

Evaluation of Illness Perception of Women with Breast Cancer in Turkey

Elanur Yılmaz Karabulutlu¹, İlknur Aydın Avcı², Özgül Karayurt³, Ayla Gürsoy⁴, Nedime Köşgeroğlu⁵, Arzu Tuna⁶, Fatma Ersin⁷, Fatma Arıkan⁸, Seda Karaman¹

¹Atatürk University School of Nursing, Erzurum, Turkey

²Ondokuz Mayıs University School of Health Sciences, Samsun, Turkey

³İzmir University of Economics School of Health Sciences, İzmir, Turkey

⁴Cyprus International University School of Health Sciences, Lefkoşa, Cyprus

⁵Eskişehir Osmangazi University School of Health Sciences, Eskişehir, Turkey

⁶Sanko University School of Health Sciences, Gaziantep, Turkey

⁷Harran University School of Health Sciences, Şanlıurfa, Turkey

⁸Akdeniz University School of Nursing, Antalya, Turkey

ABSTRACT

Objective: The aim of this study is to examine the illness perceptions of women with breast cancer and possible relationships between these perceptions and descriptive characteristics such as sociodemographic and clinical characteristics in Turkey.

Materials and Methods: The study was conducted in compliance with correlational, descriptive research principles. Three hundred eighty women with breast cancer who were treated in various hospitals in seven regions of the country were included in the study. A sociodemographic and clinical characteristics form, and The Illness Perception Questionnaire were used for data collection.

Results: The mean age of the patients with breast cancer was 49.8±11.5, among them, 83.95% were married, 37.37% were at stage 2 breast cancer, and 67.11% experienced mastectomy. It was found that the patients perceived higher personal control over illness (20.88±4.76). The patients perceived most common risk factors as the cause of the illness (19.42±6.38). This study show that variety sociodemographic and clinical characteristics of the patients affected their perceptions of illness.

Conclusion: The meaning of illness from the perspective of patient with breast cancer should be assessed. The care, education and counselling programs should be planned according to the patient's illness perceptions.

Keywords: Illness perceptions, breast cancer, women

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Introduction

Like all other types of cancer, breast cancer (BC) is perceived as a life-threatening disease; it remains as a most frightening disease for women despite the important developments in its treatment. Moreover, BC is perceived as a disease that threatens both life and womanhood, includes physical, psychological, sexual and working-life problems, has recovery and exacerbation periods, and causes short- and long-period adjustment disorders (1, 2).

According to the 2018 report of the International Agency for Research on Cancer, BC is ranked as the second most frequent cancer (11.6%) in the world. (3) According to the 2015 data of Ministry of Health in Turkey, BC is ranked first among the first 10 types of cancer seen in women and its incidence is 52.5 in one hundred thousand (4).

While the incidence of breast cancer is increasing in both our country and the world, knowing what breast cancer means for patients may be beneficial for reducing the mortality and morbidity of the disease. Illness is subjective; each person experiences it differently. Therefore, individual responses to illness are also different (5). The responses attributed to illness, beliefs about its course and duration, its perceived consequences, and special beliefs about it all affect the treatment and controllability of disease (6). How the experience of cancer is defined and perceived plays a crucial role in adjusting both to the disease and its treatment (7). Therefore, attention has been increasingly directed on the meaning attributed by patients to their cancer. Studies show that how the patients with BC perceive their illness is an important factor that determines adjustment to disease, the general distress level, psychosocial distress experienced by patients, and coping with stress (1, 8-10).

Corresponding Author :

Elanur Yılmaz Karabulutlu, e-mail: elanurkarabulutlu@hotmail.com

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Perception of illness, which differs by experience and culture is variable. The differences in illness perception cause different reactions as a response to the same health hazard (11). The perception of BC differs in race/ethnic and socio-economic groups. Individuals with a family history of BC may have incorrect perceptions, especially about the factors that cause the disease (12). Illness perceptions vary per individual and per culture (11). In a study conducted in Turkey show that most of the women reported that breast cancer is dreadful and results in death, some of the women did not perceive it as a serious or demoralizing condition (13). The breast is a symbol of femininity and sexuality in Turkish society as well as in many other societies. Thus, the loss of a breast is perceived as a traumatic life experience for women, damaging their sense of attraction and sexuality (14). With the stigmatization tagged along with the loss of one's breast, these women coped by isolating themselves from the social circle. They locked themselves within the comfort of their home to keep their disfigured body away from the public eyes (15). Studies that examined the illness perception of Japanese and Dutch patients with BC found that the Japanese women had more concerns about their illness (16). Predicted that their illness would last longer and yet could understand their illness better as compared with Dutch women (16, 17). Another study reported that Indonesian patients with BC consulting traditional healers as a cultural element had a more negative perception (18).

The perceptions of individuals with BC living in different cultures concerning the factors that cause the disease also show differences. It was determined that cancer patients perceived the most risk factors (most smoking) as illness causes in Turkey (19). The most common attributions in women with breast cancer in Western Australia were to mental or emotional factors (46.3%), especially stress, followed by lifestyle factors (38.6%) and physiological factors (37.5%), particularly relating to hormonal history (20). Brazilian woman with BC attributed breast cancer primarily to psychological causes (21). It was also found that the Dutch patients with BC think that the psychological factors mostly cause the disease (1).

Knowing what the illness means to patients helps health care professionals to better understand the feelings and behavior of patients (5). Therefore, health professionals should determine how patients perceive their illness, and care should be planned according to the needs of patients.

The aim of this study is to examine the illness perceptions of female patients with BC and to reveal cultural differences.

Material and Methods

Study participants

The study was conducted in compliance with correlational, descriptive research principles. The study was conducted in the seven regions (Marmara, Aegean, Mediterranean, Black Sea, Central Anatolia, East Anatolia, Southeastern Anatolia) of Turkey. Data of the study were collected between February 2014 and May 2015. The study population consisted women who were being active treatment for breast cancer (chemotherapy, radiotherapy and surgical treatment).

In sample selection; a city was determined by considering the population density from each region. The female patients with breast cancer who were treated in university hospitals in designated cities were included in the study. The sample size was calculated to be 350 using a power analysis, with a confidence interval of 95%, and a margin of

error of 5%. It was planned to reach at least 50 patients from each hospital in order to reach the number of samples determined by Power Analysis. Data were collected from each hospital until reach 50 female breast cancer patients who met the criteria for sampling. But the number of samples exceeded 50 in some hospitals, and therefore the sample size increased to 380.

The sample selection criteria were as follows: not having a history of cancer apart from BC, being 18 years of age and older, being able to understand and speak Turkish, being able to read and write, not having been diagnosed with any psychiatric disorders, not having metastasis, agreeing to participate in the present study, being primary breast cancer and being a woman.

Instruments

The Illness Perception Questionnaire (IPQ): The IPQ was developed by Weinmann in 1996 to assess illness perception. The validity and reliability study of the questionnaire for chronic illness was conducted by Kocaman et al. (22). The IPQ consists of three dimensions: illness identity, perceptions about the illness, and the causes of illness. The illness identity sub-dimension was not used in this study. The *perceptions about the illness dimension* consists of 38 items. The *causes of illness dimension* consists of 18 items, including the potential causes of the occurrence of diseases. This scale is 5-point Likert-type scale. Each item in the scale scores between 1 and 5. (1: I certainly don't think so, I think 5: I certainly think that) (21). Information about The Illness Perception Questionnaire is given in Table 1.

Procedure

The data collection process was carried out by all researchers. Patients were interviewed before data collection began. This research was made with women accepting to participate this research and matching to inclusion criteria. Patients were interviewed in clinic. Patients were informed about the purpose of the study, and their verbal consents were taken. An approval dated January 13th, 2014 and numbered 2014/8 was obtained from the Ethics Committee of Faculty of Health Sciences in Atatürk University. Institutional permissions were received from the hospitals.

Statistical Analysis

Statistical Packages for the Social Sciences (SPSS) version 16.0 (SPSS Inc.; Chicago, IL, USA) was used for statistical analysis and data processing. Number and percentage were used for the descriptive characteristics of patients and their characteristics concerning the disease. The Kolmogorov-Smirnov Test was used to determine whether the data were normally distributed. The descriptive statistics, *t*-test, and variance analysis were used for the data analysis, and the Bonferroni test and Kruskal-Wallis test were used to assess the difference between groups. The Kruskal-Wallis test was used for the analysis of non-normally distributed data. The significance level was set as $p < 0.05$.

Results

Sociodemographic and clinical characteristics of patients

The examination of patients' descriptive characteristics showed that their mean age was 49.80 ± 11.59 years, among them, 83.95% were married, 56.32% were elementary school graduates, and 72.89% were housewives. The examination of stage of illness showed that of the patients, 40.00% were at stage 2, and the mean time of diagnosis was 18.04 ± 21.15 months. Of the patients, 67.11% experienced breast surgery, and 70% did not have a family history of BC (Table 2).

Table 1. Sociodemographic and clinical characteristics of patients (N: 380)

IPQ	Items	Description of sub-scales	IPQ Cronbach Alpha	In this study Cronbach Alpha
Perceptions about the illness dimension				
Timeline (acute/chronic)	1-5,18	The high score indicates that the condition is perceived as chronic	0.72	0.85
Consequences	6-11	The high score indicates that the individual has a high belief in the negative consequences of the disease.	0.69	0.62
Personal control	12-17	The high score of the personal control indicates that the person has positive beliefs that he can control the disease.	0.70	0.77
Treatment control	19-23	The high score indicates that the person has positive beliefs that he can control the treatment.	0.75	0.79
The identification of illness	24-28	The high score indicates that the person understands the illness.	0.73	0.69
Timeline (cyclical)	29, 32	A high score indicates that the person has positive beliefs about the cyclical nature of the illness.	0.71	0.61
Emotional representations	33-38	The high score of emotional representations indicates that the negative emotions associated with the illness are high.	0.77	0.74
Causes of illness				
Psychological attributions	1,9,10,11,12	Stress or worry, my attitude, my emotional state, family problems, personality characteristics, overwork	0.72	0.76
Risk factors	2,4,6,8,13,14,15	Hereditary, my own behavior, dietary-eating habits, poor medical care in my past, smoking, alcohol intake, aging	0.66	0.71
Immunity	3,7,18	A germ or virus, altered immunity, environmental pollution	0.54	0.53
Accident or chance	5,16	Accident, injury, bad luck	0.25	0.21
IPQ: Illness Perception Questionnaire				

The perceptions of patients about the illness

The perceptions about their illness of patients and the causes of their illness scores are shown in Table 3. They obtained the highest mean score from the personal control (20.88 ± 4.76) and the lowest mean score from the timeline (cyclical) perception (12.18 ± 3.34).

The perceptions of patients about the causes of illness

It was found that the patients see the most risk factors (19.42 ± 6.38) as the cause of their illness (hereditary, smoking, alcohol use, aging) (Table 3).

Association between the perceptions about the illness and sociodemographic/clinical characteristics

It was found that that the patients with a high level of education obtained lower scores from the timeline, consequences, and emotional representation, whereas treatment control scores were higher ($p < 0.05$). The patients who were not working obtained higher scores from the consequences and emotional representations ($p < 0.05$). The patients who were at stage 4 of illness were found to obtain higher scores from the timeline (acute/chronic) and consequences, whereas the patients who were at stage 1 of illness were found to obtain lower scores from

the timeline (cyclical) ($p < 0.05$). Consequences scores of patients with mastectomy were found to be higher ($p < 0.05$). The patients who had a family history of BC were found to obtain higher scores from consequences ($p < 0.05$). There was not a statistically significant difference in the perceptions about their illness of patients, according to type of the surgery ($p > 0.05$). Age was to have a significant positive correlation with timeline (acute/chronic) perception timeline (cyclical) and negative correlation with personal control, treatment control, and the identification of illness mean scores ($p < 0.05$). There was also a positive correlation between the time of diagnosis and timeline (acute/chronic) mean scores (Table 4).

Discussion and Conclusion

The findings of this study show that the patients perceived a higher personal control over the illness and they perceived the most common risk factors as the causes of breast cancer. Also, this study shows that various sociodemographic (educational status, age, working status) and clinical characteristics (stage of the disease, the presence of mastectomy, family history of breast cancer, time of diagnosis) of the patients were important determinants of illness perceptions.

Table 2. Sociodemographic and clinical characteristics of patients (N: 380)

Descriptive Characteristics	Mean±SD
Age	49.80±11.59 (Min: 24-Max: 77)
Time of diagnosis (Month)	18.04±21.15 (Min: 1 - Max: 96)
	N (%)
Marital Status	
Married	319 (83.95)
Single	61 (16.15)
Educational Status	
Illiterate	38 (10.00)
Elementary School	214 (56.32)
High School	85 (22.37)
University and above	43 (11.31)
Working status	
Working	103 (27.11)
Not working	277 (72.89)
Stages of the disease	
Stage 1	68 (17.89)
Stage 2	152 (40.00)
Stage 3	100 (26.31)
Stage 4	60 (15.80)
Breast surgery	
Yes	255 (67.11)
No	125(32.89)
Type of the surgery	
Mastectomy	206 (80.78)
Breast-Conserving Surgery	49 (19.22)
Family history of BC	
Yes	114 (30.00)
No	266 (70.00)

Table 3. The perceptions illness and causes of illness dimension of IPQ scales (N: 380)

	Mean	SD	Min	Max
Illness perceptions				
Timeline (acute/chronic)	16.26	5.56	6	30
Consequences	20.08	4.40	6	30
Personal control	20.88	4.76	6	30
Treatment control	19.02	3.98	9	25
The identification of illness	16.30	4.14	5	25
Timeline (cyclical)	12.18	3.34	4	20
Emotional representations	19.42	6.38	6	30
The causes of illness				
Psychological attributions	16.72	5.63	6	30
Risk Factors	19.42	6.38	8	35
Immunity	5.44	1.95	2	10
Accident or chance	4.65	1.85	2	9

Health professionals should determine how patients perceive their illness, and care should be planned according to the needs of patients. The examination of relevant patient results in different cultures shows

that the BC perception differs in different cultures. Similar to the result of the present study, studies show that the positive thoughts of the patients with BC in India and Ireland about the fact that the illness can be controlled individually were at high levels (23, 24). As distinct from the result of present study, a study reported that although the Dutch patients with BC thought more optimistically about the fact that the illness can be controlled with the treatment, their personal control levels were low with regards managing their own status (8). It was also stated that the patients with BC in Indonesia maintain high levels of worries about the illness and their treatment control perception were low (18). A study found that the perception of Chinese patients with BC about the controllability of illness and their belief about the ability to personal control perception were at high levels and their level of worries about the illness was low (25). When the cultural characteristics of Turkish society are taken into consideration, it is seen that social support increases especially in diseases. It is thought that this social support provided to the patient during the active period of treatment is effective in increasing the perception of control.

In this study, when the perceptions of patients about the causes of illness are examined; it was found that cause of illness were most common risk factors (hereditary, smoking, alcohol use, aging). Psychological attributions were the second most common cause. Women with breast cancer in Western Australia tend to attribute the illness to many factors, including: psychological factors and stress, trauma (knocks or bruises) in the breast, religious causes, exposure to chemicals and electronic equipment, bacterial or viral infection and poor luck (26). Other study in The French West Indies was reported that most treated breast cancer patients did not have any opinions about the causes BC. Those who had an opinion reported that the causes were stress, genetic factors, and pollution were the most important BC (27). A study shows that stress and psychological/personal factors as in the example of China, are ranked first among the causes of BC (25). Bahraini women reported that the most common cause of BC is stress in their lives (28). Hence, to prevent the recurrence of this disease in the future, interventions should be conducted to improve perceptions of the risk factors and psychological causes of breast cancer.

Patients with a high level of education perceived shorter illness, duration, less negative consequences, and emotional impacts and higher treatment control. As the educational status increases, the patients perceived the illness more positively. Although the results were not statistically significant, the mean size of understanding the disease was higher in high school and college graduates. Therefore, it is thought that patients who have a better understanding of the disease and its course can develop a positive perception of illness.

The patients who were not working perceived more severe consequences, less treatment control and emotional impacts. In another study found that unemployed cancer survivors perceived more disease consequences and had more concerns and emotional representations than those who were employed (25). People experiencing greater impacts may be less likely to return to work, accounting for higher reported more severe consequences perceptions in the patients who were not working.

The patients who were at stage 4 of illness perceived a longer illness, more severe consequences. Physical and psychological problems experienced in advanced stages of the disease may be effective in perception more serious negative consequences of the illness.

Table 4. The perceptions illness according to the sociodemographic and clinical characteristics of patients (N: 380)

Illness perceptions							
Demographic and clinical characteristics	Timeline Acute/Chronic Mean±SD	Consequences Mean±SD	Personal control Mean±SD	Treatment control Mean±SD	Identification of illness Mean±SD	Timeline (cyclical) Mean±SD	Emotional Representations Mean±SD
Educational Status**							
Illiterate	18.31±5.82	22.15±4.94	20.23±5.61	18.26±3.64	16.28±5.06	13.15±3.28	20.65±5.97
Elementary School	16.75±5.57	20.60±4.22	20.73±4.80	18.60±3.95	15.84±4.10	12.56±3.24	19.71±4.77
High School	15.83±5.07	19.35±3.94	20.92±4.26	19.25±4.00	16.85±3.97	11.64±3.29	18.67±5.26
University and ↑	12.86±4.83	17.11±4.04	22.11±4.59	21.34±3.64	17.48±3.50	10.51±3.38	17.04±3.82
	F=8.249	F=12.058	F=1.266	F=6.497	F=2.598	F=6.568	F=4.918
	p++=0.000	p++=0.000	p+=0.286	p++=0.000	p+=0.052	p++=0.000	p++=0.002
Working status*							
Working	15.36±5.30	18.29±4.36	21.16±4.24	19.87±3.68	16.85±3.46	11.57±3.19	18.21±4.55
Not working	16.59±5.63	20.75±4.23	20.78±4.94	18.71±4.05	16.09±4.36	12.41±3.37	19.66±5.10
	t=-1.921	t=-4.989	t=0.694	t=2.544	t=1.767	t=-2.183	t=-2.532
	p+=0.055	p++=0.000	p+=0.488	p++=0.011	p+=0.079	p++=0.030	p++=0.012
Stage of the disease**							
Stage 1	14.63±4.98	19.10±4.47	21.67±5.48	20.05±4.33	17.25±3.95	11.60±3.43	18.51±4.69
Stage 2	15.80±4.93	19.32±4.22	20.80±4.03	18.88±3.76	15.96±3.71	11.63±3.00	19.28±4.64
Stage 3	16.97±6.02	21.14±4.32	20.80±4.86	18.77±4.04	15.79±4.62	13.40±3.29	19.56±5.14
Stage 4	18.11±6.31	21.35±4.32	20.35±5.38	18.65±3.93	16.91±4.38	12.20±3.66	19.60±5.92
	F=5.212	F=6.450	F=0.904	F=1.916	F=2.492	F=6.730	F=0.715
	p++=0.002	p++=0.000	p=0.439	p=0.127	p=0.060	p++=0.000	p=0.054
The presence of mastectomy*							
Yes	16.67±5.61	20.50±4.33	20.85±4.89	18.93±4.06	16.31±4.26	12.38±3.39	19.60±5.21
No	15.42±5.40	19.22±4.43	20.96±4.50	19.21±3.82	16.26±3.90	11.78±3.21	18.60±4.47
	t=2.072	t=2.688	t=-0.209	t=-0.649	t=0.118	t=1.636	t=1.936
	p++=0.039	p++=0.008	p+=0.834	p+=0.517	p+=0.906	p+=0.103	p+=0.054
Family history of breast cancer*							
No	16.36±5.58	20.03±4.35	20.90±4.64	19.03±3.93	16.12±4.11	12.44±3.30	19.12±4.93
Yes	14.98±5.26	19.75±4.25	21.43±4.18	20.13±3.90	17.04±4.13	11.09±3.22	19.33±5.21
	t=1.806	t=0.467	t=-0.839	t=-2.038	t=-1.625	t=2.979	t=-0.316
	p+=0.072	p+=0.641	p+=0.402	p++=0.042	p+=0.105	p++=0.003	p+=0.752
Type of the surgery*							
Mastectomy	16.82±5.64	20.66±4.19	20.64±4.84	18.70±4.04	16.28±4.11	12.54±3.31	19.53±5.15
Breast-Conserving Surgery	15.77±5.99	20.90±4.28	22.00±5.04	19.03±3.86	15.59±4.70	11.07±3.75	19.68±4.94
	t=1.199	t=-0.369	t=-1.814	t=-0.543	t= 1.063	t=0.910	t= -0.187
	p=0.255	p=0.821	p=0.647	p=0.312	p=0.330	p=0.239	p=0.973
Age***	r=0.141	r=0.047	r=-0.146	r=-0.182	r=-0.107	r=0.129	r=0.069
	p++=0.006	p+=0.357	p++=0.004	p++=0.000	p++=0.036	p++=0.012	p+=0.179
Time of diagnosis***	r=0.092	r=0.110	r=0.074	r=-0.020	r=0.021	r=0.061	r=0.063
	p++=0.010	p+=0.065	p+=0.321	p+=0.667	p+=0.648	p+=0.715	p+=0.351

*t-test was performed

**ANOVA test was performed

***Pearson correlation was performed

The patients with mastectomy perceived longer illness and more severe consequences. Mastectomy generally causes reactions, which are also seen in other physical health problems, worries and problems about cancer and special problems related to the meaning of breast in terms of womanhood and sexuality (25). Moreover, in another study show that the breast meant femininity, beauty, and motherhood. Women used quite negative statements about their appearances after mastectomy and they perceived that half themselves was missing, as individuals and women. They preferred clothes that hid their lack of breast (14). Therefore, the nurse caring for an individual as they navigate the cancer diagnosis and treatment process is in an ideal situation to conduct an assessment of body image and sexuality concerns and to start an open dialogue regarding these topics. This rapport can make it easier for patients to feel comfortable discussing their concerns related to these sensitive topic areas with the nurse, and in turn, the nurse will be able to provide the patient with resources to help patients better understand and address these concerns after cancer treatment (29).

The illness perceptions of patients who have a family history of BC are different from those who do not have such a history. The treatment control of patients who have a family history of BC was found to be higher and their timeline (cyclical) perception was found to be low, compared with those without a family history of BC. Women with a family history of BC witness different consequences of the illness and experience the effect of BC at different levels. Women go through a wide range of experience, including positive effects coping better with the illness, or being influenced by positive role models who survive the cancer. Family history of breast cancer should, therefore, continue to be accounted for in future research in this area.

As age increases, the perception related to the concern that the illness will last for a longer time increase and the perception about the controllability of illness personally and with treatment decrease. Other studies show that the personal controls of young patients were higher (25, 30). Young patients with BC have more worries regarding how they cope with their concerns about sexual dysfunction, their children, fertilization and body image (25). Moreover, the unfulfilled needs of these patients may interfere with the relationship with their spouses, career, family life, marital harmony, and emotional well-being (31). These may also cause the beliefs of young patients about the controllability of illness to decrease.

The results of this study will help that health professionals evaluate the illness perceptions of patients with BC in Turkish culture. In addition, it will help health professionals provide care by taking the culture-based results into consideration. It is recommended that health professionals who work with patients with BC should organize education and counselling programs that will strengthen the coping with BC strategies of patients, especially who have low levels of education, who are younger, who had experienced mastectomy, and those who are at more advanced stages of illness. In addition, it is a striking result that patients' perceptions of personal control are high. Therefore, it is recommended to investigate the factors affecting the high personal control in other studies with larger studies.

Ethics Committee Approval: Ethics committee approval was received for this study from the Ethics Committee of Atatürk University School of Health Sciences (2014/8).

Informed Consent: Written informed consent was obtained from patients who participated in this study.

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