Research Article

Understanding Breast Cancer From the Patients' Perspective

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Abstract

Objectives: We performed this study to seek what patients think about their diagnosis, treatment process and survivorship.

Methods: We evalued 125 breast cancer patients receiving chemotherapy in a descriptive and prospective study using a well-structured questionnaire.

Results: Most of the patients had information about breast cancer screening at the time of the questionnaire (57.6%), but the proportion of those who had prior knowledge of the disease was low (29.6%). While the most frequent sign of breast cancer was reported to be a palpable mass (53.6%), the most frequent detection method was breast self-examination (67.2%). The most frequent adverse effect of chemotherapy were reported to be hair loss (98.4%). Patients' expectations regarding the disease and adverse events were mostly stated as "I will be completely cured" (79.2% and 53.6%, respectively). Etiological factor most frequently accepted by the patients were stress (85.6%). Most of the patients received support from their families during the course of the disease (91.2%).

Conclusion: This study provides important new information for every stage of the fight against breast cancer from the perspective of cancer patients. These findings are useful for new programs and clinical decision-making.

Keywords: Breast cancer, breast screening, chemotherapy, perspective, survey

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The most frequently seen cancer type worldwide and in our country is breast cancer.[1] According to USA data, one in eight women suffers from breast cancer at one stage of her life.[2] In this common disease where early detection and screening programs are highly significant, the relative survival rate has risen from 74.6% in 1975-1979 to 90.6% in 2006 with the latest developments.[1]

In order to reach the targeted levels in screening programs and the disease detection-treatment process and to better understand which treatment and screening program features are selective and significant for patients, data should be collected with a scientific patient preference study design with standardized patient perspectives. By putting the patient's narratives and qualitative insights in foreground a more comprehensive approach to the disease management will be facilitated.[3,4] To the best of our knowledge, our study is the first comprehensive study in the field of breast cancer designed to exclusively include actual breast cancer patients in this context.

In our study, we aimed to determine the extent of disease awareness and knowledge in patients diagnosed with early stage breast cancer and in addition, investigate their perception regarding the treatment process and survivorship.

Methods

Study Sites and Participants

Patients diagnosed with early stage breast cancer and aged above 18 years and below 61 years who were treated between 01.03.2020 and 01.12.2020 and followed at the medical oncology outpatient clinic and the chemotherapy unit and received at least 3 cycles of chemotherapy containing anthracycline as a neoadjuvant or adjuvant agent were included in our study. Informed written and verbal consent was obtained from the participants. A total of 125 patients were included in the study group. Participants received assurance that their responses would remain confidential and the questionnaire was completed by leaving it to the patient whether they preferred help from the researcher and later recordings were made by the executive researcher.

Study Questionnaire

Some of the subjects of the questions in the questionnaire were selected in a way that is similar to breast cancer awareness questionnaires in order to be able to compare it with the specific questionnaires in the literature. The questionnaire was primarily designed to evaluate breast cancer awareness in patients with breast cancer and their knowledge regarding the risk factors, screening, symptoms and treatments and contained questions about what the patients went through in the detection and treatment processes. Adverse effects of anthracycline-based chemotherapy and patients' approach were included in the questionnaire by inquiring about the most frequent adverse effects accepted in the literature.

Statistical Analysis

"SPSS for Windows 26.0" package program was used in the statistical analysis of data. Categorical measurements were summarized as numbers and percentages and continuous measurements as mean and standard deviation. Comparison of categorical measurements between the groups was performed with Chi-square test, Fisher exact test and univariate regression analysis tests were used. The limit of statistical significance was taken as "p" 0.05.

Results

Demographic Characteristics

A total of 125 patients were included in this study. All of the patients included were women. Mean age of the patients was 45.96±8.9 (age range: 24-60 years). The rates and numbers formed were as shown in Table 1.

Table 1. Details of 125 study participants

Characteristrics	n	%
Age		
<40	30	24.0
40-60	95	76.0
Marital status		
Married	105	84.0
Never married	9	7.2
Divorced	5	4.0
Widow	6	4.8
Motherhood		
Yes	14	11.2
No	111	88.8
Monthly household income		
<2.500 TL	61	48.8
2.500-5.000 TL	45	36.0
5.000-10.000 TL	17	13.6
>10.000 TL	2	1.6
Education status		
Illiterate	7	5.6
Elementary-secondary	74	59.2
High school	23	18.4
University	21	16.8

TL: Turkish lira.

Knowledge of Breast Cancer Screening

When asked about their knowledge on the subject of detection-screening, 53 of our patients (42.4%) responded "No, I have no knowledge", whereas 37 (29.6%) responded "I had substantial knowledge prior to the disease, too" and 35 (28%) responded "I learned after the disease".

The patients were asked where they obtained information about the screening program. Our patients could give more than one response and the responses received from these patients and the rates among all questionnaire responders were as shown in Table 2.

Table 2. Places where they obtained information about detection-screening program

Where did you learn about Detection-screening programs?	n	%
Healthcare institutions	60	48.0
Internet	54	43.2
Friends/Relatives	41	32.8
Television/radio	38	30.4
Social media	33	26.4
Education centers	10	8.0
Books/newspapers/magazines	9	7.2

Only 61.6% (n=77) of patients who were asked "At what age do you think early screening/mammography screening starts?" wanted to answer the question, 38.4%(n=48) of patients responded as "I do not know" and the mean response received from questionnaire responders was 36.18± 1.15 years (18-58 years). The most frequently given answer was "40". Total number of patients who gave the correct answer of "40" was 25 and this number corresponded to 20% of all patients.

The patients were asked whether they thought mammography was harmful or not and 30 (24%) thought it was harmful, while 95 (70%) thought it was not harmful. Those who thought it was harmful were asked; "Did the thought that mammography is harmful prevent you from enrolling in the screening program?" and 30% of this group (n=9) gave the answer of "Yes".

Clinical Characteristics

When patients were asked about the first sign that made them suspect that they may have breast cancer, they were allowed to select more than one option and the distribution of the answers and their rates in the entire population were as shown in Table 3.

The patients were asked how they first noticed their disease and the responses were "with BSE(Breast Self Examination)" in 67.2% (n=84), "with mammography" in 5.6% (n=7) and "incidentally or with external symptoms" in 27.2% (n=34). Results are shown in Figure 1.

Diagnosis Process

Patients were asked about the first hospital they presented to following the disease suspicion inquired under the conditions of our country and 36.2% (n=37) responded as state hospital, 24.5% (n=25) as university hospital, 25.4% (n=26) as Cancer Early Detection-Screening and Education
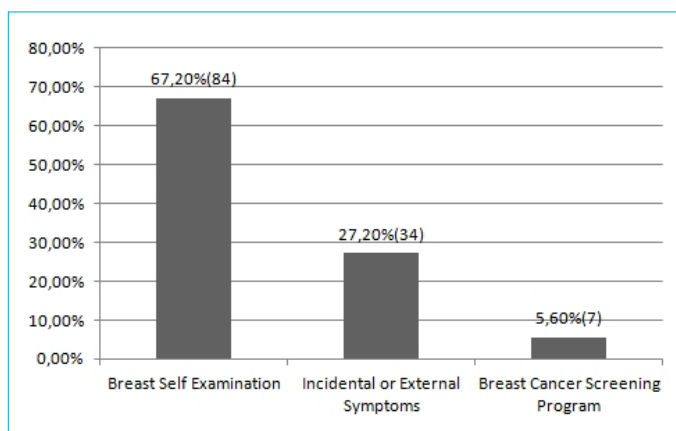
Table 3. First sign of the disease

Which of the most frequent signs of your disease did you experience at the beginning of the disease?	n	%
I had no signs	23	18.4
A lump, mass or palpable thickening in the breast	67	53.6
Pain in the breast or armpit	24	19.2
Indentation of the nipple	21	16.8
A lump, mass, palpable thickening in the arm pit	19	15.2
Size and shape change in the breast	16	12.8
Redness in the breast skin	13	10.4
Changes in the nipple	7	5.6
Discharge or bleeding in the nipple	6	4.8
Puckering in the breast skin	2	1.6

Figure 1. Graph showing methods of breast cancer detection.

Center, 12.7% (n=13) as private hospitals and 0.9% (n=1) as family healthcare centers. When patients are questioned about the first health center they applied to after the suspicion of breast cancer occurs; It was seen that state hospitals (36.2%, n=37), Cancer Early Detection-Screening and Education Center (25.4%, n=26) and university hospitals (25.4%, n=26) ranked first. Presentation to private hospitals (12.7%, n=13) and family healthcare centers (0.9%, n=1) were not very common.

When patients were asked about the branches they initially t presented following suspicion of the presence of breast cancer, the most frequent presentation was to the general surgery with a rate of 88% (n=111), followed by family medicine with 4.8% (n=6), medical oncology with 3.2% (n=4), internal medicine with 2.4% (n=3) and emergency unit with 0.8% (n=1).

The mean time to presentation to a doctor was 29.77 days (0-360).The mean time between the first biopsy taken from patients presenting to any healthcare institution and disease suspicion was 41.9 days (1-375). The mean time between the first presentation to the doctor and biopsy was 12.2 days (0-80) when all patients were reviewed.

Risk Factors and Information Needs

When patients were asked where they obtained information about "breast cancer" after they were diagnosed, they were allowed to choose more than one options. The rates and numbers of the answers given by the patients are shown in Table 4.

The patients' knowledge about breast cancer etiology was also inquired, the responses obtained and their rates were as shown in Table 5.

Treatment Process

Adverse effects experienced during chemotherapy were investigated by asking our patients all of whom had received

Table 4. Places where information was obtained about breast cancer

Where did you learn/try to learn about your disease after you were diagnosed with "Breast cancer?"	n	%
Doctors	111	88.8
Internet	59	47.2
Social media	26	20.8
Friends/relatives	26	20.8
Other healthcare professionals	16	12.8
Books/magazines/newspapers	10	8.0

Table 5. Table showing breast cancer etiology according to patients

	n	%
Stress	107	85.6
Genetics	69	55.2
Smoking	45	36.0
Radiation	39	31.2
Contraceptive use	26	20.8
Being overweight, obesity	22	17.6
Early menarche	14	11.2
Not giving birth	14	11.2
Alcohol use	12	9.6
Late menopause	10	8.0
Giving birth at late age	9	7.2
Consumption of high amounts of food of animal origin	9	7.2

Figure 2. Graph showing the adverse effects encountered during chemotherapy.

Figure 3. Graph showing patients' expectations after treatment regarding hair loss and other side effects related to chemotherapy.

anthracycline. The rates and numbers of the answers given by the patients are shown in Figure 2.

When patients were asked about their opinions on the chemotherapy and inquired about their experience with chemotherapy induced alopecia, the distribution of the responses given by the patients are as follows Figure 3.

Hope and Support

Correlation between demographic characteristics of the patients and their future expectations was analyzed. The group that thought they would recover completely made up 79.2% (n=99) of the whole group. There was no significant correlation between the demographic characteristics of the patients and their expectations from the treatment of the disease(p>0.05). Results are shown in Table 6.

Patients diagnosed with breast cancer were asked about who gave them moral support, they were allowed to choose more than one option and while 4% (n=5) said they did not receive moral support from anybody, 91.2% (n=114) said they received support from their families, 44.8% (n=56)
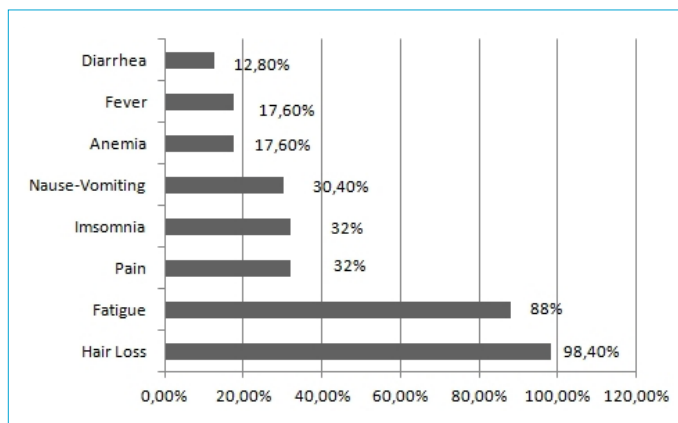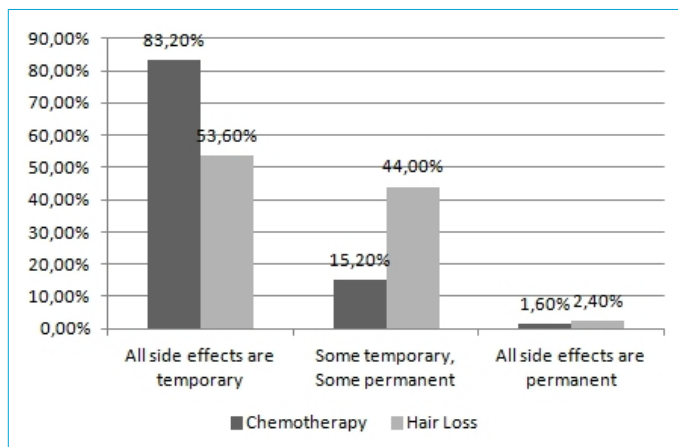
from their friends, 24.8% (n=31) from other healthcare professionals and 48% (n=60) from their doctors.

The rate of patients who received professional psychological support (PPS) during the treatment process was 18.3% (n=23). There was no significant difference between those aged below 40 years and those aged 40-60 years regarding "receiving professional psychological support". Considering the conditions of the country, there was no statistically significant difference between economic status of having an income below (p>0.05) and above "2500 TL" which is the hunger limit and other demographic characteristics and status of receiving PPS. Results are shown in Table 6.

When the correlation between expectations from the disease and the group receiving PPS was analyzed, the professional psychological support receiving part of the group that did not expect to recover completely (n=26) made up 19.2% (n=5) of this group. On the other hand, the rate of those who received professional psychological help within the group who thought they would fully recover and be

Table 6. Relationship between patients' general characteristics and their expectations from disease treatment and receiving professional psychological support (PPS)

Characteristrics	I expect full recovery			I received PPS		
	Yes	No	p	Yes	No	p
Age						
<40 (%)	26 (86.7)	4 (13.3)	0.248	6 (20.0)	24 (80.0)	0.795
40-60 (%)	73 (76.8)	22 (22.2)		17 (17.9)	78 (82.1)	
Marital status						
Married (%)	80 (76.2)	25 (23.8)	0.072	21 (20.0)	84 (800)	0.364
Unmarried (%)	19 (95.0)	1 (5.0)		2 (10.0)	18 (90.0)	
Motherhood						
Yes (%)	87 (78.4)	24 (21.6)	0.732	22(19.8)	89 (80.2)	0.463
No (%)	12 (85.7)	2 (14.3)		1(7.1)	13 (92.9)	
Monthly household income						
<2.500 TL (%)	47 (77.0)	14 (23.0)	0.563	10 (16.4)	51 (83.6)	0.572
≥2.500 TL (%)	52 (81.2)	12(18.7)		13 (20.3)	51 (79.7)	
Education status						
Below high school (%)	65 (80.2)	16 (19.8)	0.696	14 (17.3)	67 (82.7)	0.662
High school and above (%)	34 (77.3)	10 (22.7)		9 (20.5)	35 (79.5)	

TL: Turkish Lira.

free of the disease (n=99) was 18% (n=18.2). The rates of both groups were comparable.

Discussion

Previous studies on this subject were either performed on healthy volunteers or limited to certain social groups or conducted using a limited questionnaire. In this study, we aimed to look at the whole disease management process from the perspective of breast cancer patients. We investigated the entire screening, diagnosis, treatment and psychological process with a comprehensive questionnaire.

In a study performed in 2017 in a healthy general population in Italy, the rate of those who were aware of breast cancer screening was 51.4%.[5] In our study, while the rate of those who said they had knowledge about screening was 57.6%, those who knew about screening before they had breast cancer made up only 29.6% of the questionnaire responders and this is a very low rate compared to the above-mentioned study in the literature. Since healthy populations are selected in studies performed about breast cancer and considering that participants in the questionnaire do not have a special reason for knowing something about breast cancer, low rates found in the general populations can be acceptable, but even the rate of 57.6% obtained from patients diagnosed with breast cancer in our study is worrisome. The health policy in this field should be reviewed in order to increase the awareness rates.

Mammography played a role in only 5.6% of patients for detection of breast cancer. We investigated whether the cause of this low rate was the thought known as a social drawback that mammography is harmful. In the group considering mammography as harmful, the rate of those who did not enter the screening program because of this drawback was only 30% and this made up 7.2% of our entire questionnaire group. This rate demonstrated that the thought that "mammography is harmful" is not an effective cause of the low rate of mammography screening. Although it is not sufficient to make a general interpretation, our study will provide preliminary information about this subject since there is not a similar study in the literature.

BSE is the earliest step in screening for breast cancer. It is particularly recommended for developing countries.[6] But there are publications and specific reports received from the U.S. Preventive Services Task Force and American Cancer Society indicating that breast self examinations do not provide a benefit to women.[7-9] In our study, the rate of the patients whose disease was diagnosed with BSE was 67.2% and as opposed to the publications and reports not recommending BSE, it shows that BSE is currently valid especially in populations with undesired levels of mammography screening. In addition, despite its great importance, a very small part of the patients had started BSE at the recommended starting age, necessitating increased advertising about BSE. It is known from the studies in the literature that

BSE awareness is highly correlated with age and educational success.[10]

It was reported in a study performed in England in 2005 that the general population learned about current information regarding breast cancer mostly from written and electronic media (radio, TV); 48% from TV/radio, 43% from books and magazines. 40% obtained information from their close environment, 3% from the internet and 13% from healthcare professionals.[11] In a study conducted in Turkey, 39.3% of healthy volunteers obtained information about breast cancer from TV/radio, 16.12% from newspapers/magazines, 29.8% from healthcare institutions, 13% from the internet and 20% from their close environment.[12] In our study, these rates were 88.8% from doctors, 47.2% from the internet, 20.8% from social media and 20.8% from friends/close environment. The different rates found in our study compared with the literature might be attributed to the easier access of patients to doctors. Also, while the increased rates of internet and social media are noteworthy, the difference may be due to the developed global internet network, and the fact that internet and social media have currently become the basic source of communication and information.

In our study, the signs leading to suspicion of the disease were "A lump, mass, palpable thickening in the breast" in 53.6% followed by "Pain in the breast or armpit" in 19.2%. In a study conducted in the general population in our country, 80% responded as "mass in the breast, armpit" to clinical signs leading to cancer suspicion.[12] In another study aimed at the general population, the most frequent sign was "mass in the breast" in 79%, followed by "pain in the breast, armpit" in 16%.[11] Based on these findings, the thought of generally accepted breast cancer signs appears to be right. Another point we found in our study is that most breast cancer cases usually manifest themselves with a clinical sign and these signs lead patients for consulting to a healthcare facility. However, the rate of patients without any signs before diagnosis was found to be 18.2% in our study which underlies the importance of utilization of imaging modalities in screening programmes.

A major part of our patients stated that they received moral support during the disease process. The primary support was from the families (91.2%), while the doctors had a rate of 48%. 79.2% of the patients had an expectation that they would be fully cured of the disease after completion of chemotherapy. The low rate (18.3%) of those receiving professional psychological support can be attributed to the high support level that they have received from their doctors and their families, and the high rate of expectation of full recovery from breast cancer. Breast cancer diagnosis and treatment process is a major stress factor for women and psychosocial

effects of illness can significantly affect quality of life.[13] It has been reported that chemotherapy can cause serious physical and psychological problems.[14] In a study conducted in our country, it was reported that 23% of breast cancer patients need psychological support.[15] However only 18.3% of the patients in our study group received PPS. This low rate may be due to the moral support received during the treatment process by their family and attending oncologist. Another explanation could be the optimistic expectations about the disease outcome and patients' anticipation that the duration of chemotherapy related side effects would be relatively brief and recovery from the disease.

In a study performed in patients receiving anthracycline therapy and overlapping with other studies in the literature, the adverse effects most frequently experienced during the treatment were reported to be fatigue and hair loss. [16-18] In our study resulted in accordance with previous studies. In addition, these side effects are not life-threatening, however there are a number of studies have reported that they have extremely disturbing effects on the patients.[19-22] In our questionnaire regarding these undesirable effects, patients had high optimistic expectations even if they were affected by the side effects. The reason for this may be the constant relationship between the patient and the physician and family support and the belief that the treatment they are receiving will be beneficial for them.

When knowledge about the risk factors of breast cancer was reviewed, 55.2% responded as genetic factors, 36% as smoking and 31.2% as radiation. The major part of the patients which was estimated to be 85.6% gave the answer of stress, keeping it proportionally ahead of more accepted and proven other risk factors. In a study in the literature performed on volunteers, 92% of the survey respondents considered family history as a risk factor while the rate of those who cited "stressful life" was 67%[11] It is clear that more informative studies investigating this subject are required to be conducted.

Conclusion

In this study, different from the studies in the literature, we looked at the disease, screening programs and the diagnosis-treatment process from the perspective of patients with breast cancer.

In this study, knowledge about breast cancer detection/screening programs was found to be at a lower level than desired which indicates available programs are not being successful. While BSE was found to have an important role in the disease diagnosis in the study population, mammography had a low rate. It is our judgment that BSE is still keeping its validity in early detection especially in places like our

country where complıance to mammography screenıng programs remaıns at a dismal rate. Communication of information about the importance of screening for early diagnosis of breast cancer by neutral healthcare institutions directly via published or electronic media in an easily understandable and balanced way can be more fruitful for achieving high attendance rate of the targeted population.

Disclosures

Ethics Committee Approval: The study protocol was approved by the Ethics Committee of Tekirdağ Namik Kemal University, Faculty of Medicine and was conducted in accordance with the principles of the Declaration of Helsinki (30.04.2020; 2020.81.04.05).

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