

# Symptoms Experienced and Information Needs of Women Receiving Chemotherapy

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## ABSTRACT

**Objective:** This study is carried out to determine the symptoms and information necessity on chemotherapy (CT) treatment of the women with breast cancer. **Methods:** A total of 170 women older than 18 years old, who receive CT with breast cancer diagnosis, are volunteered to participate in the study. Mixed method was used in the study. Data are collected using Descriptive Data Form, Interview Form and Memorial Symptom Assessment Scale. **Results:** As a result of the cluster analysis, four clusters and the symptoms within have been obtained. These are: pain, lack of energy, feeling drowsy, sweat, swelling of hands, and feet in the first cluster; feeling nervous, difficulty sleeping, feeling sad, worrying in the second cluster; nausea, feeling bloating, change in the way food tastes, hair loss, constipation

in the third cluster; vomiting, diarrhea, problems with sexual interest, lack of appetite, dizziness, and weight loss in the fourth cluster. Women's information necessity related to the CT are follows: the effects of CT, other treatment options beyond CT, complementary methods, the effect of the CT treatment on reproductive health and sexuality, nutrition, and symptom control. **Conclusions:** The results of this study will enable determination of symptom clusters, which health professionals are easier to focus on these symptoms. An understanding information need of patients can help to ensure that individual's coping strategies and self-management.

**Key words:** Chemotherapy, information need, symptom cluster

## Introduction

Breast cancer causes a large number of mortalities and morbidities among all cancers and is the first leading cancer type among women in Turkey.<sup>[1]</sup> Besides being an organ related to motherhood, breast is perceived as a symbol of the esthetic appearance of women and sexuality.

Therefore, being diagnosed with breast cancer negatively affects a woman's life both psychosocially, emotionally, and physically.<sup>[2,3]</sup>

Surgery, chemotherapy (CT), and radiotherapy (RT) consist of the main treatment options for breast cancer.

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CT is among the most commonly used one and it may be applied alone or in combination.<sup>[4]</sup> High dose and combination treatment given with therapeutic purposes lead to the patient experience an ample amount of symptoms by causing many side effects beside curative effects. Quality of life of the patient is impaired, the recovery process is negatively affected due to multiple symptoms.<sup>[5]</sup> Therefore, it is emphasized that nursing care given to women with breast cancer who are receiving CT should be planned considering symptoms and clusters of symptoms.<sup>[6,7]</sup> Along with the assessment of side effects as a part of nursing care, improving self-management through pretreatment information and supporting patients through training about symptom management are of great importance.<sup>[8,9]</sup> Determining the information needs and informative support improves patient's compliance with nursing care planning, and it contributes to reducing physical, psychological stress of the patients.<sup>[8]</sup>

Breast cancer patients receiving CT may experience many symptoms in different ratios and symptoms are inter-related. It is recommended to generalize symptom management models focused on individual needs and improve awareness of the nurses to meet health care needs from the beginning to the end of the disease. This study was conducted to determine the symptoms and information necessity of the women with breast cancer who are receiving CT.

## Methods

### Sample and design

The study sample was consisted of women with breast cancer who were admitted to Medical Oncology Outpatient Clinic of a university hospital. The sample was composed of 170 volunteer women above 18 years, diagnosed with breast cancer, who had received at least two cycle of CT, were able to speak and understand Turkish. The descriptive and qualitative design was used in the study.

### Data collection

Data were collected using a descriptive data form (10 items), Interview Form for Information Needs About Chemotherapy and Memorial Symptom Assessment Scale (MSAS). Descriptive Data Form was composed of 10 questions inquiring sociodemographic characteristics and disease characteristics of the patients. Interview Form for Information Needs About Chemotherapy form was developed by the researchers to determine information needs about CT, what used a qualitative design, utilizing semistructured interviews to explore issues about which patients want to be informed about CT. The form is composed of open-ended questions inquiring the subjects they want to be informed about CT. One question related

to research namely "Do you need information about chemotherapy treatment;" "If yes, could you then explain in which areas do you need information?"

Memorial Symptom Assessment Scale is used with the aim of evaluating the symptoms experienced by the patients in the last week and composed of 32 items. MSAS are evaluated with respect to frequency, severity, and distress. Three dimension were chosen as potentially relevant to symptom evaluation; severity of symptom, frequency with which it occurs and distresses it produces. The scale has subscales as "physical symptoms (PHYS)" (lack of appetite, lack of energy, pain, feeling drowsy, constipation, dry mouth, nausea, vomiting, change in the way food tastes, weight loss, feeling bloated, and dizziness), "psychological symptoms (PSYCH)" (worrying, feeling sad, feeling nervous, feeling drowsy, feeling irritable, difficulty concentrating) and "general distress index (GDI)" (feeling sad, worrying, feeling nervous, feeling irritable, lack of appetite, lack of energy, pain, constipation, dry mouth, and feeling drowsy). Turkish validity and reliability study of MSAS was performed by Yildirim *et al.*<sup>[10]</sup> In general of scale Cronbach alpha ranged from 0.71 to 0.84.<sup>[10]</sup>

### Statistical analysis

Data analysis was performed using Statistical Package for the Social Sciences 21 package program. Numerical variables were shown as a mean  $\pm$  standard deviation, categorical variables were shown as number and percent. Average values were used for distribution of the scores obtained from MSAS. Hierarchical clustering analysis was used for creating symptom clusters. Clustering analysis was not performed for the symptoms seen <20%. The distance between clusters was found with Euclidean dimension. The responses of open-ended questions were grouped, and frequency tables were formed.

### Ethics approval

Ethics committee approval was obtained from Gazi University (approval number 26.02.2015/77082166-604 .01.02-41421). Permission from Gazi University Health Application and Research Center Medical Oncology was obtained for the field application of the study. The women who receive CT were informed about the subject of study, and informed consent was obtained.

## Results

### Participant demographics

Mean age of the women was  $48.08 \pm 11.68$ , 80% were married, 41.8% were graduates of the elementary school. Of the women, 28% were stage I, 14.7% were stage II, 35.7% stage III, and 11.4% stage IV breast cancer, 75.4% had

undergone surgery; of the women who underwent surgery, 40% underwent left mastectomy, 31.2% right mastectomy, and 20% total mastectomy; and 36.5% had a chronic disease other than cancer. Cyclophosphamide and doxorubicin are the most commonly used CT drugs (29.5%). Other CT drugs are paclitaxel and herceptin (20.2%), docetaxel (12.4%), and epirubicin (5.6%). Of the women, 12.2% received the third cycle CT, 10.1% fifth cycle CT. Mean number of CT cycles is seven. Nearly 16.7% of patients are receiving concurrent RT treatment.

### Symptoms experienced and information need by the patients

The symptoms experienced by women during CT are as follows, respectively; pain (97%), fatigue (82.9%), and sweating (71.8%). Sexual activity-related problems are seen to be among the first leading “almost constantly experienced” symptoms (23.5%), sweating and lack of energy were among the first leading “frequent” symptoms (27.9%; 27%). Sexual problems are the first leading “very severe” symptoms (11.8%). Severe symptoms include dizziness (43.1%), and hair loss (31.4%). Sexual problems (8.8%) are the first leading problem which causes distress. The mean scores of the subgroups of the MSAS are shown in Table 1. There was a statistically significant difference between the state of surgery and educational status to the MSAS psychological point averages ( $P < 0.05$ ). Patient of underwent surgery of MSAS psychological point averages are significantly higher. Average of the psychological score in those with high educational status is significantly lower. There was no statistically significant difference between GDI, PHYS, and PSYCH between age, stage, chronic disease, diagnostic time, and marital status.

Four clusters were obtained as the result of cluster analysis. The first cluster includes pain, lack of energy, feeling drowsy, sweat, swelling of arms, or legs. The second cluster includes feeling nervous, difficulty sleeping, feeling sad, and worrying. The third cluster includes nausea, feeling bloating, change in the way food tastes, hair loss, and constipation. The fourth cluster includes vomiting, diarrhea, problems with sexual activity, lack of appetite, dizziness, and weight loss. The outcome of content analysis was classified into six themes. The six themes were: the effect of CT, symptom control, complementary methods, effect of CT on sexuality and reproductive system, nutrition and other treatment. Women expression about want to be informed is shown in Table 2.

## Discussion

### Symptoms experienced by the patients

The most common symptoms were found as pain (97%), lack of energy (82.9%), and sweating (71.8%) in our study.

**Table 1: The mean scores of the subgroups of the memorial symptom assessment scale**

MSAS Subgroups	Minimum-maximum	Mean ±SD
GDI	1.00-2.34	1.75 ± 0.48
PHYS	1.00-2.25	1.66 ± 0.63
PSYCH	1.00-3.66	2.42 ± 0.78
TMSAS	0.67-2.89	2.04 ± 0.87

TMSAS: Total Memorial Symptom Assessment Scale, PSYCH: Psychological Symptom Subscale score, PHYS: Physical Symptom Subscale score, GDI: Global distress index score, SD: Standard deviation

**Table 2: Patient expression of about information needs**

Participants	Patient expression
≠ 3	They only said I should not eat pomegranates or grapefruits. Some patients said peanuts are also harmful. We were not told about what to eat during the ongoing treatment process. Can I drink natural milk instead of pasteurized milk by boiling it? What should I do?
≠ 118	I read on the internet that some herbal treatments shrink tumors. I sometimes think about using. I need information needs about herbal treatments
≠ 129	I experience problems. I do not feel well after chemotherapy. I have joint pain. I have nausea, vomiting, fatigue. I go to sleep as soon as I reach home, but I know I also have responsibilities at home. I need support for getting used to the symptoms
≠ 10	I had sexual desired when I had one breast, but I started to feel like as if I am a man after they removed the second breast. I sometimes think if a person can have no desire or feeling, but really, there is nothing. I do not want it. I would like information on how to fix this situation
≠ 58	Problems started about my menstruation while receiving CT treatment. My periods stop sometimes. Will it be fixed after the treatment? Will I start to have periods again after the treatment? I am worried about what is waiting for me in this process. I want to get pregnant in the following years. I want to have a child. I hope chemotherapy does not affect my other organs
≠ 60	If chemotherapy treatment does not work what are the other effective treatments?
≠ 107	I am curious about the treatment process for my illness, my chances of recovery, Effects of CT and what is waiting for me in this process. Will I be saved from this disease with CT? What will I experience during this process?

CT: Chemotherapy

Similar to our study, fatigue, sleep disorders, and pain were reported as the most common symptoms in the study of Fiorentino *et al.*<sup>[11]</sup> and So *et al.*<sup>[12]</sup>

Women may experience many health problems due to vaginal dryness, decreased libido, and also breast's being an organ which represents sexuality.<sup>[3]</sup> Sexual activity problems (23.5%) were detected to be the “nearly always experienced” (23.5%). Fobair *et al.*<sup>[13]</sup> have reported that 28% of sexually active women experienced severe problems about sexual functions. In the literature, sexual activity problems are reported by two-third of all women receiving CT.<sup>[13,14]</sup> Women experience sexual activity problems due to the problems which could directly affect sexual function such as changing physical appearance resulting from surgical treatment, CT-related vasomotor symptoms, vaginal dryness, and decreased libido.<sup>[2,15]</sup>



### Cluster of symptoms

Concurrent symptoms in cancer patients may lead to cluster of symptoms through interaction.<sup>[16]</sup> Four clusters of symptoms were detected in our study. Symptoms in one of these clusters include pain, lack of energy, feeling drowsy, sweat, and swelling of arms or legs. The most common cluster of symptoms was found as pain, sleep disorders and fatigue in line with the literature.<sup>[17,18]</sup> Similar to our results, Byar *et al.*<sup>[19]</sup> detected that fatigue, feeling drowsiness and pain symptoms were within the same cluster. The reason for this may be that pain and fatigue developing due to breast cancer itself and its treatment is a complex syndrome which affects physical functions and emotion of the subject.

Emotional and behavioral symptoms develop in the course of diagnosis and treatment of women with breast cancer.<sup>[13]</sup> PSYCH such as difficulty in sleeping, feeling nervous, feeling sad, and worrying took place within the same cluster in our study. Phligbua *et al.*<sup>[5]</sup> have reported that feeling sad, worrying, feeling nervous, and feeling irritable were found within the same cluster, similar to our study. Ridner<sup>[20]</sup> have reported that difficulty in concentrating, decreased physical activity, and psychological stress were within the same cluster.

In our study, third and fourth cluster are both related to gastrointestinal system. Gastrointestinal symptoms such as vomiting, weight loss, diarrhea, lack of appetite and dizziness, problems with sexual interest were found within the same cluster in our study. Nausea, vomiting, diarrhea, and lack of appetite symptoms were found in the same cluster in the study of Kurtz *et al.*<sup>[21]</sup> conducted with cancer patients. Lack of appetite and vomiting may result in impaired nutrition, fatigue, and all these PHYS is thought to result in sexual activity problems.<sup>[21,22]</sup> Breast's being an organ which influences femininity perception and experiencing depressive symptoms due to loss of this organ may be the other reasons for this condition. The third cluster of symptoms was detected to be consisted of nausea, feeling bloated, change in the way food tastes, hair loss, and constipation. William and Schreier<sup>[23]</sup> detected that constipation was seen together with nausea in 50% of breast cancer patients. In the study of Süren *et al.*<sup>[24]</sup> symptoms were consisted of gastrointestinal symptoms such as nausea, vomiting, lack of appetite and constipation. Molassiotis *et al.*<sup>[25]</sup> detected in their study conducted with qualitative interviews that symptoms such as nausea, vomiting, feeling bloated, lack of appetite, and change in the way food tastes were seen together. CT agents, antiemetic drugs' increasing constipation risk, constipation-related to feeling bloated may be reasons for this condition.

There was a statistically significant difference between the average score of educational status, surgery, and

psychological point averages in our study. As the level of education increases, patients may develop ways to cope effectively with stress, and the development and change of positive attitude toward health can be the cause of this situation. Furthermore, functional impairment and body image problems due to surgical treatment may be negatively affecting the psychological well-being conditions of individuals.

### Information needs of patients about chemotherapy treatment

Patients' being informed about treatment options and potential side effects is reported to improve patient compliance and facilitate coping with the problems.<sup>[20]</sup> Most of the patients have stated that they were informed about the CT in our study. However, more than half of the informed patients reported that they found the information "partially sufficient." Similarly, Kav *et al.*<sup>[26]</sup> reported that 42.9% of the informed patients found the information "partially sufficient."

In this study, it was seen that participants need information about CT process, side effects of CT, other treatment. Saraswathi (2005) showed that side effects of CT were the issue which was the most commonly needed to be informed issue in the course of CT, recurrence risk was the issue most commonly needed to be informed about after completion of treatment.<sup>[27]</sup> Tay *et al.*<sup>[28]</sup> revealed that patients needed information about side effects of CT.

In this study, 30.6% of the women reported that they needed information about sexual life and reproductive health. Similarly, Takahashi and Kai reported that health-care workers did not provide information about sexuality for the women who were receiving treatment for breast cancer.<sup>[29]</sup> In addition, they stressed that similar results were obtained in the studies conducted in Asia. Sexuality is one of the important components of health although is not of vital importance. Breast is one of the organs which represent sexuality in females. The reason for the great need for information about sexuality in our study may be health-care workers' neglecting this issue as Turkey is a West Asia country where sexuality is a taboo.

Being diagnosed with breast cancer is a process which affects the women both physically and psychologically. The study detected that patients needed information about symptom management. Landmark *et al.*<sup>[30]</sup> reported in a qualitative study conducted with breast cancer patients who were actively being treated that information and support about physical, emotional, and social aspects of daily life and psychosocial support came in the foreground.

## Conclusion

The results of this study revealed that breast cancer patients receiving CT experience many symptoms in different ratios and symptoms are inter-related. We also detected that patients needed information about the effects of CT, symptom control, and psychosocial support. It is suggested that experiencing intensive symptoms and unmet information needs may be inter-related. It is recommended to generalize case management models focused on individual needs and improve awareness of the nurses to meet health care needs from the beginning to the end of the disease. The results of this study will enable determination of symptom clusters, which health professionals are easier to focus on these symptoms. Patients call for clinical attention on information needs. The evaluations of information needs of the treatments is important as part of the nursing care. An understanding information need of patients can help to ensure that individual's coping strategies and self-management.

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### Conflicts of interest

There are no conflicts of interest.

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