

Exploring Lived Experiences of Married Pakistani Women Post-Mastectomy

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ABSTRACT

Objective: This qualitative descriptive exploratory study aimed to explore the lived experiences of married Pakistani women, 2 years post-mastectomy. **Methods:** Twelve participants were recruited through purposive sampling from outpatient oncology clinic from a tertiary care hospital in Pakistan. Interviews were audio-taped and transcribed, and then themes and sub-themes were identified. **Results:** Women verbalized a range of their experiences throughout the span from diagnosis to mastectomy. One over arching theme, quality of life and four main themes and their subthemes emerged from the data. Following are the

themes; from history to diagnosis, worries, coping strategies, and recommendations. **Conclusions:** The study findings revealed that effective coping strategies were beneficial for these women, as these women coped well after being diagnosed with breast cancer. Strong recommendations were made by the participants for the formulation of support groups, which could help them reduce their anxiety through information exchange.

Key words: Breast cancer, coping strategies, post mastectomy, quality of life, support groups

Introduction

Breast cancer diagnosis can be distressing and overwhelming for the patients and their families. Yet, survival from breast cancer has increased in number. According to the World Health Organization^[1] “breast cancer survival rates vary greatly worldwide, ranging from 80% or over in North America, Sweden, and Japan to around 60% in middle-income countries, and below 40% in low-income

countries.” Hence, it is evident from statistics that the survival rate is higher where there are more awareness and availability of health-care facilities. However, it cannot be denied that low-income countries also have a significant number of survivors. Increased survival rates have promoted concerns regarding the experiences of women with breast cancer and their personalized and

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customized ways of coping with this disease after ward. The aggressive nature of the treatment of cancer may affect the quality of life of the patients in all aspects and may impair the functioning^[2] despite knowing that breast cancer could have been a fatal disease, these survivors look to the future with optimism. Women seem to be determined to regain their health and have developed a faith in the breast cancer treatment with the hope that they will get cured.^[3]

Nurses play a vital role in providing care to the patients, including patients with breast cancer. With the increasing number of breast cancer patients, hospitals need to provide quality nursing care, which in turn would increase patient satisfaction. Moreover, nurses' role has extended from just providing physical care to educating patients, teaching, and counseling. Hence, nurses having these skill scan also facilitate patients to develop a variety of coping strategies, there by bringing more sense of contentment to the clients. Nurse navigation programs can help people who are under served and lack access to medical facilities; they can also increase the satisfaction level among patients.^[4] In Pakistan, there are no established navigation programs, which can assist patients from diagnosis treatment. In this context, nurses are with the patients whether they come as outpatient or in patients, from admission discharge. Therefore, it is important that they understand the experiences of married women post mastectomy, as these could help identify the stressors, and the coping and survivorship experiences of these women, especially from the Pakistani context. Moreover, understanding these experiences could add valuable knowledge to the body of literature. This could further assist nurses to support women with breast cancer.

Breast cancer is the leading cause of death women worldwide. According to the annual cancer registry Pakistan, in 2012, breast cancer incidence was the highest among the top ten malignancies. Women use multiple strategies to fight with the disease. It is important to conduct a qualitative study to explore their experiences and concerns during treatment of breast cancer.

The aim of this study was to explore the lived experiences of married Pakistani women for more than 6 months up to 2 years post mastectomy. To fully understand the phenomenon, the researchers wanted to also know the women's descriptive circumstances through demographic data to assist with understanding the data. Following were the questions posed to participants for data collection.

What were the challenges experienced by the research participants, more than 6 months up to 2 years post mastectomy. What concerns did the participants have and what strategies were utilized by the research participants

to face the challenges of post mastectomy? Other prompts were also used to explore in detail about the experiences of participants. These questions gave the researcher an opportunity to explore in depth the experiences of breast cancer patients.

Methods

Samples

It is difficult to access participants with out medical assistance. Therefore, a breast surgeon working in a cancer clinic was approached, and then the researcher further explained the study and took consent if the participants were willing to participate in the study.

This study has used qualitative descriptive-exploratory design to have in-depth exploration and analysis of the phenomenon. Participants were recruited purposefully from an outpatient unit of a tertiary care hospital in Karachi, Pakistan. Twelve Pakistani women diagnosed with breast cancer and had bilateral mastectomy were recruited for the study.

Participants were recruited on the following inclusion criteria: (1) 25 years of age and above, (2) married and living with husband, (3) unilateral or bilateral post-mastectomy without reconstruction, (4) more than 6 months and up to 2 years of survivorship, and (5) willing to get their interviews tape recorded. Participants were excluded who had known psychiatric illness, multiple cancers, and metastasis to other organs.

Ethical approval

A written consent form was signed by the participants for voluntary induction in this study. The study was approved by the Institutional Ethical Review Committee of the Aga Khan University Hospital, Karachi, Pakistan. Hence, the same hospital was used for research.

Data collection and analysis

Semi structured in-depth interviews were taken for data collection. Open ended questions gave the researcher an opportunity to probe. Two pilot interviews were done in to modify the interview guide for rich data collection. Interviews were scheduled on agreement with the participant and researcher. Interviews were held in a separate room to maintain privacy.

The interviews were manually transcribed verbatim. Data were read and re-read to identify key words and phrases. Then coding was done. According to Creswell, 2013,^[5] "the process of coding involves aggregating the text or visual data into small categories of information, seeking evidence of the code from the different database being used in the study, and then assigning a label to the code". Then the emerging themes and sub-themes

from the data were identified. Transcripts were revisited to identify any missing information and finalization of themes and sub-themes were done. All the researchers had agreed on identified themes and sub-themes so that rigor of the study could be maintained. The entire study findings were purely reported and no researcher bias is observed.

Rigor of the study

The rigor of the study was subjected to Lincoln & Guba’s^[6] four criteria of maintaining trustworthiness that is credibility, dependability, confirmability, and transferability. Credibility was maintained through interactive questioning of the participants, frequent debriefing with the supervisor and committee members, as well as peer scrutiny. Dependability was ensured by reporting the study in detail so that another researcher can repeat the study, thereby protecting the credibility of the findings.^[6] Confirmability was ensured by checking the audio-taped interviews and transcriptions for congruency. Moreover, the findings have been reported purely from the participants’ data and are not researcher biased. This process was carried out by the researcher and checked by the supervisor. Transferability means that findings can be transferred to similar situations; the results of this study may be applied to similar contexts, as women may have similar experiences related to breast cancer.

Results

Sample characteristics

All of the twelve participants were married females and currently living with husband. No one had undergone reconstruction. As stated above, the researchers included demographic data not as a measurement tool but rather to understand the circumstances of the women and to assist in data analysis. The demographics of participants are mentioned in Table 1.

Four main themes, along with their sub-themes and an over-arching theme Quality of Life emerged from this study; Figure 1 represents all the derived themes of the study.

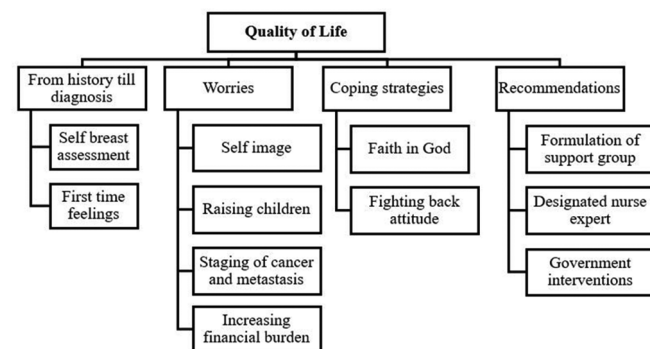


Figure 1: Themes and Sub-themes

Theme: From history till diagnosis

The main theme from history till diagnosis has two sub-themes that are self breast assessment, and first time feelings.

Sub-theme: Self breast assessment

This study revealed incidents in which participants’ self-examination of breasts led to identifying a lump and subsequently, confirmed the diagnosis of breast cancer. Some of the participants emphasized its importance. Participant 4 narrated “I did self breast examination and found (a) lump in my breast. Hence I contacted the doctor for a diagnosis. She advised a mammogram, and it was confirmed that I had breast cancer.” On the contrary,

Table 1: Demographic characteristics of participants (n = 12)

Characteristics	Percentage [n (%)]
Gender	
Female	12 (100)
Age (years)	
30-39	2 (17)
40-49	5 (42)
50-59	4 (33)
60-69	1 (8)
Marital status	
Married	12 (100)
Have children	12 (100)
<2 children	2 (17)
>2 children	10 (83)
Children’s age <18 years	2 (17)
Children’s age >18 years	10 (83)
Education	
Primary school	1 (8)
Middle school	3 (25)
High school	2 (17)
Intermediate school	3 (25)
University	3 (25)
None	-
Occupation	
Housewife	8 (67)
Unemployed	-
Professional	4 (33)
Place of work	
Health care facility	2 (17)
Educational organization	1 (8)
Business firm	1 (8)
Status of house	
Owned	10 (83)
Rented	2 (17)
Household income	
Rs. 5000-20,000	1 (8)
Rs. 20,000-40,000	2 (17)
Rs. 40,000-60,000	3 (25)
Rs. 60,000-100,000	1 (8)
More than Rs. 100,000.00	3 (25)
Pt refused	2 (17)

participant 10 revealed that “In ultrasound, it was diagnosed that I have malignancy... but I went to religious places for healing. After 4 months I felt that the lump size has increased and started having nipple discharge. Then I went to the doctor again”. Such delay in diagnosis may prove to be life-threatening as the disease gets more advanced.

Sub-theme: First time feelings

Depression and denial were commonly felt by the participants at the time of diagnosis. Some participants rejected the diagnosis as not true and opted for a re-test of the procedure, while most of the participants felt depressed and shocked to hear about their diagnosis for the first time. Participant 6 explained, “I was completely depressed, lost and was not accepting the diagnosis. I was waiting for some miracle to happen and hoped (that) my reports would change.” Counseling participants at this difficult time assisted them to make informed decisions. While, Participant 9 informed that she “searched the internet about the best breast surgeons and oncologists in Pakistan” and then visited the hospital well prepared for her treatment.

Theme: Worries

Worries can make an individual anxious about certain situations. The theme worries has four sub-themes, self-image, raising children, staging of cancer and metastasis, and increasing financial burden.

Sub-theme: Self-image

In this study, most of the participants were worried about their self-image before, during, and, especially, after mastectomy. Participant 1 verbalized that “I feel incomplete because of the absence of one breast. I was upset at my hair loss, because I had long hair.” However, some of them also shared that covering themselves with *abaaya* (veil) or covering the head with a scarf has helped them, because it hides the fact that there is only one breast or there is no hair. Only one participant was worried about her self-appearance at the time of death. Recalling it, Participant 9 disclosed, as I did not tell anyone about my disease, I was worried about the bath (that will be given to me) at the time of death, people will come to know that I don't have a breast. Therefore, my daughters have assured me that they will give the last bath to me.” Another important aspect of the self image is loss of breast, which can negatively affect woman's sexual relationship with spouse. However, these women were so positive and grateful that their husbands were very supportive at this crucial time. Expressing the same, one of the participants verbalized that, “my husband was very supportive; I showed him my surgery site and told him there is no breast now. He immediately hugged me and said he does not love my body, he loves me. He used to pray for my

life.” Moreover, many participants felt that their husbands were very supportive and some of them mentioned they have become even more loving and supportive than before.

Sub-theme: Raising children

Some of the participants expressed their worries in regard to the raising of their children, as they were uncertain about the consequences of breast cancer. One participant was worried about the hereditary implications of breast cancer, that her children might become victims of the same disease in the future. Participant 11, considered the future of her three daughters and mentioned, “I get worried that.... they (daughters) don't get this disease (genetically) in the future. I keep asking doctors about this as well. I hope God keeps them safe.”

Sub-theme: Staging of cancer and metastasis

Only two participants expressed concern about the time gap from testing the disease to the staging of their cancer. They were worried about its metastasis to other organs. Participant 7 verbalized, “I was worried and hoped that the cancer is in (the) initial stage and (that it) is treatable.”

Sub-theme: Increasing financial burden

Some of the participants found that arrangement of finances was a major cause of concern, as it increased the financial burden and affected the normal day to day functioning of the family; while some were able to finance the whole treatment from their own pocket. Participant 3 shared, “arranging finances was a big problem for us. My husband took a loan for my treatment. Now we hope that my son will soon finish his studies and will be able to repay the loan.” Moreover, one participant talked about borrowing money from the family. She also mentioned that there was a difference between the estimated and final bill given by the hospital, which added to the financial burden and added that, “The increasing financial burden was more stressful than the illness itself.”

Theme: Coping strategies

The fourth main theme refers to those strategies which assisted the participants to deal with the cancer treatment. The sub-themes are: faith in God, and fighting back attitude.

Sub-theme: Faith in God

All the participants expressed that during their treatment, their biggest relief came from religious belief and practices. Participant 5, stated, “I strongly believe in God. I believe that this disease is from God; he tests people and will also give me the strength to fight back the disease.”

In addition to believing in God, religious practices helped participants in handling their stress and getting peace of mind. For some participant, along with the medical

treatment, there was a preference to go to the *Spiritual healer* and ask for guidance. The guidance included performing some religious rituals along with giving of charity. As Participant 6 mentioned, "I visited a spiritual healer, he gave me some holy verses to recite and gave holy water to drink and suggested to give Sadqa and Kherat (charity given as part of a religious ritual)."

Most participants had trust in and expressed gratitude to God as their coping strategy. Participant 5, expressed gratitude and envisioned the disease as a way to start a new life all over again, she used these words, "I firmly believe that it's a sins cleansing journey and God has given this disease to me so that my sins are redeemed. It's an indication from God not to indulge in sins again."

Trust in God included leaving everything to God and accepting that the ultimate decision will be in favor of the participant. Participant 1 said, "I trust in God so I left everything to God. Whatever is in my fate will come to me."

Sub-theme: Fighting back attitude

This coping strategy helped participants to bear the serious side effects of cancer treatment, as they fought back while keeping a positive and brave attitude. Participant 2 verbalized this sentiment, "I decided that it is better to smile and complete the treatment instead of crying and complaining." Whereas Participant 1 said, "I didn't take stress at all; didn't think much about surgery and losing my breast." She further shared, "I convinced myself that I have to fight back this cancer." These comments reflected their spirit of fighting against the disease.

The study also highlighted an incident where normality was forced by exogenous factors, rather than endogenous ones, because the participant had not disclosed the disease to any one, besides close family, and, thus, she had to demonstrate normality in her daily function. Participant 9 shared, "I did not want people to notice that I don't have a breast. So I tried to be normal."

Theme: Recommendations

This theme has three sub-themes, which are: formulation of support group, role of nurse navigator, and government interventions.

Sub-theme: Formulation of support group

The study findings revealed that most of the participants were in favor of formulating a formal support group. However, only two participants considered it to be a time consuming exercise. Participant 2, being in favor of a support group, suggested, "I think there should be a support group for breast cancer patients because, in the initial phases, women get worried about many things, so there must be someone who has gone through it and can

share their experiences. I am willing to be a part of such support group."

The study also revealed that an informal type of support group was present at the clinic in waiting area or during sessions of chemotherapy; as participants have either lent support or received support from other participants while undergoing similar treatment. "When I came for chemo for the first time, I was crying but one patient gave me strength by telling her story about fighting back cancer, now I try to help other women who need help." Participant 5, shared a slightly different opinion, she stated, "support group is fine as far as knowledge sharing is concerned, but sharing experience may not be nice because everyone has a different experience." Highlighting the counter productivity that a support group may provide, Participant 6 mentioned, "If someone has had a bad experience and she shares it with other women, they may lose confidence."

Sub-theme: Designated nurse expert

Only one participant indicated the need for an expert nurse who is available and can be contacted any time over the phone. Participant 3 expressed, "I think there should be someone to contact at the hospital other than doctors. Because during chemo and radiation there are side effects and minor things and each time I could not come to the hospital. So there should be someone available over the phone".

Sub-theme: Government interventions

The government related interventions discussed by participants included educating masses about breast cancer, facilitating diagnostic arrangements, and providing cost effective cancer. This is especially necessary when the alternatives to bear such costs, in the shape of health insurance, are minimally available and hardly used. Participant 5 suggested, "I would suggest that awareness programs should be conducted in small towns where people do not have awareness about breast cancer." Participants also stressed the need for government funded, free or discounted diagnostic tests, and treatment for the cancer patients. Participant 1 noted, "Government must arrange interventions for under privileged people here, because they can't bear the expenses of the treatment."

Discussion

Due to the long term treatment of cancer and mastectomy, individuals go through a lot of stress and anxiety. This stress and anxiety can lead to a compromised psychological distress, which can affect the functioning of an individual. These themes are discussed below in the light of the published literature.

Most of the study participants highlighted their experience regarding how they found out the need to see

the doctor and their feelings at the time of diagnosis and their reactions after receiving the diagnosis of breast cancer. Concurrent to the current study, participants felt depressed after diagnosis and remained so, after their treatment had begun. These patients also felt that they needed to be in constant contact with their doctors. Long gaps between follow ups were not appreciated by them.^[7] A comparative study done in Pakistan and London, by Banning *et al.*,^[8] supports the findings of the current study and reveals that, “for all breast cancer women the location of a breast lump was an upsetting, petrifying, threatening and extremely scary experience.” The lack of awareness about screening tests caused a delay in approaching a doctor and getting diagnosed and treated for breast cancer on time.

Another important finding in the current study was about the self- image of women and their relationship with their husbands after mastectomy. Most of the participants reported that they were worried about their body image after breast removal and felt incomplete. Similarly, a study in the USA, by Fobair *et al.*^[9], showed that out of 549 women who had undergone mastectomy, half of them had body image concerns. The most commonly reported body image problems were embarrassment about the removed body part, worries about sexual attractiveness, and a feeling of being less feminine. Similar to this study, most of the participants in the current study also expressed their concerns about their altered body image which shakes a woman’s identity and poses grave challenges.

Some of the participants in this study reported that covering themselves with a *chaadar* or cloak helped them, because it covers the whole body. A cloak is usually worn over the clothes and is also loose fitting, so it does not accentuate the body’s shape. This is a unique finding as no other study, to the best knowledge of the author, has reported the advantage of covering self with a cloak after mastectomy.

Another, the concern of the participants was related to raising children. Unlike the West, children in the Pakistani culture stay at home with parents beyond 18 years of age or till they get married, and sometimes even after marriage, therefore, the participants in this study were concerned about their upbringing. According to the National Cancer Institute, about 24% of the cancer patients have <18 years old children, which could be the reason why parents were more worried and anxious about their upbringing. Choosing the appropriate words and time to reveal the diagnosis to their children and maintaining a routine for them at home was the biggest challenge faced by these parents who had been diagnosed with cancer.^[10] In addition, parents with cancer can feel guilty and depressed; therefore, support from health care professional, is vital for these patients.^[11] Only

one participant expressed her concern about the possible transfer of breast cancer to her daughters. According to the American Cancer Society,^[10] <15% of breast cancer patients have a family member with cancer, while according to Pakistan - Country Profile of Cancer and Cancer Control 1995-2004, only 3% of breast cancer women had a family history of cancer.

In the current study, a few of the participants reported that their relationship with their husbands had become stronger after cancer diagnosis. A study done in Turkey also reported an improved relationship between couples after the wife had been diagnosed with breast cancer.^[12] Similarly, most of the participants in the current study reported that mastectomy had not affected their physical relationship with their spouse and did not voice any concerns regarding sexuality after mastectomy and chemotherapy. On the contrary, literature also identifies that; mastectomy can have serious implications related to sexuality and can badly influence an individual’s relationship with spouse.^[13] However, a study reveals that women diagnosed with breast cancer initially hesitated to share their experiences with the family members and friends however, some received unexpected support from their families and felt that they were not alone in their battle. On the contrary, some women thought that they were being too much cared for whereas they wanted their care givers or spouses to treat them normally.^[14]

An important finding extracted from the current study was the employment of coping strategies during the disease process and treatment. Since all of the study participants were practicing Muslims, they reported that they prayed to Allah, and recited verses from the Holy

Quran to cope with the ordeal of breast cancer. A study done on Muslim Pakistani women with breast cancer reported two commonly used strategies; one was belief in the power of God and the other was reading verses from the Holy Quran.^[15] thus confirming the current study findings. Similarly some research in the United States also reported increased observations of religious practices, like offering prayers, reading scriptures, and attending church meetings, by the cancer survivors.^[16] In the current study, having complete faith in God was reported as a great strength, which kept the participants’ morale high throughout the treatment of breast cancer.

An extensive amount of literature exists on support groups for cancer survivors. However, in Pakistan it is not common for patients to seek information or support through support groups. At the time of research there were no support groups for breast cancer patients. Formulation of a support group is not only crucial for patients but also for their families, to provide better support and care.

A study done in China, found that support groups provide emotional and informational support to cancer participants. Group interactions bring feelings of comfort and confidence among participants.^[17]

Online support groups have also become a common source, particularly for patients who cannot meet face to face for any reason. A study was done in the USA about twitter support group, in which participants had tweet chats. The study found that participants reported tweet chats as “safe and comfortable”. Although hospital based teaching cannot be replaced by the social media, it has a significant impact on the reduction of anxiety.^[18]

One of the sub-themes, which emerged from interviewing participants, was the need of an expert nurse, formally known as an oncology nurse navigator (ONN). “ONN is a professional registered nurse with oncology specific clinical knowledge who offers individualized assistance to participants, families, and caregivers to help overcome healthcare system barriers.”^[19] In Pakistan this role has not fully emerged as yet. Although there are experienced nurses in oncology but they do not completely perform all the roles of ONN.

Finally, interventions by the government were also emphasized by the current study participants. Pakistan is a developing country and there is no funding allocated particularly for breast cancer patients only. A few Non-Government Organizations work for these patients but not all patients can benefit from them. Moreover, there is no cancer registry system available. Annual reports must be published by the government about cancer incidence, so that health policy and management are looked into and funding can be arranged nationally and internationally for poor patients.

Due to lack of awareness about health screening programs, cancer is mostly diagnosed in the advanced stages in Pakistan. Thus patients have to bear expensive treatment with poor prognosis. In a comparative study of China, India, and Russia, it was identified that most of the populations who live in rural areas do not have access to screening programs. India being the second most populous country in Asia has the highest burden of cancer, so the Indian government initiated the National Cancer Control Program in 1975 with the development of a cancer registry program. In 2010 more than seven billion Indian rupees were provided as fund to this program. Similarly, an initiative was under taken in 2009, by the government of China, for screening women for cervical and breast cancer and millions of people benefited from it. In Russia, due to increased incidence of cancer, a National Priority Health Project was started to prevent cancer, in 2009. In some regions of Russia, like Moscow, breast cancer screening

programs are running well.^[20] These research findings reveal that a few Asian countries have initiated some projects to control breast cancer but there appears to be no initiative taken in Pakistan as yet.

Limitations

This study has contributed valuable knowledge but also has some limitations. Urdu is the national language of Pakistan, most of the interviews were conducted in Urdu, there is a possibility that the essence of some of the quotes may have been lost during translation.

As this study was conducted in a university hospital located in an affluent area, it is possible that the perspectives of patients from the lower socio-economic class may not have been captured fully. Since only married females with children were recruited for the study, the findings are limited and cannot be generalized. However, rigor of the study was maintained and the extracted themes truly reflect participant’s views.

Conclusion

This qualitative study aimed to explore the 2 years post mastectomy experiences of married Pakistani women with breast cancer. This phenomenon has been widely explored in the West but very limited literature exists in the Pakistani context. The findings revealed that these women received extensive support from their families, especially husbands. In addition, various forms of support and coping strategies kept them functioning. When compared to western literature, husband’s support came out as a unique finding of this investigation. This study also revealed that most women in this context were not worried about husband’s reaction towards their physical or sexual relationship. This study suggests that breast cancer support groups should be formed, which can provide psychological support to these women. Government interventions should also be initiated to identify and treat breast cancer at an early stage.

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Conflict of Interest

There are no conflicts of interest.

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