tea, St. John's Wort tea MBP: Massage

CT: Complementary Therapies; NP: Natural products; MBP: Mind and Body Practices

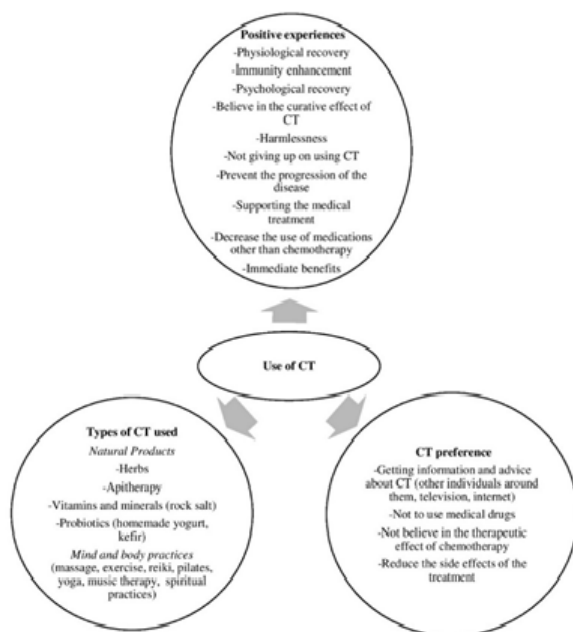


Figure 1. Beliefs and experiences of breast cancer patients about the use of CT: themes and subthemes.

'When I got the flu, I used to drink sage rather than taking any medicine right away. Sage is good for sore throat as well. It helps with fever. I prefer to use herbal things so that the disease does not progress and I do not resort to medication immediately.' (N, 49 years old)

'I preferred apitherapy to reduce the side effects of chemotherapy. When I used apitherapy, the side effects of the drug disappeared faster.' (Ç, 59 years old)

Few of the participants did not believe in the therapeutic efficacy of chemotherapy and pinned their hopes on other methods.

'Even physicians do not know whether chemotherapy will help. They have written in my medical report that there is no guarantee that you will recover after chemotherapy treatment. I do not believe that chemotherapy will help me. That's why I think complementary medicine can be used. I saw it on the internet. A woman with breast cancer was trying to heal herself naturally. I think what the woman was doing was very logical.' (N, 49 years old)

'The physicians did not give me much hope. They said the disease was progressing. That's why I chose it ... The disease is progressing. I tried all the chemotherapy and radiotherapy options.' (P, 47 years old)

Theme 3. Positive Experiences: Under this theme, 10 sub-themes specified in Figure 1 were determined. All of the participants stated that they saw a physiological improvement as a result of CT use, and the vast majority stated that natural products strengthened immunity.

'Turmeric was strengthening me. I was getting stronger than I was. It made me feel better. It made my body and face beautiful as well.' (T, 42 years old)

'I was taking propolis to strengthen my immune system. Propolis has wound healing properties as well. My tooth was aching. I put it directly on my tooth and slept at night. I rinsed my mouth with propolis and I slept like that.' (N, 49 years old)

The vast majority of participants stated that when they used CT, they spiritually felt better and healed.

'I used Iranian saffron. It increased my commitment to life. I become happier and more peaceful. I think I will recover and overcome the disease. If my pain gets worse again, I will consider using it. When my pain was relieved, I became more peaceful and happy.' (P, 47 years old)

Approximately half of the participants stated that they believed in the curative effect of CT.

'I know that sage is definitely curative and prevents diseases.' (EY, 50 years old)

'Apitherapy improves my immune system, I believe that I will

recover because it makes me feel good. I use it because I think it contributes to my recovery.' (Ç, 59 years old)

Approximately half of the participants stated that they did not suffer any damage from CT use and one third stated that they would not give up on CT use.

'I have never experienced any harm of garlic. I always got the benefits. The only thing is that I have gastritis, so every 3-4 days I swallow it or sometimes chew it.' (G, 48 years old)

'I never think of giving up on turmeric. I even think of using it not only as a mixture, but drinking like tea.' (EY, 50 years old)

Regarding positive experiences, few of the participants mentioned that their disease progression stopped, CT supported the medical treatment, decreased the use of medications other than chemotherapy, and they saw immediate benefits.

'When I used Iranian saffron, I had no negative experience. My pain was relieved. I received a good PET result and I think this was because of Iranian saffron. It helped me feel better. My movements improved. I did not have a negative experience. If I had, I would stop using it immediately.' (P, 47 years old)

DISCUSSION

This is the first qualitative research aimed to understand and report the beliefs and experiences of breast cancer patients on the use of CT in Turkey. It was determined that the CT method most commonly preferred by breast cancer patients was natural products. Among Turkish cancer patients, natural products are the most commonly used CT method and the rate of use varies between 30-98%^{8,9,15,22}. The reason why Turkish patients mostly prefer natural products (herbs, vitamins and minerals) is the ease of use of non-prescription drugs¹⁵. In a study conducted in South Korea, it was found that natural products were the second most preferred method after exercise and yoga¹⁰. In a study conducted with breast cancer patients in Malaysia, it was stated that the frequency of CT use was 70% and that natural methods were preferred after mind-body therapies⁷. In a study conducted in Europe, the rate of use of natural products was 38.3%, and it was determined that natural products were preferred after mind-body therapies²³. In the present study, it was observed that the participants mostly preferred herbs among natural products. Consistent with our results, two studies conducted on Turkish breast cancer patients indicated that ginger, turmeric, black seed, green tea and sage were the most preferred herbal products^{8,9}. In a study conducted in Malaysia, it was found that

herbal products such as cactus juice, mushroom (lingzhi) and ginseng were mostly preferred⁷. In another study conducted in Germany, it was found that herbal products were preferred after substances such as A, C and E¹⁶.

In the present study, it was determined that the participants used massage, exercise, reiki, prayer, music therapy and yoga, respectively, among mind and body practices. It is stated that mind and body practices take the second place among the most common CT methods used by Turkish patients¹⁵. In the study of Yeşil et al. prayer was one of the most frequently used CT methods⁸. In the study of Yıldız et al. it was determined that spiritual/religious practices took the second place among all CT methods with a rate of 23.3%²². It has been determined that the rate of using mind and body practices among cancer patients is very low in Australia. In the same study, it was stated that Australian cancer patients used methods such as hypnosis, meditation, biofeedback, reiki, energy healing, therapeutic touch, aura therapy, music therapy as mind and body practices²⁴. In a study conducted with cancer patients in Australia, it was determined that mind and body practices were the second most commonly preferred method after natural methods. In the same study, it was emphasized that the most frequently used methods were prayer, massage, deep breathing and meditation²⁵. In two studies conducted in Malaysia, it was determined that the most commonly used mind and body practices were prayer, meditation and massage, respectively^{7,14}. In a study conducted with cancer patients in Germany, it was stated that the most commonly used mind and body practice was prayer¹⁶. When the results of these studies are evaluated, it is seen that the rate and types of CT use vary according to geographical and cultural differences.

In the present study, the reasons for participants to prefer CT were stated as getting information and advice about CT, not using medication, not believing in the therapeutic efficacy of chemotherapy, and reducing the side effects of chemotherapy. It was found that the participants received information and advice about CT methods mostly from the individuals around them, television, Internet, and certified doctors on mind and body practices, respectively, and these results were consistent with the study of Arıkan et al¹⁵. A study in South Korea found that 76.9% of the participants obtained CT

information from individuals around them and 14.1% from the media²⁶. In a study conducted in Germany, it was determined that 41% of patients responded family members and friends and 41.7% responded printed media when asked about their source of CT information²⁷. In a study conducted in Australia, it was found that 60% of cancer patients obtained information from family and friends²⁵. Berretta et al. reported that the most common sources of information were media and friends²⁸.

In the present study, it was determined that CT was preferred not to use other medications or for reducing drug use, and because of the severe side effects of chemotherapy and radiotherapy. Similarly, Arıkan et al. found that 69.6% of the participants preferred CT for easier healing of the disease, 13% for the reduction of the side effects of chemotherapy, and 13% for the physical mental contribution¹⁵. In a study conducted with cancer patients in Australia, strengthening the immune system, maintaining health and well-being, and providing treatment/control of cancer were cited as reasons for CT use²⁵. In another study, the reasons for CT use were reported as supporting the immune system, reducing the side effects of medical treatments, and reducing the risk of cancer recurrence¹⁶. A study conducted in Italy found that the vast majority of cancer patients used CT to reduce the side effects of chemotherapy²⁸. In the present study, it was found that reducing the side effects of chemotherapy was one of the reasons for CT use, and this result was consistent with the literature^{16,28-31}. Similarly, Smith et al. found that patients used CT for the treatment of cancer, reducing the side effects of chemotherapy, and symptom management³². In a study in Taiwan, it was found that many patients preferred CT to improve their quality of life³³.

The most frequently emphasized positive experiences of the participants regarding CT use in this study were physiological recovery and strengthening immunity. Similarly, other studies reported that cancer patients using CT experienced physiological recovery^{15,28,34}. A study in South Korea reported that improvement in overall condition, psychological relief, and reduced side effects of cancer treatment were positive experiences of patients with lymphoma using CT²⁶. In a study conducted in Ireland, 67% of oncology patients reported positive effects of CT³⁵. In another study conducted with cancer patients, yoga was found to improve sleep quality³⁶. Consistent with this study, a study conducted with cancer

patients in Saudi Arabia reported that the use of CT was effective in improving mood, appetite, physical strength and immunity, and pain relief³⁷. In a study conducted in Malaysia, it was determined that 4.1% of patients having CT experienced the side effects of CT³⁸. In the present study, psychological recovery and harmlessness were determined among other positive experiences and these results were consistent with the literature^{25,34,38}. In the study of Hunter et al. it was found that more than half of the patients thought that using CT was effective and 91% of the patients believed that CT had no harmful effects²⁵.

This study had a limitation. Patients who accepted to participate in this study constituted the sampling group. These patients were thought to have a positive attitude. Patients who were not willing to participate in the study may have different beliefs and opinions about complementary medicine.

CT use is very common in Turkey. In terms of CT methods, breast cancer patients prefer mostly natural products, followed by mind and body practices. These methods are mostly preferred to prevent disease progression, not to use medical drugs, to reduce the side effects of treatment, or because patients do not believe in the therapeutic efficacy of chemotherapy. Most patients were satisfied with the CT modality that they used. Patients using CT stated physiological recovery and strengthened immunity as positive experiences. Patients want information from healthcare professionals about how CT use may affect the treatment process. However, patients received little guidance and training from healthcare professionals about the use of CT, and preferred to use social communication channels and resources for information.

Since patients prefer natural products first among CT types, it is necessary to question the patient's CT use especially at the first consultation after diagnosis, and CT use should be reported during treatment and follow-up. For this reason, oncology physicians and nurses who interact the most with the patient to provide guidance for continuation or termination of CT use in the light of evidence-based literature is very important in terms of patient safety and health outcomes. In addition, there is a need for studies with large survey evaluating patients' beliefs and practices about CT. Then, knowledge about this subject can improve significantly.

Yazar Katkıları: Çalışma konsepti/Tasarımı: AT; Veri toplama: AT, Mİ; Veri analizi ve yorumlama: AT, Mİ; Yazı taslağı: AT; İçeriğin eleştirel incelenmesi: AT, Mİ; Son onay ve sorumluluk: AT, Mİ; Teknik ve malzeme desteği: AT, Mİ; Süpervizyon: AT, Mİ; Fon sağlama (mevcut ise): yok.

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