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Women Experiences of Using External Breast Prosthesis after Mastectomy

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Objective: The aim of this study was to identify the experiences of breast cancer patients using external breast prostheses (EBP) in the context of the Pakistani society.

Methods: A qualitative descriptive exploratory design was used in the study. In-depth individual interviews were conducted with 15 postmastectomy women using EBP. A semi-structured interview guide with open-ended questions was used for the interviews. The analysis of the data was organized into four categories according to the study questions including reasons for using EBP, feeling about EBP, challenges for using EBP, and coping with lost breast. Each category was further divided into subcategories.

Results: Women used EBP because they felt strange, incomplete, and embarrassed in front of other people, due to the asymmetrical shape of the chest after mastectomy. They faced several challenges with regard to obtaining and using the EBP. While EBP was used as an alternative of their lost breast, they experienced sadness and embarrassment. They found it challenging to take care of the EBP and were required to make changes in their lifestyle. However, they accepted living with their lost breast, either through rationalization, family support, or faith and prayers, which helped them to cope.

Conclusions: The study findings have given insight into some real experiences of mastectomy patients. Mastectomy not only affects women's physical health but also their psychological health, as a result of which they become reluctant to socialize. Using EBP can help them to improve their body image and body posture. Health-care providers' support is very important to the families of the patients specifically where patients are very shy to openly seek information due to cultural constraints.

Key words: Breast cancer, breast prosthesis, cancer survivors, mastectomy

Introduction
Globally, breast is the most common site of cancer in women.\(^1\) It is estimated that globally, more than 1.38 million people are diagnosed with breast cancer each year.\(^2\) The number of breast cancer cases is escalating in developing countries.\(^3\) Among Asian countries, Pakistan has the highest rate of breast cancer as one out of every nine women suffers from breast cancer.\(^5\)\(^6\)

Most women diagnosed with breast cancer require some surgical intervention combined with other modalities of treatment, including radiation therapy, chemotherapy, and...
Mastectomy is a common treatment modality for breast cancer in which partial or full affected breast is removed to prevent further spread of cancer. Mastectomy causes a change in the appearance of the breast, causing a major effect on women’s self-image and a decreased sense of femininity that can lead to anxiety and depression; so much so that they avoid visiting public places. Therefore, rehabilitation after mastectomy is integral to women’s health promotion. Most of the women select breast restoration and symmetry through breast reconstruction or external breast prosthesis (EBP). Reconstructive surgery is very costly for an ordinary person in Pakistan because people in Pakistan have lack of a general health insurance system; most people have to pay from their pocket for the required health services. Consequently, very few women can afford to have reconstructive surgery. Considering this factor, the focus of this study was to explore the experience of women with EBP only.

Studies from developed countries have suggested that EBP helps to overcome stress and improve women’s self-esteem after they have been through a mastectomy. However, this phenomenon remains unexplored in developing countries like Pakistan.

**External breast prostheses**

EBP is an artificial breast form that is used to replace the natural breast after a complete or partial mastectomy. EBP provides symmetry and a natural shape to the body, and it improves the body posture.

EBPs are available in two types, adhesive and conventional. Adhesive prostheses are attached to the woman’s skin with an adhesive strip, they are appropriate for extensive wear, whereas conventional prostheses are worn inside the bra, which is made up of a special pocket to hold the prostheses. The care of the EBP is very important. Prostheses should be clean every day with warm water and dried with a clean towel to remove perspiration and dirt. If the prosthesis is made up of silicone, it should be prevented from contact with sharp objects such as a pin or scissors. Literature regarding EBP from developed countries suggests that EBP are available in a variety of sizes, shapes, textures, and colors to suit the different age and ethnicity of women. They are also available with or without the nipple and areola.

Some researchers in Western countries have reported the advantages and disadvantage of using EBPs. In Brazil, Borghesan et al. found that 56.6% of postmastectomy women were satisfied with EBP; however, some women reported pain and discomfort on the surgical site with EBP; a common complaint was its displacement during activity. In Netherlands, Thijs-Boer et al. compared the preference of “conventional EBP” over “adhesive breast EBP.” The study findings suggested that women preferred an adhesive EBP over the conventional one as it was perceived to be a body part which stuck on the skin, as compared to a conventional EBP, which continued to be external. Similarly, in Germany, Münstedt et al. reported that 90.7% of the postmastectomy women were using self-adhesive EBP to improve their body image. Using mix methodology, Kubon et al. compared the preference of custom-made EBP over conventional EBPs among postmastectomy women in Canada. Although the quantitative part of their study showed no difference between custom-made EBPs over conventional EBP, qualitative part of the study reported more comfort and satisfaction with custom-made EBP.

Studies from Ireland revealed that the high cost of EBPs is a major challenge for women who use them. Likewise, in Canada, Fitch et al. also reported that the cost and care of EBPs was the main concern of those women who were using it. Other challenges include lack of information regarding EBP, fitting time, lack of privacy, the characteristics of the fitter including gender, competency, and the attitude; Gallagher et al. found that lack of information about EBP caused dissatisfaction. Self-satisfaction and self-confidence improve if women get adequate information from breast cancer nurses (BCNs). Moreover, provision of accurate information by health-care provider can help to correct misinformation and false beliefs about EBP.

Roberts et al. reported women after mastectomy that initially viewed the EBP negatively, but, over time, women felt that it maintained their femininity, normality, and body image and that it improved the quality of their life. Similarly, in America, Glaus and Carlson reported that satisfaction level remained high in those women who used EBP for more than 5 years after surgery, as compared to those who used it for fewer years.

In their study of investigating pattern of using EBP in India, Ramu et al. found that high education level, young age, and living in city contribute to higher utilization of EBP. The researchers also reported that most of the EBP users wanted to improve the quality of EBP, including comfort, size, and shape as well as reduce the cost of EBP. Similarly, in a systemic review conducted in China, Liang and Xu identified that six factors impact EBP use among postmastectomy patients worldwide. This includes comfort, appearance, cost of EBP, as well as the survivors’ mental status, fear of reconstructive surgery, and availability of supportive information about EBP. Hojan et al. in Poland, found a noticeable difference in young women’s gait depending on whether or not they used EBP.

**Aim**

The aim of this study was to identify and describe experiences of women using EBP after mastectomy in the context of a Pakistani society.
Methods

Sample and participants

Using a qualitative exploratory descriptive design, fifteen women with breast cancer who were using EBP participated in this study. These participants were recruited from the breast oncology clinic in a private tertiary care university hospital in Karachi. This clinic is responsible for providing treatment as well as rehabilitation services to patients with breast cancer. The rehabilitation services include provision, fitting, and management of EBP. The EBP clinic is led by the nursing staff, twice a week. Based on their specific needs, detailed information is provided to patients. Approximately 4–5 postmastectomy patients use this service every week. EBPs are also sold at these clinics.

Efforts were made to have variation in participants’ age, occupation, years of surgery, and type of surgery. Participants were informed about this study through their oncology clinical nurse when they came for their follow-up in this clinic. The information was shared at that time and those who agreed to participate were approached. In addition, some participants were recruited through snowball technique. Ethical approval was obtained from the Institutional Ethical Review Board (3366-SON-ERC-14) to conduct the study. Before starting the study, the researcher explained the purpose of the study and confirmed the volunteers’ willingness to participate. Confidentiality and anonymity were also assured by providing pseudonyms to participants. Interviews were carried out privately, and a written consent form was signed by each participant.

The data were collected between April and May 2015, using a semi-structured interview guide. Face-to-face in-depth interviews were conducted with the participants. Each interview lasted at least 30–60 min and all the interviews were audiotaped. Nonverbal communication was noted in field notes. All the interviews were recorded in Urdu. To reduce the chance of error, all interviews were first transcribed in the same language and then translated into English by an expert who had command over both the languages. Demographic information of the participants was also obtained at the beginning of the interview as an ice-breaking strategy.

Statistical analysis

Data were analyzed using the steps proposed by Creswell. After completing each interview, responses of all the participants were collated according to study questions. The researcher reads the transcriptions several times to get a sense of the interview. After organizing the data, words, phrases, and sentences relevant to the questions were highlighted and coded. Furthermore, all the relevant codes were group together to create categories and subcategories as required.

Results

The ages of the fifteen interviewees ranged from 35 to 61 years, with a median age of 45 years. Their demographic information is summarized in Table 1. Clinical information of the participants who were using EBPs are illustrated in Tables 2 and 3. The tables demonstrate that most of the participants received information about EBP after their surgery from a nurse.

The analysis of the data from interviews was organized into four categories according to the study questions: reasons for using EBP, feeling about EBP, challenges of using EBP, and coping with lost breast. These categories are explained below with support from participants’ excerpts.

Reasons for using prostheses

The participants revealed several reasons of using EBP including sense of incompleteness, staring by others, and final appearance. The most common reason was that using EBP gives a sense of finality, comfort, and confidence. Several participants confirmed that usage of EBP ensured the feeling of self-organization and self-esteem. However, some women were motivated to use EBP because it improved self-confidence. These findings are supported by participants’ excerpts:

Table 1: Demographic characteristics of the participants (n=15)

<table>
<thead>
<tr>
<th>Characteristics</th>
<th>n (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age (years)</td>
<td></td>
</tr>
<tr>
<td>35-40</td>
<td>7 (47.0)</td>
</tr>
<tr>
<td>41-45</td>
<td>2 (13.0)</td>
</tr>
<tr>
<td>46-50</td>
<td>2 (13.0)</td>
</tr>
<tr>
<td>&gt;50</td>
<td>4 (27.0)</td>
</tr>
<tr>
<td>Marital status</td>
<td></td>
</tr>
<tr>
<td>Married</td>
<td>10 (67.0)</td>
</tr>
<tr>
<td>Unmarried</td>
<td>3 (20.0)</td>
</tr>
<tr>
<td>Widow</td>
<td>2 (13.0)</td>
</tr>
<tr>
<td>Qualification</td>
<td></td>
</tr>
<tr>
<td>Secondary</td>
<td>2 (13.3)</td>
</tr>
<tr>
<td>Intermediate</td>
<td>2 (13.3)</td>
</tr>
<tr>
<td>Graduate</td>
<td>11 (73.3)</td>
</tr>
<tr>
<td>Profession/occupation</td>
<td></td>
</tr>
<tr>
<td>Homemakers</td>
<td>10 (67.0)</td>
</tr>
<tr>
<td>Working women</td>
<td>5 (33.0)</td>
</tr>
<tr>
<td>Postmastectomy time (years)</td>
<td></td>
</tr>
<tr>
<td>≤1</td>
<td>3 (20.0)</td>
</tr>
<tr>
<td>&gt;1-5</td>
<td>9 (60.0)</td>
</tr>
<tr>
<td>&gt;5</td>
<td>3 (20.0)</td>
</tr>
</tbody>
</table>
Participants also highlighted that men glare first at women's breast, then the rest of the body. Naila recalled, "After surgery when relatives were coming to visit me in the hospital, they were looking at my chest, instead of asking me about my condition. This action made me feel very awkward. I wanted to secure myself … I was hiding my body under the bed sheet".

Women also perceived that breasts are a sign of female identity; their physical outlook is complete only with the presence of both the breasts. Their body shape looks uneven, unbalanced, and hollow from inside. Therefore, to restore the symmetry, they have to use EBP. Rashida shared, “My body lost its beauty as a woman, after surgery. It looked very ugly as one side was empty and other side sagged. I had a lot of pain in my breast but wearing the EBP helped.”

**Feeling about prostheses**

Participants experienced sadness and depression as well as embarrassment when they saw EBP first time; however, they changed their lifestyle as time passed. They felt that there was no replacement for the original breast; however, they accepted the EBP to improve their distorted body image. As Nida voiced, “Nothing can fill the empty space, which we see every day; yes, nothing can replace it (cried); however, the EBP has helped me to hide the surgical scar.” Similarly, Sabeen shared, “When I took prostheses in my hand it felt like a piece of rubber.” Hina, elaborating her feelings with sorrow, said, “The first time when I took the EBP in my hand, it looked very funny. I cried the whole day and I complained to God …. However, being a practical woman, I accepted it. I know I have to live with this”.

Participants also shared their experience of being embarrassed when the EBP got displaced or dislodged from its original place. Naila recalled, “When I was reciting my prayers, and I prostrated (sa’ada), suddenly my EBP came out from the bra and fell on the floor. Oh my God, it was such a bad experience, which I will never forget”. Similarly, Sabeen shared,
"Once I was in a party, I noticed that somehow both of my EBPs were coming out. My bra rode up. Both my EBPs reached my neck. That was such an embarrassment as a woman that I still remember it. I felt lost and left the party and came home".

To overcome the above-mentioned challenges of wearing EBP, the women employed different strategies in their dressing. Some participants reported that they use thick cotton rather than lawn or chiffon, and some wear loose-fitting dresses with a high neck, or an abaya – a full-length outer garment. One participant shared, “There was no symmetry in the shape, and the clothes did not fit properly, so I have started wearing anabaya most of the time” (Rashida).

Challenges of using external breast prosthesis

The participants described several challenges, such as access and quality of EBPs, as well as its affordability, and care. Most of the participants highlighted the issue of unavailability of sizes and variety of product. Fatima, a mother of a very small child, narrated, “I took time from my house chores and went to the hospital to buy the product, but I could not find my appropriate size, and there was no variety in it. It was an unpleasant experience.” Shabana also complained,

"After the surgery [Mastectomy], I got chemotherapy; it was very difficult for me to come specially to buy the product. I came for my regular checkup in the clinic, and I requested the nurse, but she told me that we have fixed days for selling the EBP”.

Some of the participants disclosed that their family was the main decision-maker about buying EBP. They had very little say about it. However, their family was more concerned about the treatment and surgery. Although using the EBP was very important for the patient, it remained a neglected aspect by the family, as Lizna explained,

"After mastectomy, my family thought I am an old lady and a widow; therefore, I do not need to wear the EBP…. but I thought, as a woman, it is my right to look complete. After surgery, I felt incomplete".

The participants also reported that due to cultural norms, women, particularly those coming from rural areas would feel shy to ask questions about EBP. Abida narrated the story of one patient who was admitted with an infection on the surgical site. On inquiring the patient, she learned that the patient had stitched her homemade EBP using grain (bajra), and after a few days, insects grew inside the EBP pocket and this caused severe skin infection on the surgical site. Such things increase the patients’ burden during the course of the disease. One of the participants thought nurses may emphasize on the importance of using EBP as a part of the treatment. She said,

"In our country, awareness regarding health measures is already very low. Most women are dependent on their families, but they can never ask directly for EBP from their families. Therefore, nurses can take a lead and advocate on behalf of their patients and help them secure their body image (Fatima)".

The participants voiced that written information about EBP should be made available, including shop locations, and this should be given to the patients and their families to enforce the important of rehabilitation after mastectomy. Lizna verbalized,

"Before the surgery, the doctor told me that she will share the information, but after the surgery, she forgot. I was unaware about the availability of the product in the city. If the doctor had given me this information in writing, it would have helped me”.

The challenges of wearing silicone EBPs as opposed to cotton EBPs were different. The participants described two challenges of wearing silicone EBP. One issue was weight, and the other was related to texture. Abida described two challenges of wearing silicone EBP. One issue was weight, and the other was related to texture. Abida explained,

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give more attention to cleaning the EBP to prevent skin infections. Maria shared,

"I am a single parent, and I am the only financial supporter in my family. I work in an office, so I need to maintain my personal hygiene; therefore, I need to change my bra every day. This product is very expensive, so I bought only one bra, so I have to wash it every day".

Coping with lost breast

Participants had learned to cope with the loss of their breast. They gradually accepted the reality and coped using different strategies, such as acceptance with rationalization, faith in God, family support, and participation in distracting activities.

Working women reported that wearing the EBP the whole day increased their comfort level and acceptance as well. One participant explained, “I am a working woman, so I need to find an alternate for my breast. Therefore, I selected EBP. Initially, I found it a little odd, but as time passed by, my comfort level increased, and I accepted it” (Hina). Likewise, Abida clarified the importance of EBP in her life as follows,

"I thought that when someone’s hand is amputated, it is replaced with an artificial one. Similarly, if any part of the body is removed, an artificial alternate is available for it. The same way I found an alternate for my breast. I think it is good to have something instead of living without it".

Women expressed the significant role of their family in their early recovery, such as unmarried women received support from their parents and siblings; however, married women received support from their spouses. Naiila expressed her feelings, “After marriage, breasts are connected with sexual intimacy with the partner. After mastectomy, I had anxiety about facing this situation; however, my husband accepted me in my new image. It decreased my helplessness and increased my coping.”

Most of the participants coped by having trust in God; according to their faith, it is only God who gives courage to cope with the problems. Rashida elaborated, “I think without God’s will nothing can happen; it is God who gives us courage. He saved me from a dangerous disease, so using an artificial breast is no issue.”

Some of the women mentioned that reciting prayers, reading holy verses from the Quran, or reciting the name of God on a rosary increased their acceptance to face the reality. It also enhanced their will power to face the situation.

A few participants found it helpful to cope using distracting activities, for example, Shabana shared,

"My mother taught me that God lives in the human heart, so if you want to decrease you worries, you need to help human beings because it makes Allah happy. I started voluntary services. I gave my numbers to patients who needed my help. I really feel good when patients call me and I help them".

Discussion

This study provides insight into women’s experiences of using EBP after mastectomy. Although wearing EBP helped them to restore their body image in front of others, it remained a compromised solution to their lost breast. The use of EBP was not only important for cosmetic purposes but also for a balanced body posture, increased confidence, and improved socialization.

Islamic teachings emphasize the importance of visiting the sick. Islamic values also stress that the relatives of the sick should use kind words, pray for the sick patients’ early recovery, and advise the sick to have patience.[32] However, women in this study felt uneasy when they were visited by their relatives in the hospital. The difference in feeling could be due to the surgery of the intimate part of women, which is linked with their sexuality. Moreover, in Muslim culture, women’s sexuality is not discussed or disclosed in front of everybody. Hence, women who undergo mastectomy probably feel more disturbed because although people visiting them do not mention it, the patients feel that those people pity them for losing their womanhood.

The current study also found that older women felt ignored by their families as they assumed that body image was not important in old age, thus wearing EBP was not considered that important after mastectomy. This stereotype is probably due to the influence of the Pakistani culture, where sexuality is linked with age. Therefore, old women get less attention in this context. However, women’s femininity is not attached only with age; it is connected with their gender.

Moreover, due to cultural taboo and lack of awareness, many women do not feel comfortable to ask directly about EBP from health-care providers. To maintain their body image, they stitch prosthesis from lentils, which has dangerous effects on their body.

The participants experienced several issues related to access and affordability. The current study highlighted that the hospital had fixed days for providing EBP, so they had to come, especially to buy it. However, when they went on the appointment day, they had difficulty in finding the appropriate size and variety of the product. This issue created a lot of frustration among those women who were on chemotherapy, radiation, or those who were coming immediately after the mastectomy. Likewise, women who specially came to buy the EBP from different cities also faced difficulty in finding EBP of appropriate size in the hospital. Gallagher et al.[20] in Ireland mentioned a similar finding in their studies.
Similar to the findings of previous studies, the participants in the current study also reported that cost was a big issue for them as EBP is very costly. Therefore, affordability was the main concern for all of the women. It is worth mentioning here that due to lack of a general health insurance system in the country, most people have to pay from their pocket for the required health services. In the current study, working women were financially supporting their families while homemakers were dependent on their families. Moreover, the participants reported that the diagnosis and treatment of cancer had already put a heavy financial burden on their families, so rehabilitation after mastectomy was not so important, especially since using EBP was perceived as a cosmetic expenditure only. Therefore, most of the women tried to find an alternative that is how they compromised on the quality of the EBP. Some had stitched their own EBP, using cotton or foam, and a few women also found different lingerie shops that sell EBP and bras for cheap prices.

Challenges related to using EBP were identified. For example, silicone EBP is very heavy; hence women, especially working ones, find it difficult to carry it for the whole day. A few participants who were using cotton experienced different challenges than the silicone EBP. They said that the cotton EBP does not give symmetry to their breasts because it has less weight as compared to a normal breast. These findings correspond with the available literature. Furthermore, in the current study, women who were required to work in the kitchen reported that the silicone EBP is very fragile; thus, they had to take extra precautions to take care of it, which was an added burden for them. In the Pakistani culture, women spend long durations of time in the kitchen while cooking, so heat could be one of the reasons that silicone EBP gets easily damaged. Moreover, in Pakistan, women cook food in a traditional way, which requires moving the hand very frequently to mix food on the stove; this can cause friction on the EBP and damage it.

Participants in this study also highlighted issues regarding lack of written information regarding EBP usage. Usually, verbal information is given by doctors and nurses after the surgery when patients are already overwhelmed with the effect of the treatment. Due to the anxiety, it is very difficult for them to recall or understand anything at that point. It would be very helpful for them if this information is provided in a written format so that those women who can read and write can read it anytime. Moreover, in the Pakistani society, the family is responsible for taking decisions for the treatment on behalf of the patient. Written information will reinforce the family to understand the importance of women’s feelings after mastectomy.

Several authors emphasize the role of BCNs in providing support and information to the patients for making decisions about EBP. However, participants in the current study revealed that nurses had very limited knowledge about EBP. Nurses’ support is very important to the families of the patients specifically where patients are very shy to openly seek information, due to cultural constraints.

Women expressed that they went through a lot of grief and sorrow when they saw the EBP for the first time. They also shared that EBP was a foreign object, and it was a reminder of their amputated breast because they had to remove and wear it every day. These findings are congruent with findings of Gallagher et al.

The narratives revealed that women’s acceptability of wearing EBP was enhanced if they wore it consistently. Especially those working women who had to maintain their image at their workplace showed more satisfaction with wearing it. Similar findings were reported earlier by Claus and Carlson that the satisfaction of women increased when they wore EBP for a long time, as compared to those women who wore it intermittently.

Women in this study received support from various sources with regard to EBP; married women predominantly received support from their spouses, which enhanced their acceptance of their new image. Likewise, unmarried women received positive support and encouragement from their families to cope with EBP. These findings are in line with those of a previous study conducted in Pakistani context. Faith in God and power of prayers was another source of their coping, which increased their willpower to accept the reality and cope with wearing EBP. Torres et al. also mentioned similar findings in their study in America.

Limitations

This study was conducted in a private health organization where two-thirds of the participants were highly educated and belonged to higher socioeconomic class; hence, their view may have been different from those women who belong to low socioeconomic background. In addition, although efforts were made to recruit patients with both unilateral and bilateral mastectomies, only one participant with bilateral mastectomy could be recruited, all the other participants had unilateral mastectomy, so the findings are more representative of patients with unilateral mastectomy.

Conclusion

This qualitative study indicated that the use of prostheses may have implications for both the patient’s physical and psychological health. Considering the cultural norms of Pakistani society, women may be shy to inquire about EBP. Therefore, this should be a part of
routine care in which nurses can initiate the discussion and provide appropriate information about EBP. Multiple sources of information should be available to the patients, such as written brochures and videos on the types of EBP, its importance and procedures for its care, and the techniques of wearing it; moreover, while sharing information regarding EBP with patients, nurses should discuss first the advantages of using EBP and then its cost so that the patients and their families may not be deterred by its cost and may first consider its benefits. Clinical nurse instructors should plan in-service sessions to educate the clinical staff about the importance of the EBP for the rehabilitation of mastectomy patients. The oncology team must have a breast cancer support group, which will allow postmastectomy patients to share their experiences more openly and learn from the experience of other patients. Hospitals must have facilities for those patients who have medical reimbursement for their health coverage; this could be added to their bill, by considering it as a part of the total treatment.

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Conflicts of interest

There are no conflicts of interest.

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