

## ARAŞTIRMA/RESEARCH

### A QUALITATIVE STUDY ON THE PROBLEMS AND NEEDS OF PATIENTS WITH BREAST CANCER DIAGNOSED WITH CHEMOTHERAPY

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#### ABSTRACT

**Aim:** This study was conducted to determine the problems and needs of breast cancer patients receiving chemotherapy.

**Methods:** A qualitative study involving 24 women with breast cancer under chemotherapy. The data were collected through an in-depth individual interview using the Patient Information Form and the Semi-structured Interview Form. The raw data was then analyzed and interpreted using "content analysis technique". Necessary permissions were obtained from related institutions of Dokuz Eylül University and from all patients.

**Results:** The obtained data were divided into two main categories; Patients' Problems and Patients' Needs. Patients' Problems includes physical, psychological and sexual problems and also the problems about interpersonal relationships. Patients' Needs consists of needs related to health care professionals, family, as well as those about various institutions and organizations.

**Conclusion:** As a result, it is thought that the presence of a counseling unit along with treatment centers will be fruitful in terms of informing as well as meeting the needs of the patients. In addition to advising on these units, it is recommended that counseling services be provided at home before and during the chemotherapy period.

**Keywords:** Breast cancer; chemotherapy; qualitative research; side effects

#### ÖZ

##### **Kemoterapi Alan Meme Kanseri Tanılı Hastaların Sorunları ve İhtiyacı Üzerine Niteliksel Bir Çalışma**

**Amaç:** Niteliksel olan bu çalışma kemoterapi alan meme kanserli hastaların yaşadıkları sorunlar ve gereksinimlerini belirlemek amacı ile yapılmıştır.

**Yöntem:** Bu çalışma, bir üniversite hastanesinin Tıbbi Onkoloji Bilim Dalında kayıtlı olan meme kanserli kadınlar üzerinde planlanmıştır. Veriler, Hasta Bilgi Formu, Yarı Yapılandırılmış Görüşme Formu kullanılarak derinlemesine bireysel görüşme yöntemi ile toplanmıştır. Toplamda 24 kadın çalışmaya dahil edilmiştir. Dokuz Eylül Üniversitesi Girişimsel Olmayan Araştırmalar Etik Kurulu'ndan izin alınmıştır.

**Bulgular:** Elde edilen veriler içerik analizi sonucunda iki ana temaya ayrılmıştır; hastaların yaşadıkları sorunlar ve hasta gereksinimleri. Çalışmada hastaların yaşadıkları sorunlar teması; fiziksel sorunlar, psikolojik sorunlar, kişilerarası ilişkilerde sorunlar, cinsel sorunlar şeklinde ve Hasta gereksinimleri başlığı altında, sağlık personeline yönelik gereksinimler, aileye yönelik gereksinimler, diğer kurum ve kuruluşlara yönelik olarak kategorize edilmiştir.

**Sonuç:** Tedavi merkezlerinde bir danışma biriminin bulunması, hasta ihtiyaçlarının karşılanmasına ek olarak bilgilendirme açısından da verimli olacağı düşünülmektedir. Bu birimler tarafından sağlanacak önerilere ek olarak, kemoterapi öncesi ve süreç boyunca evde danışmanlık hizmetlerinin verilmesi önerilmektedir.

**Anahtar Kelimeler:** Meme kanseri; kemoterapi; niteliksel araştırma; yan etkiler

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## INTRODUCTION

Surgery, chemotherapy, radiotherapy and hormone therapy are primary breast cancer treatments. One or more of these treatments can be deployed based on the patient's physical condition or disease state. The goal of chemotherapy is to diminish cancer cells, while at the same time inhibiting cell proliferation and paving the way to control the disease progression. This method helps to relieve patient's symptoms and reduces the chance of relapse, thereby lowering the risk of mortality caused by the disease (1).

Unfortunately, this popular method also affects other healthy cells along with cancer cells and thus causes some unwanted side effects. Patients in this process, in addition to physical problems, also suffer from sexual and psychological issues (2). These symptoms which stem from chemotherapy, negatively impact both the patient's treatment process and her life. Due to this, early determination and prevention of these side effects is of the utmost importance. Patients who are to receive chemotherapy often have inadequate or no knowledge about the treatment. Providing relevant information was found to play a significant role in the positive advancement of the treatment process (3,4). It has been determined that patients not only require information from health care professionals, but they also have additional expectations such as receiving emotional support, and to be listened to (5-7).

In addition to receiving information in a clinical setting, several studies have shown that patients also need home visits (8). While some patients do receive the required information and counseling at clinics prior to starting their chemotherapy treatments they are indeed left without professional support to cope with these problems. Because of that, the side effects that patients experience after chemotherapy, management of such side effects, and the determination of patient needs should be prioritized. Nursing interventions planned in line with these expectations will help facilitate symptom control, leading to a direct improvement in quality of life. The aim of this study is to collect problems and needs of breast cancer patients receiving chemotherapy in coherent and categorized form.

## MATERIALS AND METHODS

**Design:** The study was performed qualitatively using in-depth individual interview method.

**Setting:** This study was conducted at a university hospital between July and November 2016. Interviews were done in the outpatient treatment chemotherapy center of the hospital.

**Population:** The study group of the study consists of women with breast cancer registered in the medical oncology department of a university hospital.

Criterion sampling method was used for sample selection. Inclusion criteria were: being 18 years old or older, the ability to read and write Turkish, having no communication problems, being newly diagnosed for breast cancer, having no metastasis, receiving chemotherapy at least once a week at commencement of the study. The study involving 24 women with breast cancer under chemotherapy. Patients who agreed to participate in the study were interviewed. While the sample size was not calculated these interviews were terminated once the data obtained reached the point of saturation.

**Data Collection Tools:** In the study, the forms described below were used;

**The Patient Information Form:** This form was created from 14 questions using different sources (3, 5, 9). The questions include age, education, marital status, occupation, income status, social security status, number of children, family type, stage of illness, time of disease diagnosis, name and duration of treatment protocol, specific drugs used, and the number of cycles of chemotherapy.

**Semi-Structured Interview Form:** A semi-structured interview form was used to identify the problems and needs associated with breast cancer patients receiving chemotherapy. The form consisted of two primary questions and additional sub-questions. The interview form was evaluated by five experts; two clinical nurses, two academic nurses and a physician before its final form was given.

**Data Collection Method:** The data was collected using the in-depth individual interview method. Interviews were held face-to-face in a quiet environment and recorded on a voice recorder. Interviews were started with two initial questions prepared by the researchers based on the 'semi-structured interview form'. Following this, sub-questions to deepen the interview were asked. The questions were asked according to incoming responses; not in a standard order. The researcher

repeatedly summarized patient responses during interviews to ensure internal validity and prevent misunderstandings. Checks as to whether the patients were understood correctly were made as standard. Interviews were continued until patients presented a new concept, or made a statement about the research topic. A total of 24 in-depth individual interviews were conducted.

**Statistical Analysis:** In order to increase the internal validity of the recorded data, the written text was transcribed by a third person fluent in both Turkish and Persian. Later on, the data was rechecked from the recorded voice, confirming that the text records were correct and complete. This ensured the reliability of the data. The raw data obtained from the voice recordings was then analyzed and interpreted using "content analysis technique". Interviews and the content analysis were carried out by two different researchers in order to address "unanimity" and "bias." Only after careful scrutiny, a consensus was reached.

**Ethical Considerations:** Before starting the study, necessary permissions were obtained from the Department of Medical Oncology of a DEU Hospital and DEU Non-interventional Research Ethics Committee. Additionally, a written consent was obtained from participating patients after explaining the purpose of the study and prior to in-depth individual interviews. Also, it was done according to the ethical standards of

human experimentation established in the Declaration of Helsinki in 1995.

**Limitations of Research:** Due to the nature of qualitative research, the obtained results cannot be generalized to all breast cancer patients receiving chemotherapy. The findings are limited to the cultures and socioeconomic status of patients treated at a university hospital.

## RESULTS AND DISCUSSION

The socio-demographic and medical characteristics of patients with breast cancer who received chemotherapy are summarized here. The average age of women participated in the study was  $45.71 \pm 8.84$  years. 37.5% of the women were university graduates, 75.0% were married and 95.8% had children. 41.7% of patients received paclitaxel, 33.3% of patients received paclitaxel/trastuzumab and 25.0% of patients received EC (Epirubicin, Cyclophosphamide) protocol. The data obtained from in-depth individual interviews, related to the problems and needs of patients with breast cancer who received chemotherapy was subjected to content analysis. Patients' Problems includes physical, psychological and sexual problems and also the problems pertaining to interpersonal relationships. Patients' Needs consists needs related to health care professionals, family, as well as those pertaining to various institutions and organizations (Table 1).

**Table 1.** Problems and Needs of Patients with Breast Cancer Who Received Chemotherapy

Main Themes	Categories
<b>1. Problems</b>	Physical Problems
	Psychological Problems
	Sexual Problems
	Problems pertaining to Interpersonal Relationships
<b>2. Patient Needs</b>	Needs Pertaining to Health Care Professionals
	Needs Pertaining to Patient's Family
	Patient's Problems Pertaining to Other Institutions and Organizations

The physical problems experienced by patients with breast cancer receiving chemotherapy are mainly as follows:

*Exhaustion, fatigue;* Patients report that after almost every cycle, they experience weakness for at least 5-10 days limiting their ability to do basic tasks. "It was a strange situation, I was exhausted and tired, and I didn't have the power to go from the living room to the kitchen. You always need someone, you cannot do things you have to do" (2<sup>nd</sup> participant, 39 years old).

*Hair loss;* According to the patients' statements this symptom was mostly seen after the second

cycle or at the end of the first cycle. Patients stated that they were most affected by this symptom.

*Nausea;* in some patients nausea started on the first day, but most patients stated that it started on the second day and continued for 3-7 days. "I felt nausea from the first day, I still feel it, when I smell perfumery or a sharp smell I feel nauseated right away. It was very strong the first day" (15<sup>nd</sup> participant, 50 years old).

*Change in taste;* most of the patients who had this symptom also had an odor sensitivity. Some patients have reported that this problem leads to nausea and loss of appetite.

*Anorexia*; Most of the patients are experiencing this problem for different reasons such as odor sensitiveness, disgust, fear of nausea. Additionally, some patients had a loss of appetite until 1<sup>st</sup> - 8<sup>th</sup> day. *"There was excessive loss of appetite. You don't want to eat anything. A tiny bit of food becomes like a big meal, and that's because the stomach does not want it"* (6<sup>nd</sup> participant, 40 years old).

*Constipation*; this side effect was experienced in different chemotherapy cycles in patients. Some patients have increased their fluid consumption by altering nutrition for constipation.

Other physical symptoms seen in patients can be listed as: diarrhea, burning sensation in the nose and eyes, numbness in hands and feet, menstrual irregularity, changes in skin and nails, hot flush, sweating, mouth dryness, mouth sores, disgust from food, body pain, excessive appetite, gaining weight, decrease in blood values and increase in blood pressure.

The physical problems experienced by patients with breast cancer who received chemotherapy are as follows; fatigue, hair loss, nausea, change in taste, odor sensitivity, loss of appetite, constipation, menstrual irregularities or cuts, skin dryness, changes in nails, hot flush, sweating, mouth dryness and sore (3, 9, 10). In this study patients were expected to experience certain physical symptoms due to chemotherapy. However, the severity and duration of these symptoms varies. This is considered to be related to the protocol of the received treatment. It was also found that patients are applying some unconventional methods. While some of these methods do have a positive impact on patient health there are some others that have negative effects. This situation is thought to be the result of a lack of information as well as inadequate and incorrect information sources. Among the physical problems fatigue is considered important because it affects all participants after chemotherapy (11, 12). In the current study, all patients experienced fatigue and tiredness.

Psychosocial problems are another category of problems in these patients that have always been emphasized by patients. Some of these problems include: Fear, worry, anxiety, sadness, hopelessness, being sensitive, feel of regret, anger, and self-isolation.

As they came from the patient's statements, several fears could be identified such as, fear of abandonment by family and society, fear of getting an infection during sexual act, fear of death, fear of not recovering, and cancer

relapse. *There are such spouses that after they find out that their partner has this illness they leave their spouse instead of fighting with the disease. No matter how much you trust your partner, you will fear this"* (3<sup>rd</sup> participant, 43 years old).

Patients who received chemotherapy treatment also stated that they experienced problems such as emotion complexity, sadness, restlessness and having hard time accepting this process. In addition, patients are also indirectly experiencing psychological problems caused by physical side effects of chemotherapy. For example, disruption of body image due to hair loss can lead to psychological effects. *"The worst side effect was that my hair came out in my hand [her voice was trembling, her eyes filled with tears and she cried] it was a very uncomfortable moment. My father had a friend who was a barber, I went to him and told him that I am your costumer today. I felt so bad when I saw my bald head, nothing else has hurt me more."* (5<sup>nd</sup> participant, 52 years old).

In this process, although some patients cannot cope with psychological problems, some other patients have overcome these problems by use of various methods. It is noticeable that emotional supports of family help patients to overcome psychological problems besides physical issues. Moreover, some patients also stated being diagnosed early resulting in having a higher chance of recovery, as well as getting fewer side effects than predicted, was a morale booster for them. *"You should be always strong and love your life. Now on November 17th my treatment will be finished and 18th of November is my birthday. This will be a fresh start for me as if I am born a second time, with God's help"* (6<sup>nd</sup> participant, 40 years old).

Some other patients do not want to get detailed information about their diseases. They believe that information of the treatment process and the side effects will only cause anxiety and depression. *"I didn't know how intense chemotherapy was, I didn't want to know, because knowing these things before chemotherapy psychologically affects every person. I didn't want to be affected. That's why I did not get information about it"* (17<sup>nd</sup> participant, 55 years old).

Gregurek, Bras, Dordevic, Ratkovic, Brajkovic stated that psychological problems of patients, based on their order of frequency, can be listed as following: lack of sexual desire, departure from social activities, being anxious about future, anger, and having problems in

interpersonal relationships. Additionally patients were exposed to psychological disturbances due to adverse effects of their treatment (13). Patients are exposed to psychological problems due to the community's view on cancer. Among the side effects hair loss was determined to be the factor that psychologically affected patients the most (14-16). According to patients' expressions and results of Helms hair loss is considered to be the symbol of death and loss of health (17). Moreover, Rosman discussed that this complication at the same time adversely affects sexuality and body image of patients (18).

Being always as a side effect of chemotherapy, hair loss compared with other complications is an important indication of cancer. It makes these patients identifiable in the society. So, this condition itself can cause psychological problems for patients.

Patients reported that they didn't have sexual activity for various reasons such as not feeling good, sexual reluctance, vaginal dryness, fear of getting infected, and impaired body image. Additionally, some couples didn't think that it was necessary to enter into sexual relationship during the treatment process. Patients also seemed embarrassed by this important issue and avoided getting information or finding a reliable source. *"The only thing that I wanted to ask was about the sexual relationship, I was afraid to ask about it, I don't know if it was appropriate? Numerous times I wanted to ask a doctor about it but I could not ask. I was embarrassed."* (4<sup>th</sup> participant, 37 years old).

Cancer patients are expected to experience sexual problems due to the physical and psychological symptoms (19, 20). In spite of having questions regarding sex, patients are not informed about safe sexual activities during the chemotherapy treatment process, and may not be inclined to consult about it either. Because they perceive talking about sexuality as a taboo. So, they fear of being judged by others. Considering the importance of sexual activity in preserving family framework, it appears that the existence of sexual problems among breast cancer patients undergoing chemotherapy over time can have a negative effect on family relationships. For this reason, health care professionals must provide the patient and her partner with necessary training and counseling to prevent future problems.

Problems pertaining to interpersonal relationships were studied at three categories; family members, friends and others. Most patients often suffer from lack of understanding and lack

of support by family members. Some of them also have limited their social relationships, because of wrong behaviors of friends and acquaintances. *"My friend opened my scarf suddenly, she wanted to see how it was like, I was shocked and upset, and I cried the whole way to my home. This incidence was very upsetting for me."* (5<sup>th</sup> participant, 52 years old). *"The way people look at me disturbs me. I only leave my home when I come to the hospital or when I have to."* (23<sup>rd</sup> participant, 43 years old).

Under the Patient Needs section, the needs pertaining to healthcare professionals include different topics. Most patients with breast cancer who have received chemotherapy in the study expected interest and psychological support from health professionals. Patients were asking health care professionals to take care of them during this difficult period, to be closely involved with them, and to follow up on their health condition even by telephone. Also, according to the patients, healthcare professionals need to have positive communication skills. *"The nurse's sympathy is important, because a patient needs psychological support. Because their psychology is already problematic, one misdirected behavior or inappropriate conversation can affect the patient."* (16<sup>th</sup> participant, 52 years old).

Our study revealed that ways patients cope with side effects of chemotherapy are based on incorrect and outdated knowledge. It has been determined that many patients are applying some outdated methods. Some of the patients incorrectly assume that they will have the same problems as those who had received chemotherapy in the past; especially if their family or friends have experienced it.

The patients with breast cancer who were participating in the study lacked knowledge about the chemotherapy process, its side effects and effective ways to cope with such side effects. In most of the patients that did have information about these issues, it was determined that the information was superficial or obtained from an unreliable source. For example, as a source of information they use the Internet, TV health programs, or advice from other patients who have received chemotherapy. *"In the morning I used to eat ginger on empty stomach, to boost my resistance and to support medicines."* (9<sup>th</sup> participant, 32 years old).

Some of the patients emphasized that both patients and their relatives should be informed prior to the start of chemotherapy. *"I think families or those who are taking care of the patient should*

*be aware. They should be informed about how to treat the patient and what to do. They should be taught to always show their best behavior. You are sick at the moment, naturally you cannot do much, they don't allow your relative to come inside with you, in my opinion this is a major drawback of the system." (17<sup>nd</sup> participant, 55 years old).*

Some of the patients stated that the provided information was extremely technical, not specific to their need and often feasible due to socioeconomic situations. *"I got scared from that booklet. I could not apply any of them. You will eat and drink in extremely sterile environments. There was extremely technical information. It was not something everyone could do. It is something that can neither be done in the home environment nor could patients afford it." (1<sup>st</sup> participant, 43 years old).*

During the interviews, participants were found to have specific needs pertaining to their relationships with other family members. Patients expected more understanding, psychological support and more attention in the home environment from their family members.

Patients expressed having expectations from other institutions and organizations during the treatment process. Some of the participants stated that specific units in the hospitals, such as menopause polyclinics could be useful in terms of providing information.

*"As to the training given to a person in the post-menopausal period, counseling should be provided for patients like us. Because not having this information can endanger patient's life." (17<sup>nd</sup> participant, 55 years old).*

Referring to the chemotherapy process as a whole; in addition to physical, sexual, psychological problems, patients also face interpersonal problems. The interpersonal problems that patients often have include: lack of support within the family, feeling of shame among other family members due to patient's appearance, the way people talk about patient's circumstance and their curious looks. Atesci, Oguzhanoglu, Baltalarlı, Karadag, Ozdel and Karagoz reported that regularly patients did not receive adequate emotional support and assistance from their families and sometimes even feel abandoned. The problem is often compounded due to patients being more emotional than they were prior to their illness and likely due to the physical side effects (21).

Akçay and Gozum pinpointed the lack of patients' information about the chemotherapy

process, its complications, and how to deal with those complications (9). This important issue was quite evident in our study too. In this regard, Chan and Ismail concluded that in order to have a positive progression of the treatment providing necessary counseling before starting the treatment would be important. However, some patients in our study also stated that they did not want to receive any information about chemotherapy, its side effects and methods (3). Patients think that being informed about their symptoms will lead to experiencing more severe psychological symptoms. Some other patients tend to seek information from health care providers to verify their information. Other patients, however, use unreliable resources to get their information (5). As a result, patients who receive chemotherapy treatment are affected negatively by their lack of knowledge and misinformation and this affects their behavior and expectations towards symptoms.

The socioeconomic condition of patients, lack of family support, the provision of educational material in booklet form only, and a lack of counseling specifically tailored for the individual, cause some information to be ignored by patients. Thus, the information given will not often be applied correctly; if at all. On the other hand, patients may experience stress when they read and interpret the booklet at home alone. For this reason, in order to benefit from the contents of the booklet as much as possible, the counselor can provide an individual-specific instruction by modifying that information according to the patient's circumstances.

In this research, participants expressed their certain expectations from health personnel, families, and foundations and organizations to have a successful chemotherapy process. Patient's needs pertaining to health care professionals take the form of, showing affection towards them, providing psychological support, providing individual oriented counseling, easy access to personnel, providing support in the application of specific techniques that require a trained professional (6, 7, 22). Also, the case that has been emphasized by patients is the inclusion of family members in the training provided by professional staff. According to Baskale, Serçekus and Gunusen the expectations of the patients from health care personnel are mainly the following: providing information about the disease and the treatment process, understanding them, emotional support, spending more time for them and listening them (5).

In this regard, it is considered that health care staff must have strong interpersonal skills in order to provide information to patients and then to provide adequate psychological support. Since hospital conditions, time constraints, and the mental state of the patient often do not provide this opportunity for smooth conveyance of information, it may be more appropriate for healthcare professionals to meet patient's needs by talking to them face-to-face at home.

Apart from healthcare personnel, patients also have expectations from family members. Unfortunately patients experience problems when these expectations are not met. For this reason it may be helpful to consider providing additional counseling programs for family members during the counseling process.

Furthermore, we believe that it would be useful to have an institution or polyclinic specifically for patients receiving chemotherapy. The need for such an organization and foundation stems from the inability of patients to reach to resources and the lack of social and family support.

## CONCLUSIONS AND RECOMMENDATIONS

Considering the various problems and needs as a result of the interview with the patients at ambulatory medical center, most of the patients requested that there is a consultancy and information unit, as well as a specialist consultant or health personnel in this field.

Information that patients expected to receive from health care professionals were general information about the disease, treatment options, chemotherapy process, its side effects, and finally, ways to cope with these complications. They believed that randomized and dispersed information of health staff during chemotherapy was often unhelpful and at the same time, learning this information during stressful process of chemotherapy was nearly

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impossible for patients. In most cases, patients who are at home or away from the relevant health center are facing chemotherapy-related problems while they cannot easily access the health staff.

The population of this disease consists of women. Because of some cultural and particular social conditions women cannot express any problems to everybody. Therefore, in order to overcome these difficulties and facilitate the process of chemotherapy and reduce psychological forces, it is recommended that a counseling and information unit could be established alongside the treatment center to raise the level of awareness of patients. In addition to patient counseling, informing patient's relatives can also be of great benefit. Because these are in close contact with the patient, they have to follow a series of cases. In addition, it is recommended that counseling should be started before the chemotherapy process begins and regularly continue until the end of the course, and even if necessary, the patient will be able to access the counselor by telephone. These units can also provide home-based counseling services for these patients. In this context, access to a counselor or specialist for a patient will also have psychological benefits in addition to physical benefits. The Advantage of Home-based Counseling in compare with counseling in a health unit is providing conditions for health professional to get information about patient's socioeconomic status and the level of support that they receive from other family members. Consequently, informing the health staff about these items will lead them to a concise treatment and counseling.

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