

## Psychological Reactions among Women with Breast Cancer after Mastectomy: A Qualitative Study

Asmaa Hafez Afefe Barakat<sup>1</sup>, Amal Elias Abdel-Aziz<sup>2</sup> Hanan Abd El Rahman Mostafa Kandeel<sup>3</sup>

<sup>1</sup>Lecturer of Psychiatric/Mental Health Nursing Department, Faculty of Nursing/Ain Shams University University, Egypt

<sup>2</sup>Lecturer of Psychiatric/Mental Health Nursing Department Faculty of Nursing/Ain Shams University University, Egypt

<sup>3</sup>Lecturer of Maternity & Gynecologic Nursing Department, Faculty of Nursing/Alexandria University University, Egypt

Corresponding Author Asmaa Hafez Afefe Barakat

**Abstract:** Following the diagnosis of breast cancer and after a mastectomy, many women experience serious psychological reactions. These reactions can adversely affect their treatment outcomes and cancer prognosis. This study is aimed at exploring psychological reactions of women with mastectomies at both stages of cancer diagnosis and mastectomy surgery. This qualitative study was applied to a sample of seventeen women with breast cancer diagnosis and after bilateral mastectomy surgery who received cancer treatment (chemotherapy) at the Radiation Oncology & Nuclear Medicine Center which is affiliated with the Ain Shams University Hospitals. Results of this study revealed that there are seven psychological reactions among subjects: 1. denial reactions after identification of having breast cancer and mastectomy surgery, 2. fear of unknown, cancer recurrence and death, 3. disturbed body image, 4. low self-esteem and a feeling of inferiority, 5. lack of partners' emotional involvement and relationship, 6. avoidance of social activity and lack of interaction (however, support of parents, siblings and children are reported by subjects), 7. praying and religious activities for hope and obtaining support from God were reported in this study. Conclusion: Breast cancer and mastectomy surgery have negative psychological outcomes among women since the breast represents not only a significant physical part of women but also the ideal body image and feelings of femininity, attractiveness and self-identity. Recommendation: Patient medical and psychosocial support and counseling should be implemented by health team members before and after mastectomy surgery until the completion of cancer treatment.

**Keywords:** breast cancer, mastectomy, psychological reactions

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### I. Introduction

Worldwide, breast cancer is rapidly increasing and places in the highest rank after lung cancer. As well, it has become the most prevalent cause of cancer death among female patients with an incidence rate of 12.5% (Fouladi, Pourfarzi, Ali-Mohammadi, Masumi & Agamohammadi, 2013). It is the most prevalent cancer diagnosis among women in many developing countries. In Egypt, breast cancer represents 38.8% of total female cancer cases and its incidence also increases with age (Ibrahim, Khaled, Mikhail, Barak & Gamal, 2014). According to the results of the National Cancer Registry in Egypt, in a retrospective cross-sectional epidemiological study in 2015: breast cancer incidence increases among females and comes first (36.4%) followed by lymph node cancer (6.5%), blood (5.3%), colorectal (4.4%), and ovarian cancer (4.3%) (Elsheikh et al., 2015). However, breast cancer among young women is considered more aggressive and associated with a poor prognosis (Farouk, Abd El Hamid & AbdElNaby 2016). Also, the Egyptian women seek medical treatment very late because of a lack of awareness and illiteracy as well as a presence of psychological denial to face the reality as cancer is synonymous to death. Therefore, more than 60-80% of breast cancers are admitted for clinical treatment at an advanced stage (Ismail et al. 2013).

A diagnosis of cancer can cause serious psychological problems due to many factors such as uncertainty in treatment, physical symptoms, fear of recurrence and death, and changes in the woman's personality, body image and sexual life. Difficulties in daily activities, family problems and lack of support are also serious factors that affect psychological aspects (Keskin & Gumus, 2011; Fox et al. 2013 and Ismail et al. 2013). In Arab countries, women with breast cancer are facing two major threats. First is the woman's life

since breast cancer is the second most common cause of cancer death among women. Second is the woman's psychological image as a competent woman, particularly regarding sexuality, femininity, body image, and maternal issues. This image can be significantly altered after surgical excision of this commonly accepted cultural symbol of femininity (El-Hadidy et al. 2012).

Mastectomy is a frequently performed surgical procedure but is emotionally stressful among women. It affects a woman's identity, her perception of herself as a woman, her femininity, and her self-confidence which are all closely bound to her body-image (Farooqi, 2005). A woman undergoing mastectomy has to deal with the loss of a body part, which is important to her femininity and sexuality. After mastectomy and the treatment process, a woman's body image and concerns related to her situation can negatively affect both her physical and emotional health. The woman's preoccupation about body image, family life, the recurrence or metastasis, and partners' attitudes can dominate her daily life (Fox et al., 2013 and Koçan & Gürsoy, 2016).

#### **SIGNIFICANCE OF THE STUDY**

Women's health status is important for the health of their children, family, and community, in addition to the traditional roles of women as wives, mothers and primary caregivers to their families. Women with breast cancer have to deal not only with the trauma of disfigurement but also with the fear of rejection from their partners and loss of femininity. Breast cancer treatment changes body reality and affects body presentation. Thus, this study on women's mental health as regards their psychological reactions to breast cancer and mastectomies can help to provide better understanding about women's psychological aspects as well as developing effective strategies to improve women's physical and mental health (Denewer, Farouk, Mostafa & Elshamy 2011; Koçan & Gürsoy, 2016 and Sherman, Woon, French & Elder, 2017).

**This study is aimed** at exploring psychological reactions of women with mastectomies at both stages of cancer diagnosis and mastectomy surgery and how they express their subjective feelings toward this event in order to help healthcare members, especially nurses, in developing ways of counselling and supporting patients medically and psychologically before and after a mastectomy as well as until the completion of cancer treatment. To achieve this aim, the following question was developed:

What are the psychological reactions perceived by women as a result of breast cancer diagnoses and after a mastectomy?

## **II. Subjects & Methods**

- 1. Study design:** a qualitative, explorative study design. Since the quantitative methodology cannot provide answers regarding how and why questions, as well as understanding the motives behind personal behaviors.
- 2. Sample and setting:** The study was conducted of 17 Egyptian women (12 from rural and 7 from urban areas) with the primary diagnosis of breast cancer and aged from 31-52 years old who had bilateral mastectomy surgery performed and received cancer treatment (chemotherapy) in Radiation Oncology & Nuclear Medicine Center which is affiliated with Ain Shams University Hospitals. Subjects who had other chronic medical conditions or were taking anti-psychiatric drugs were excluded from the study.
- 3. Study tools:** A semi-structured questionnaire with open-ended questions was developed by the researcher based on the review of the literature. These general questions helped the researcher to initiate and maintain the flow of conversation during the interview. The open-ended questions include the following: The process of discovering the lump, the length of time to go to the physician, the woman and family reactions to breast cancer recognition, the decision and process of mastectomy surgery and treatment after mastectomy, the woman's feelings toward a new body figure, family, husband and pain, and the woman's fears.
- 4. Data collection phase:** the data was collected from January 2014 until March 2015. During this phase, every participant was interviewed individually before the time of therapy because after therapy the participant tended to be tired and unable to speak and stay. Participants were interviewed from one to three sessions depending on the participant approval and the number of treatment sessions. The first time of meetings was restricted among participants; women were afraid of being criticized and judged. They could not express themselves openly and unrestrictedly and make sincere verbalization. Therefore, the researcher made much effort to establish a mutual trust relationship and rapport with each participant to feel more comfortable and less stressed by using therapeutic communication techniques; respect, active listening, reflection, and empathy. Some of the communication techniques provided were to understand and obtain more precise information such as restating and clarifying requests (e.g., could you please explain more, please give me an example, I understand from you that...). To obtain details, depth of information, and expression of participant's feelings, the researchers tried to maintain interviews as open as possible so they could avoid directing the participant according to the researchers' track. Each interview was recorded immediately after each session. Accordingly, analysis of each interview was completed before the next one.
- 5. Ethical considerations:** The authorities of the mentioned settings agreed on the study protocol. The participants were informed of the purpose and the method of the study. As well, they were given the full

decision to continue or withdraw so that oral consent was obtained. The participants were assured that all information and their identities would be kept private, therefore, each of them were given a code for this reason.

**6. Data analysis:** The data analysis was based on a grounded theory developed by Corbin and Strauss, 1990 which was divided into the two following phases:

6.1 The first phase was open coding. It is the process of breaking down data into pieces for examining, comparing, conceptualizing and categorizing it into concepts (Corbin & Strauss, 2008). During this phase: each main sentence is a labeled section (coded) of data that a researcher identifies as significant for representing. Some statements irrelevant to the study aim are excluded. After that, the researcher is allowed to group similar sentences to better understand the data and categorize them into main sentences or main concepts to reduce its number and facilitate relating them under the main psychological concepts.

6.2 The second phase (Axial coding), the classified psychological concepts based on the analyzed data were revised and refined (Corbin & Strauss, 2008). Forty six codes were put under the six major themes. The data analysis was also reviewed by three experts in psychiatric/mental health nursing and two experts from Maternity and Gynaecological nursing before and after translation into English, and the necessary modifications were done. One of the psychiatric/ mental health experts recommended adding the women's statements regarding religious activity and spirituality as one descriptive category and part of the women's psychological reactions. Thus religion and spirituality became the seventh major theme.

Based on the data analysis and experts revision, there are seven major themes that were reported by the subjects: 1. denial reactions after identification of having breast cancer and mastectomy surgery, 2. fear of the unknown, cancer recurrence and death, 3. negative body image, 4. low self-esteem and a feeling of inferiority, 5. lack of partners' emotional involvement and relationship, 6. social activity and support, and 7. religion and spirituality.

**Grounded theory** is a specific qualitative methodology. This is a process in which the researcher derives and develops concepts from the data. This methodology helps the researcher to step back and critically analyze the situations, think abstractly and consider the alternative meanings of phenomena. Activities or events in the raw data are given a conceptual label, called a code. The data analysis process becomes progressively more numerous and more abstract (Corbin & Strauss, 1990; Packer-Muti, 2009). There are two stages of qualitative data analysis: The first stage is open coding which is the process of breaking down, examining and comparing, conceptualizing and categorizing data. The second stage is the axial coding whereupon the process reassembles data fractured during open coding by relating the categorizing data to its subcategories to form a more precise and complete explanation of the phenomena (Corbin & Strauss, 2008; Lawrence & Tar, 2013 and Karen et al., 2015).

### **III. Results & Discussion**

The data of this study comes from a sample of 17 women after bilateral mastectomy surgery and who received chemotherapy and radiotherapy. All of them were married and aged from 31 to 52 with low socioeconomic status. Regarding residence, 11 subjects came from urban areas and the remaining from rural areas. As regards the level of education, 7 women were illiterate, 4 of them read and write, and the remaining had middle education. Only 3 subjects were employed and the others were housewives. Regarding income, most were unsatisfied with income. According to the results analysis, there are seven psychological reactions reported by the subjects as follows:

#### **1. Denial reactions after identification of having breast cancer and performing mastectomy surgery:**

Women with breast cancer introduce several psychological reactions as the first reaction when they are informed they need to have a mastectomy. Those various reactions express the result of a shock stage among women (Fouladi, et al 2013). In the current study, about two-thirds of the subjects (11 of them) reported that they experienced shock and denial as initial reactions to breast cancer and mastectomy. There are several statements that represent the women's emotional and behavioral reactions after being informed that they have breast cancer: "I thought that the gynecological doctor does not have good experience to diagnose my case, I have to go to another doctor; I went to many doctors who said the same, I am shocked; I believed that there is a mistake in the lab results; I have to go to another lab to repeat the test again; At first, I feel that I am in a dream but after that, I return back to home and I was crying; I saw changes in my nipples and lump and believed that it is an abscess and everything will be Ok; I cannot understand what happened to me, after returning to my home I cried". Two of the subjects mentioned that they were shocked because their family did not inform them about breast cancer and surgery; one of them stated that "my husband told the doctor not to inform me now, I knew one day before surgery. Another studied woman stated that "my family explained that the doctor said that the surgery is removing the tumor and I was shocked when I knew at the time of surgery my breast will be removed.

Preoccupation with caring for the family after their life ends, was another reaction after cancer diagnosis among eight of the subjects. There were the following statements: "I am thinking about my children, who will care for them when I die; I am afraid that my husband will marry and my kids will suffer after me."

It can be observed from the women's information in the current study that many of the subjects have denial and avoidance to face the reality of having breast cancer. This analysis is supported by **Shrestha in 2012** who asserted that certain factors can affect the women's shock reactions to mastectomy such as family and social support, impact of surgery on women, her family in the future and the way a physician communicates & supports. Another analysis is that low education and socioeconomic levels can aggravate shock and avoidance reactions among women with breast cancer by intensifying or modifying the reality. This analysis is agreed by **Campas & Luecken in 2002** who reported that less formal education leads to poor psychological adjustment to breast cancer by avoiding emotions, thoughts, or information related to the disease.

## **2. Fear of unknown, recurrence and death:**

All of the subjects of the current study reported fear of cancer relapse and metastasis and uncertainty about the future of cancer as well as the impact of long-term cancer therapy. These worries can be noticed in the women's statements as follows: "I am afraid of death; All of the people I knew died of cancer; It is just a time and death is coming; Doctors do not tell me if I am ok or not, if there are alternatives rather than chemotherapy or not." This result is consistent with **Shrestha in 2012** who mentioned that fear of recurrence and the unknown future are common among women after mastectomy. Those above statements can reflect that women have a feeling of hopelessness regarding recovery from cancer and have anxiety about a lack of trust in the medical system.

Another possible explanation is that subjects have low education and cannot understand the treatment regime which provokes anxiety and uncertainty about their future. Also, the physicians did not involve the patient in the treatment process. This explanation is agreed by **El-Hadidy et al., 2012** who found that some physicians refuse to allow patients to share in clinical decisions and keep the patients in passive roles.

## **3. Negative body image:**

The breast is an important part of the female body which is a source of femininity, sexual attractiveness, and feelings of being worthy and confident. A mastectomy can break the woman's self-image of worthiness and provoke a feeling of nonbeauty and unattractiveness (**Shoma et al 2009; Przedziecki et al., 2013 and Ominyi& Nwodom, 2014**). In the present study, there are reported statements among subjects such as follows: "I try to accept my body, but I cannot; I cannot look in the mirror until now; Sometimes I feel a stranger from my body (depersonalization) especially after the loss of my hair, eyelashes, and eyebrows; I avoid any social gathering to expose my body especially in front of my mother-in-law and sister-in-laws.

It can be observed from the women's statements that the loss of breast as a part of body image can adversely affect the whole woman's personality and produce negative thoughts and depression. There are such statements which convey depressive feelings among the subjects: "I am not worthy anymore; I do not have the confidence to face my family and friends with a naked chest; I am not good for anything; I am crying when I look at the mirror." The current results are consistent with **Arroyo & López in 2011, and Toum, Ibrahim, Zaki, Khair in 2014** who discussed the women's psychological problems derived from a mastectomy and suggested that feelings of depression among women leads to low self-esteem as a result of a feeling of self-rejection, and feelings of stigma and shyness.

Concerning disturbance of body image among subjects, the current study showed that the process of cancer treatment may lead to skin discoloration, hair loss, loss of eyebrows and eyelashes, and also arm swelling caused by lymph edema, all of which provoke a fractured body image. This analysis can be evidenced by the following women's stories: "*I always cover my head because of hair loss in front of my husband and relatives.*" About half of the subjects in the present study experienced loss of self-identity (depersonalization). Women after mastectomies cannot recognize themselves as well as becoming increasingly unfamiliar. This can be because losing a part of a women's body is equivalent to losing a part of femininity. Correspondingly, **Arroyo & Lopez in 2011; Grogan, S. & Mehan, 2017 and Sherman et al. 2017** highlighted that most of the interviewed women understand that the removal of the breast is an attack on their femininity.

## **4. Low self-esteem and a feeling of inferiority:**

The current study revealed that feelings of inferiority and low self-esteem were common among two-thirds of the subjects (especially the younger women). They declared that they are less of a women and that they are not like the other women. They reported a feeling of being not worthy. One of the subjects stated that "when I am with my relatives, I feel shy and less than them." Three of them mentioned the same idea and said that "I am not a female in front of husband's eye." Two of them stated that "I maintain silence when I am with my mother and sisters-in-law because I have nothing to talk about it." These results are agreed with **Arroyo &**

**L'opez in 2011 and Kyprianou et al. in 2014** who suggested that most of the women after mastectomy reported a feeling of low self-esteem and inferiority.

##### **5. Lack of partners' emotional involvement and relationship:**

A sexual relationship is an important issue that enhances individual physical and psychological development, and increases intimacy among spouses (**Nweze & Maureen, 2014**). Sexuality is always affected by the individual's perception of his/her appearance, sexual interests and reactions, and relationship. The disease process and its treatment regime have adversely impacted on the sexuality functions and spouse intimacy (**Fouladi et al., 2013 and Fallbjörk, Rasmussen, Karlsson & Salander, 2013**). In the current study, the researchers tried indirectly to ask the subjects about perception of their husband's reaction to their cancer experiences to initiate the matter of psychosexual adjustment. Some aspects are discussed and reported by the women such as husband emotional caring and involvement, expressing of affection, husband perceiving the woman as a female attraction, husband negative reactions to scare, husband initiation of intimate relations, and the impact of husband 's positive or negative reactions to women's emotions and marital satisfaction. Some aspects of husband's satisfaction, initiation of sex, and sexual activity are difficult to be explored because of the Arab culture, norms and Islamic values that do not permit the woman to speak about these areas. Two of the subjects mentioned that "sex itself is not important for me rather than my impression about my husband's reaction", and her sexual interest as being sexually attractive in front of her husband's eyes. These women's reports are supported by **Wimberly, Carver, Laurenceau, Harris & Antoni in 2005**, who mentioned that most of the concerns among women who have experienced disfigurements of their breast, perceived sexual satisfaction in the form of women's femininity and sexual attractiveness for their partners. One of the subjects in the current study stated that "I saw my husband's face expression that conveyed rejection because of my empty chest." Seven women reported that "my husband cannot see their bodies and they cannot satisfy them as females."

As regards to sexual relationship and marital intimacy among subjects in the current study, there are other statements among them conveyed anxieties and fears of marital discord and broken relationship: "I am afraid that my husband will marry, he is still young, and I became less female; My husband tries to produce intimate feelings and overprotection, but I am sure for a short period". Seven of the subjects in the current study also reported sexual avoidance behaviors as evidenced by the following statements: "I avoid sexual relation because of my appearance; I did not feel comfortable to share my husband's bed; I am not interested at all, I am occupied with my disease process and surviving."

##### **6. Social activity and support:**

One of the other categories obtained in the current study was the social interaction among the subjects. Most of the subjects reported that they are more sensitive with people around them especially husband, husband 's family and friends. This sensitivity is so much so that any reactions, either comments or gestures, from surrounding people can irritate their emotional reactions and social involvements. These are some of the following statements that have arisen from the women in the current study: "I prefer to be alone; I avoid any visits from neighbors and friends; I feel irritable and anxious in front of others; I do not like anyone talking about my surgery and treatment." This analysis is supported by **Arroyo & Lopez in 2011** who found that the women with mastectomies experienced non-delusional self-references as their affected breast were observed by others.

Concerning social interaction in the current study, more than half of the women found social support from their families. The following women's statements can convey family support: "I feel comfort when I talk with my sister and mother; My sister regularly comes to help me in the households duties and takes care of my kids at the time of receiving cancer treatment; I cannot go anywhere without my sister; My oldest daughter takes care of her siblings."

According to the subject's statements in the current study, all women suffered with different degrees of lack of social involvement. As well, they feel upset with people asking about their physical state. Three of the women kept the disease secret from their friends and neighbors. The subjects have a lack of seeking social contacts and involvements with others rather than family. These results are in agreement with **Arroyo & Lopez in 2011** who mentioned that the women with mastectomies always feel irritability with people's curiosity about their physical conditions and especially if they look constantly at the surgical site. Women experience fear of rejection which leads them to not seeking social contacts. Another study also supported the current study and asserted that the mastectomy patient's role in social and interpersonal situations may be altered in various ways after surgery. Many women stayed isolated and hesitated to attend any social function until one or two years after the mastectomy due to loss of hair, nausea, vomiting, and tiredness from chemotherapy and changes in skin color (**Shrestha 2012**).

In the current study, two women reported some ideas of references that they are being observed by others. The following statements are evidenced by them: "When I go out, I feel that I am observed; Sometimes feel that my relatives look at my chest constantly." It can be observed from the subjects' statements that women are alert and over sensitive to the behaviors of others. This sensitivity and false interpretation of people's reactions lead them to be socially inactive. This result is congruent with **Arroyo & Lopez in 2011** who recorded nondelusional references among women with mastectomy as being observed by people.

In addition to the women's sensitivity, maladjustment in marriage is another factor that can be noted especially among women who live in rural areas. Some of the women reported that their husbands spend most of the time outside the home and there little chance for family interaction. This analysis is in agreement with **El-Hadidy et al. in 2012** who proved that husband especially in rural areas is not overly worried about his woman's fate and shows little emotional support to the health of his wife. He asked his wife to seek her treatment in her parents' home and not return until she has cured. This study also mentioned, there is culturally accepted practice in many subjects under study that a family usually accompanies a female patient in the cancer clinic.

#### **7. Religion and spirituality:**

Religious beliefs and activities are the common methods used by women with breast cancer to face the stress of disease and life events. They need to be connected with God for help and support, as well as they feel less alone (**Gall & Cornblat, 2002**). It is apparent from this study that most of the subjects (14 in number) reported that religious activities are the most comforting source in dealing with the cancer experience. Also, they perceived breast cancer suffering with a positive prospective. There are such mentioned statements that are reported from the subjects: "I always talk with my God, God is the only one supporting me and relieving my stress; When I feel that everything is blue, I remember my God who is the one supporting me; I am not asking God for healing, I am praying to tolerate pain and difficulties; I believe that everything is in the palm of Allah's hand and Allah will compensate my distress in heaven; I put my life and death on my God's hand; I have a persistent feeling that God is with me especially at the time of pain and discomfort; I believed that suffering is a way to clean our mistakes and it causes us to remember our dependence on God; Suffering is a test from God for life in paradise; God reminds us that life is not worth compared to the heaven; I feel comfort when my family prays for me."

In the present study, the religious and spiritual belief in God presented as a most positive outcome among women with mastectomies. The close connection with God has many functions for those women such as support, encouragement, feeling of inner peace and faith, and relief of pain and distress resulting from the cancer process. As well, they have positive meaning and perception towards life's fate. In particular, many researches have mentioned the importance of faith, and God support such as **Gall & Cornblat, 2002, Thune-Boyle, Stygall, Keshtgar & Newman, 2006 and Fouldi et al., 2013**. They asserted that a positive relationship with God helped the women with breast cancer create and maintain a more optimistic and hopeful attitude in the battle against cancer. The women seek guidance from God regarding specific decisions to be made and on specific religious beliefs. They also experienced enjoyment in the context of this relationship. In this way, the current study concluded that religious activities and spirituality help the women to make intolerable life events to be more tolerable.

On the other hand, the present study also showed that three of the subjects had feelings of helplessness and hopelessness. One of them mentioned that, "I asked God to terminate my life because of pain and discomfort from the chemotherapy." One of these women said, "I do not want my family to suffer anymore because of me, they will be better without me." The other one said, "I did not make mistakes in my life to have cancer, I prayed many times but God did not answer me." Furthermore, **Gall & Cornblat, in 2002**, supported the current study and mentioned that only two women had negative spirituality and feelings of despair, which resulted in feelings of disappointment that God did not answer them to heal their cancer.

#### **IV. Conclusion**

This study contributed information for women in the early stage of mastectomy. Women with a mastectomy suffered from psychological pains as a result of physical changes (disturbed body image) and the cancer process. There are seven psychological reactions reported by the subjects during their cancer experiences and mastectomy. They include: 1-denial reactions after identification of having breast cancer and performing mastectomy surgery, 2-fear of unknown, recurrence and death, 3-disturbed body image, 4-low self-esteem and feelings of inferiority, 5-lack of partners' emotional involvement and relationship, 6-avoidance of social activity and lack of interaction, 7-praying and religious activities for hope and obtaining support from God.

#### **V. Limitations Of The Study**

There are some limitations in the present study as follows: First, the participant was under the chemotherapy treatment protocol, so that she was too sick and debilitated to tolerate the length of the session so sometimes it was difficult to obtain the full information. The second, some aspects related to partner relationships were difficult to be discussed by some of the subjects. Those women have a belief that these sensitive issues related to sexual complaints and needs are religiously forbidden to be discussed or explored.

## VI. Recommendations

1. Patient medical and psychosocial support and counseling should be implemented by health professionals before and after a mastectomy until the completion of cancer treatment to discover the effective coping mechanisms with new healthy quality of life.
2. Women should be fully informed about their cancer and treatment regime as well as the short and long-term plan of cancer treatment.
3. Breast reconstruction surgery, if possible, should be encouraged to maintain a normal female body image.
4. Support groups for women with mastectomy are necessary to cope with alterations in body image and sexuality.
5. Promoting education of early detection and screening of breast cancer is important to improve the prognosis.
6. Conducting further qualitative studies to assess the process of coping among women post mastectomy.

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