

RESEARCH COMMUNICATION

Relationships Between Psychosocial Adjustment and Hopelessness in Women with Breast Cancer

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Abstract

Objective: Several physical, psychological and social variables influence women with breast cancer. This study was designed to analyze the relationship between psychosocial adjustment and hopelessness in a group of such women in Turkey. **Method:** The subjects were 90 women with breast cancer recruited at Ege University School of Medicine Department of Radiation Oncology Nurse Counsellor Unit and Tülay Aktaş Oncology Hospital Outpatient Chemotherapy Unit. Data were collected using an Introductory Information Form and Psychosocial Adjustment to the Illness Scale - Self-Report (PAIS-SR) and the Beck Hopelessness Scale (BHS) and analyzed by Pearson Correlation Analysis. **Results:** The mean age of the women was 49.4 ± 11.0 . It was found that the level of psychosocial adjustment of 63.3% of the women was "poor". A positive relationship was determined between PAIS-SR mean score and BHS mean score of the women with breast cancer ($r = 0.731$, $p < 0.01$). **Conclusion:** It was observed that as the psychosocial adjustment worsens, as the level of hopelessness of the women increases. In the light of this relationship, it was concluded that the attempts to increase hope and therefore the support for the psychosocial adjustment of patients should play a vital role in increasing their quality of life.

Keywords: Breast cancer - psychosocial adjustment - hopelessness - Turkey

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Introduction

Breast cancer is the most common malignant cancer in women worldwide. The diagnosis and treatment of breast cancer is a time of stress and a thoroughly life-altering experience. Diagnosis of breast cancer in women may seriously affect their identity, perception, domestic and social life and simple daily routines. The sadness of the female patients with breast cancer mainly stems from the physical transformation that their body undergoes over the course of treatment, the reality of their physical appearance, the chronic nature of the illness and the losses to breast cancer they have previously experienced. Many studies emphasize that the psychological distress of female patients with breast cancer during and after treatment should be properly addressed. In fact, anxiety and emotional distress may cause the breast cancer to recur. Many women with breast cancer consider their diagnosis to be the most stressful experience they have ever gone through and state that they have had symptoms of post-traumatic stress disorder and have felt desperate, lonely and hopeless over the course of treatment after diagnosis (Palsson and Norberg, 1995; Lyons et al., 2002).

Although reactions to a breast cancer diagnosis vary from patient to patient, 30% of the female patients suffer from anxiety, extreme distress and depression over the course of a year following their diagnosis (Hordern, 2000). Studies have shown that the psychological impacts

of a breast cancer diagnosis include: anxiety, depression, denial, anger, concern for the future, lowered self-esteem and self-respect, hopelessness, desperation, fear of recurrence, suicidal thoughts, pain, sadness and fear of death (Spiegel, 1997; Ferrell et al., 1998a; Rustoen and Begnum, 2000). Despite these psychological problems, 70-80% of the female patients adjust to their new condition after dealing with the initial crisis (Rustoen and Begnum, 2000). The physical and emotional adjustment may differ from one particular treatment to another. Certain stages may also be more shattering and stressful compared to others (Hoskins and Haber, 2000).

Psychosocial adjustment to an illness is influenced by everything that has to do with the illness and its treatment. Psychosocial adjustment to an illness could affect the course of an illness positively or negatively (Adaylar, 1995; Spiegel, 1997). Patients suffering from feelings of desperation and hopelessness regard their diagnosis as a death penalty and think that there is nothing they could do. They downplay the positive signs of progress and adopt a strict "all-or-nothing" attitude in their all evaluations. Negative thinking causes stress, worry and sorrow in patients and makes them adopt a rather hopeless and pessimistic outlook on life and reality. It also undermines their ability to develop effective coping styles with their illness and to adjust to their treatment (Özkan, 1993). In his study, Levine (2005) observes a negative correlation between quality of life

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and maladaptive adjustment responses such as feelings of desperation, hopelessness and preoccupation with intrusive thoughts. Studies indicate that the degree of adjustment for patients with breast cancer is determined by a variety of factors that include level of self-respect, social stress, social support, psychological support, sense of control, emotional distress, stage of illness, type of surgical operation, symptoms concerning the illness and its treatment, degree of physical competence, patients' perceptions of their illness, patients' coping style with their condition and patients' relationship and cooperation with health professionals (Irvine et al., 1991; Spiegel, 1997).

Hope gives us the energy to live and helps us look to future (Kocaman, 2008). It is the best means of lessening the feelings of pessimism, powerlessness, desperation and hopelessness. It helps us better cope with our problems, set certain future goals for ourselves, and also get motivated to achieve them (Felder, 2004; Öz, 2004). Hope gives one strength to solve problems, cope with loss, sadness and illness and adjust oneself to illness (Rustoen et al., 1998; Kocaman, 2008).

Hopelessness is also one of the most frequent and important conditions described in medically ill patients (Dunn, 2005). Hopelessness has been associated with poor adjustment to illness (Grassi et al., 1993). Patients suffering from a feeling of hopelessness are reluctant to participate in their treatment; they lack motivation and receive health care passively. This issue is of utmost importance especially for chronic illnesses that require patients' active participation in treatment (Kocaman 2008). In a 10-year follow-up investigation of patients with breast cancer, hopelessness was shown to predict both recurrence of illness and reduced survival time (Watson et al., 2005).

Hope plays a major role in the adjustment of patients to their illness and treatment (Chen, 2003). Hope could help with reducing their feelings of uncertainty and benefit patients both physically and emotionally (Wonghongful et al., 2000; Felder, 2004). As Felder (2004) suggests, hope is an essential element of the lives of patients with cancer. In his study on patients diagnosed with cancer, Felder shows that hope helps patients better cope with their illnesses. Many other studies also indicate that hope may have a positive impact on the course of illness. According to Evangelista et al., (2003) patients with high levels of hope have a better prognosis and enjoy a higher quality of life. Similarly, Chen (2003) states that patients with high levels of hope live longer.

It is known that a variety of physical, psychological and social factors play a role in the adjustment of patients with breast cancer to their illness. This study was designed to analyze the relationship between the psychosocial adjustment and hopelessness in the women with breast cancer.

Materials and Methods

A cross-sectional survey design was used in this study. The study was designed to ascertain the levels of hope and psychosocial adjustment to illness in patients who visited the chemotherapy and radiotherapy units in the

hospital after having had a surgical operation. According to the hospital's policies and procedures, patients receive instructions in the hospital on how their home care should be delivered, and they begin chemotherapy and/or radiotherapy after about a month after their surgical wounds are healed.

A total of 90 female patients with breast cancer that had been receiving treatment in the chemotherapy and radiotherapy units of a university hospital participated in this study.

Collecting of data took 6 months. The sample group consisted of consenting patients whose communication skills were not impaired.

Three tools were employed to collect the data. "Introductory Information Form" includes questions about the patient's age, level of education, level of income, marital status; about their thoughts and feelings on the level of support they receive and about the illness itself. There are also some questions as to whether the patients have any of the symptoms they are likely to suffer from such as pain, lymphedema, lymphangitis. Beck Hopelessness Scale was employed to measure their level of hope. Psychosocial Adjustment to the Illness Scale-Self-Report was employed to ascertain their degree of adjustment to illness.

Beck Hopelessness Scale (BHS)

This scale was developed by Beck and colleagues (Beck et al., 1974). The validity and reliability of this scale in Turkey was assessed by Seber in 1991. The scale consists of 20 items, and the scoring range is from 0 to 20. High scores indicate higher levels of hopelessness. Patients are supposed to respond to the scale by themselves. The answers that coincide with the key are given 1 point and those that do not, 0 (Savaşır and Şahin, 1997). In this study, the Chronbach's Alpha coefficient for BHS was determined to be 0.87.

Psychosocial Adjustment to the Illness Scale - Self-Report (PAIS-SR)

This tool, which was developed by Derogatis and Lopez in 1983, is a multidimensional scale that aims to assess patients' psychosocial adjustment to their illnesses. PAIS-SR measures patients' interaction with people around them as well as with other elements that constitute their psychosocial environment. The scale consists of 46 items. These items are divided into 7 groups that represent different areas of psychosocial adjustment. These areas, which constitute the sub-scales of PAIS-SR, are as follows

1. Health Care Orientation (8 items)
2. Vocational Environment (6 items)
3. Domestic Environment (8 items)
4. Sexual Relationship (6 items)
5. Extended Family Relationships (5 items)
6. Social Environment (6 items)
7. Psychological Distress (7 items) (Derogatis, 1986).

For each question in this scale, there are four options, which are descriptive phrases that indicate different levels of adjustment. Participants are asked to choose the

answer that best describes their experience. By assigning each item a score from 0 to 3, participant responses are quantified. Every response indicating impairment in the patient's quality of life since diagnosis is assigned a score of 3, while an improvement or lack of change is assigned 0. In PAIS-SR scale, low scores indicate a "good psychosocial adjustment", whereas high scores indicate a "poor psychosocial adjustment". In PAIS-SR, scores below 35, between 35-51 and over 51 taken to indicate "good psychosocial adjustment," "fair psychosocial adjustment," and "poor psychosocial adjustment" respectively. It was Adaylar (1995) who translated this scale into Turkish and assessed the validity and reliability of it. In his study, the internal consistency of a sample comprising patients with an acute or chronic physical illness was determined to be 0.94, while for patients with chronic illness, it was 0.92 (Adaylar 1995). For our sample of female patients with breast cancer, the Cronbach's Alpha coefficient of PAIS-SR was determined to be 0.93.

Data were analyzed using the SPSS 11.5 software package. Distribution and frequency analyses were used to evaluate the samples. Student's t-test was used to examine differences. Correlation analysis was performed with Pearson's r coefficient test.

Results

The mean age of the women was 49.35 ± 10.99 . Of all participants, 42% were high school graduates, 55% were unemployed, 75% were married and 82% had at least a child. 71% of the patients were going through menopause, and 65% of them earned a monthly income just enough to cover their monthly expenses. All patients had a companion taking care of them.

The mean duration of illness among the participants was 6.21 ± 1.89 months (range=3-9 months). Of all participants, 80% had a total mastectomy, while 20% had a partial one. The percentages of the patients that were receiving chemotherapy and radiotherapy were 48.9 and 51.1 respectively.

The thoughts and feelings of the patients about breast cancer are shown below in Table 1. 93.3% of the participating patients shared the opinion that "No one can go against God's will but I agree to whatever is necessary to cure my illness", while 80% chose "I am worried about future", 72% "I believe I will have to undergo pain, sorrow and distress over the course of my treatment", 55% "I'm sad" and "I have complicated feelings", 43.3% "I feel desperate", 30% "I am scared" (Table 1).

It was found that for only 13.3% of the women the level of psychosocial adjustment was "good", while for 23.3% and 63.3%, it was "fair" and "poor" respectively. The mean hopelessness score for the participants was 9.77 ± 4.59 .

There was no meaningful correlation between the mean age of the participants and their hopelessness score ($r = -0.089$, $p = 0.404$). A meaningful negative correlation was observed between the age of the participants and the total PAIS-SR score ($r = -0.228$, $p = 0.030$).

A meaningful positive correlation was identified between the duration of illness and the hopelessness score

Table 1. The Thoughts and Feelings of the Patients about Breast Cancer

Thoughts and feelings (n=90)	n*	%
I'm scared	27	30.0
I'm sad	50	55.5
I'm worried about future	72	80.0
I'm angry	10	11.1
I have complicated feelings	50	55.5
I feel desperate	39	43.3
I believe I will have to undergo pain, sorrow and distress over the course of my treatment	65	72.2
No one can go against God's will but I agree to whatever is necessary to cure my illness	84	93.3

*Participants were allowed to choose more than one answer.

Table 2. The Relationship between the PAIS-SR and BHS Scores of the Patients (n=90)

PAIS-SR - BHS	r	p
Health Care Orientation	0.31	0.002
Vocational Environment	0.32	0.002
Domestic Environment	0.49	0.000
Sexual Relationships	0.29	0.005
Extended Family Relationships	0.57	0.000
Social Environment	0.57	0.000
Psychological Distress	0.49	0.000
PAIS-SR (Total)	0.73	0.000

($r = 0.331$, $p = 0.001$) as well as between the duration of illness and the total PAIS-SR score ($r = 0.261$, $p = 0.013$).

When the PAIS-SR scores of the patients were examined in relation to the type of the surgical operation that has been performed on them, it was only patients who had a total mastectomy that had a meaningfully higher score in the category of sexual relationship ($t = 2.469$, $p = 0.015$). When the PAIS-SR scores were examined in relation to the type of treatment, the only meaningful difference in score was observed in the category of social environment. Similarly, the patients who were receiving radiotherapy was determined to have meaningfully higher scores in the category of social environment ($t = 2.254$, $p = 0.027$). Neither the type of surgical operation nor the type of treatment had a meaningful impact on the hopelessness scores ($p > 0.05$).

When the relationship between the PAIS-SR subscale scores and the hopelessness scores were studied, a fairly positive correlation was observed between the hopelessness scores and the scores in each category of the BHS, i.e., health care orientation, vocational environment, domestic environment, sexual relationships, extended family relationships, social environment and psychological distress (Table 2).

Discussion

Reactions and behaviors of patients are fundamentally determined by their perception and interpretation of their illnesses. All women that participated in our study knew that they were on the earlier stages of breast cancer on the basis of the results of their surgical pathological examination. Most patients held the opinion that "No one can go against God's will but I agree to whatever is necessary to cure my illness". In the light of this statement,

it could be concluded that most patients conceive their illness on religious grounds and from a fatalistic perspective. However, this statement also demonstrates that the participants have confidence in the science of medicine. Drawing on the interviews they conducted with women with breast cancer ("I prayed to God, and broke down, and asked him to carry me through this because I couldn't do it on my own."), Lyon et al. also conclude that spiritual awareness and hope go hand in hand in most women with breast cancer (Lyons et al., 2002).

The most common concerns of women with breast cancer resemble the general concerns of all patients with breast cancer: fear of recurrence, fear of death and will to live (Ferrell et al., 1998a; Rustoen et al., 1998; Wang et al., 1999; Landmark and Wahl, 2002; Figueiredo et al., 2004). The women that participated in our study was also found to be worried about their future. Especially during the periods when they received chemotherapy, these women felt sad and desperate, believing that they would have to undergo pain, sorrow and distress. In their study, Lyons et al., (2002) interview many women on their experiences of breast cancer. Among them, a Christian women states that "After chemotherapy, I cried for days for what I had been going through". She also suggests that although the distress she had to go through due to chemotherapy has impaired her strength in coping with her illness, she was able to feel stronger and cope with her illness better when all her family prayed for her. Similarly, the Muslim Turkish women that participated in our study expressed their anxiety about the future of the course of their disease and the scary uncertainty of chemotherapeutic and radiotherapeutic treatments. This uncertainty was also seen to bring about expectations of pain and sorrow. These women also suggested that their observations of their social environment as well as everything they see on TV and read in books confirmed them in their expectations. This feeling of confirmation may have a negative effect on these patients' level of hope and their adjustment to illness.

It should be noted that in Turkey gender roles for men and women are strictly defined. It could be maintained that gender role expectations of women in Turkey are stronger compared to their western counterparts. Keeping house clean and taking care of her husband and children are considered to be a woman's natural duties in the traditional Turkish culture. Women are supposed to organize the essentials of life and familial bonds in the household (Öner and İmamoğlu, 2000). A woman's illness interrupts the daily routine in her household and thus requires reassignment of certain roles and responsibilities. All these changes in family life may explain the anxieties many women suffer from after diagnosis. It should be noted that Turkish family culture also embraces such values as supporting the ill, keeping their company throughout the course of their treatment, helping their family with house chores and taking care of their children (Fadıloğlu et al., 2006). Most women in our study had a relative keeping their company and taking care of them. Having the social and psychological support of their mother, father, spouse, siblings, children as well as of friends especially for those who live by themselves may have helped the patients better

adjust to their illness and boosted their levels of hope.

As a new and uncertain condition, cancer diagnosis may have a shattering impact on those who have been just diagnosed and leave them hopeless (Rustoen et al., 1998). Both negative and positive attitudes towards cancer may drastically alter a patient's quality of life. There is a positive relationship between a patient's status of health and his or her emotional coping style. In women with breast cancer, coping style, level of social support and level of spiritual and religious commitments affect adjustment to illness (Lyons et al., 2002). The patients in our study were determined to have higher levels of hopelessness than what was found in some of the earlier studies (Solak and Başer, 2003; Tan and Karabulutlu, 2005).

Three factors could have a positive effect on the adjustment of the patients in this study to their illness: none of them were metastatic, they were receiving social support, and they engaged in religious practices that provided them with spiritual strength. In spite of all these factors, the level of psychosocial adjustment of most patients was determined to be poor. In their study on patients diagnosed with breast cancer, however, Butler et al. have found that the psychosocial adjustment of 72.4% of the patients in their study were "good", 28.4% were fair and 5.8% were poor.

In our study, a negative correlation was observed between the duration of illness and the level of hopelessness. This may have to do with the fact that the treatment of breast cancer takes a lot of time and energy and has a wide range of side effects. Moreover, the progress made over the course of treatment may not be perceived favorably by the patient due to the chronic nature of the illness. However, there are certain studies on patients with cancer in which no meaningful relationship was identified between the duration of illness and the level of hopelessness (Vellone et al., 2006; Aslan et al., 2007). The patients in our study suggested that they suffered from swelling after leaving the hospital and thus had to keep their arms on a higher level while lying down. They also stated that they have avoided straining the arm that was most affected by surgery and were mostly doing the recommended arm and shoulder exercises. These data indicate that the instructions given to the patients in the hospital play an important role in patients' adjustment to their new lives. However, despite the improved adjustment to physiological condition that longer disease durations may bring about, it was found that both psychosocial adjustment and the levels of hope deteriorate as the duration of illness gets longer.

Several studies suggest that women in the older age group regard breast cancer as less threatening for their future lives (Wyatt et al., 1993; Ferrel et al., 1998b). Similarly, the results of our study indicate that psychosocial adjustment gets better as the age of the patients increases. It could be maintained that fewer responsibilities concerning children and family life, accomplished life goals and fewer expectations of life underlie the finding in question.

It was also found that the psychosocial adjustment gets worse as the duration of illness increases. However, there

are some studies in the literature suggesting a positive relationship between the duration of illness and the adjustment to it (Özkan and Turgay, 1992; Keller, 1998).

Even though different surgical methods bring about different results, all surgical operations cause a number of physical and psychosocial problems. Among these physical problems are pain, infection, disturbed tissue perfusion and lymphedema. Psychosocial problems include emotional hardships of having a stressful life, fear of recurrence, depression, body-image distortion, and sexual dysfunction (Budin, 2005). The results of this study suggest that women who had a total mastectomy have increased adjustment problems in sexual relationships. Avis et al. also suggest that women who had a total mastectomy have more body-image related issues than women who have undergone protective surgery. The sense of bodily deficiency that follows total mastectomy dramatically affects a patient's relationship with her husband. Several studies also show that mastectomy has an adverse impact on the sexual lives of patients (Aygin and Aslan 2005; Budin 2005; Fobair et al., 2006).

The results of our study suggest that women who were receiving radiotherapy have a poorer adjustment to their social environment compared to women who were receiving chemotherapy. This may have to do with the fact that having to visit the hospital frequently keeps the patients receiving radiotherapy away from their social environment. Patients receiving chemotherapy, on the other hand, come to hospital once in every three weeks.

The results of our study also indicate that as the level of hopelessness of the patients with breast cancer rises up, their adjustment to health care orientation, vocational environment, domestic environment, sexual relationships, extended family relationships and social environments worsens and their level of psychological distress increases. These results demonstrate that hope plays an important role in patients' psychosocial adjustment to breast cancer.

In conclusion, the presence of hope could improve the psychosocial adjustment of the women with breast cancer. Education and counseling of the patients as well as adopting psychotherapeutic approaches could also prove effective in boosting the levels of hope and psychosocial adjustment. Nurses may assume greater responsibilities as educators, counselors and coordinators to improve the levels of hope and psychosocial adjustment. Nurses should keep track of and evaluate the psychological and social condition of the patients after the surgery as they undergo different types of treatments like chemotherapy and radiotherapy. They should also give patients helpful instructions and motivate them to adopt behaviors and attitudes that are more conducive to better adjustment. In addition, they should organize psychological support groups in which patients could freely express themselves.

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