RESEARCH ARTICLE

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The Lived Experience of Ethiopian Women After Mastectomy due to Breast Cancer: A Qualitative Study

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Abstract

Background: The impact of breast absence on women's lived experiences is not well studied in Sub-Saharan Africa particularly in Ethiopia, with implications for service design. This study aimed to explore the lived experiences of Ethiopian women after mastectomy due to breast cancer. **Methods:** A qualitative study approach was used to explore the experiences of women who underwent a mastectomy at the oncology unit of Tikur Anbessa Specialized Hospital. Before the commencement of the study, consent was obtained from each respondent. An in-depth interview was conducted with twelve post-mastectomy women using a semi-structured interview guide. Audio-recorded data were transcribed verbatim and translated into English. Data were coded, sorted, and themes were developed manually based on the thematic analysis. **Results:** Five themes illustrating the impact on the women's life after mastectomy were identified and categorized into (1) Perceived alteration in physical and psychosocial aspects, (2) Perceived social support, and adapting to life after mastectomy. **Conclusion:** Our finding suggests that women who underwent mastectomy need holistic care including physical, psychosocial, and emotional support from their family, society, and healthcare professionals.

Keywords: Lived experience- women- breast cancer- mastectomy- Ethiopia

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Introduction

Breast cancer is the second leading cause of morbidity and mortality among women worldwide [1]. According to the global burden of disease report of 2017, an estimated 1,960,681 breast cancer cases were recorded [2]. The highest burden of breast cancer was reported in sub-Saharan African countries including Ethiopia [3]. The incidence of breast cancer was estimated to be one out of three in Ethiopia [4]. Hence, the issue of cancer is changing into Ethiopia's main health liability.

In Ethiopia, mastectomy is the most common surgical treatment for breast cancer [5]. However, the decision to undergo mastectomy increases a serious psychological, physical, and functional impact on women due to the surgical alteration of their breasts [6]. Hence, It is incumbent upon women to accept the surgical removal of breasts which causes a permanent amendment to their body image [7]. Moreover, seeing a wound and/or scar at the site of the removed breast, perceptions of femininity [8], and impaired family relationships are major concerns that affect the quality of life among women with post-mastectomy [5, 9]

Even though mastectomy has been shown to improve clinical outcomes [10], Patients who underwent a mastectomy need physical and psychological support that improves their quality of life. Thus, a detailed understanding of women's experience regarding life after mastectomy is one of the most important strategies for improving the quality of life among women with breast cancer [11]. Healthcare workers especially nurses can play a vital role in providing quality patient care by providing physical care, teaching, and counseling about post-operative care [12].

Previous qualitative research aimed at understanding the lived experience of women with mastectomy has been conducted in predominantly high-resourced settings [12, 13]. In Ethiopia, several studies conducted on breast cancer have quantitatively described the time of diagnosis, the survival status of breast cancer, and the effectiveness of chemotherapy [14-17]. However, no empirical studies have attempted to explore the lived experiences of Ethiopian women after mastectomy due to breast cancer. Therefore, this study aimed to explore the lived experiences of Ethiopian women after mastectomy due to breast cancer.

Materials and Methods

Study Design, Settings and Periods

A qualitative descriptive phenomenological study design was conducted at the cancer center of Tikur

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Anbessa Specialized Hospital (TASH), Addis Ababa, Ethiopia, from April – May 2020. TASH is the largest referral hospital found in Addis Ababa, the capital city of Ethiopia. It is a training center for many medical students from national and international countries. In Ethiopia, the standard and major services for both adult and pediatric cancer patients are provided only at the cancer center of TASH.

Participants

The list of women who have undergone mastectomy was obtained from the TASH cancer center. Using a purposive sampling method, adult women above 18 years old who underwent a complete mastectomy with no mental illness and volunteered to participate in the interview were included. Whereas women who have undergone a lumpectomy, or breast reconstruction and are seriously ill/ unable to provide information were excluded. Accordingly, a total of twelve women participated in an In-Depth -Interview (IDI) during their follow-up visit and the selection of participants was stopped after data were saturated (meaning we couldn't get new information from the answer responses).

Instrument and Materials

Data concerning the experience of women after mastectomy were gathered using an open-ended interview guide. A semi-structured instrument was developed by the researcher based on the literature. The questions were first prepared in English and translated into the Amharic language. Subsequent probes and follow-up questions were used to continue the conversation. The interview questionnaires were reviewed by a group of experts, on their appropriateness and relevance. Then they suggested that the interview guide was appropriate to collect data. A pilot test was conducted in St. Pawlos Hospital. Three authors conducted an in-depth-interview that took from 35-50 minutes. The researcher took field notes, recorded all detailed information, accomplished interpretation and analysis.

Trustworthiness of The Study

Since, trustworthiness (creditability, confirmability, dependability, and transferability) is the backbone of a qualitative study [18], the researcher strictly used the following strategies to enhance trustworthiness. To ensure credibility, the in-depth interview, debriefing, and adequate information were administered consistently to each interviewee. Sufficient time was allocated for data collection. Data gathering was continued until data saturation, thematic analysis procedures were properly followed, audio-taped records and transcription were repeatedly compared for consistency. Dependability was achieved through the dense description of the methodology used. All interview materials, transcriptions, findings, interpretations, and recommendations were kept. Appropriate supervision, discussion, and responses to any claim from the study participants were made. Three experienced researchers in the qualitative study reviewed the thematic analysis.

Data Management and Analysis

Data were coded, sorted and themes were developed based on the procedure proposed by [19]. Four research investigators were involved in the data coding and analysis. Initially, transcription and translation of the interview material were performed. Words, sentences and paragraphs were the most content of our transcript interviews. Then, the participant's main idea, impression and information were checked. Themes and sub-themes were written into the analytic commentary. The final outputs of the analysis were carefully checked for their relevance.

Results

Participant Description

Twelve women who underwent a mastectomy procedure were interviewed. The participating women aged between 28 and 65 years old. Three-quarters of the participants were Christian followers and 66.7 % of them were housewives. About 41.6% of the respondents have attended primary education and 58.3% of them had > 2 children. Nearly, three fourth of the participants had a unilateral mastectomy with a duration of > 11 months (Table 1).

Further, perceived alteration in body image, perceived psychosocial response after mastectomy, perceived support from family and health professionals and coping with the lost breast were identified and categorized into (1) Perceived alteration in physical and psychosocial aspects (2) Perceived social support and adapting to life after mastectomy (Table 2).

Category 1: Perceived Alteration in Physical and Psychosocial Aspects

Theme 1: Perceived Alteration in Body Image

Participants experienced that they had negative feelings about their body image. They described that the breast was a part of their body, beauty, and attraction. However, some of them felt incomplete after undergoing mastectomy

For example, a 38-year-old woman described:

Breast is a women's identity that is used for many purposes. However, just now I am feeling incomplete because I lost one of my breasts

Further, a 37-year-old woman worried about her body image and explained it this way

The breast is the most important part of a women's body that is used for feeding the baby. But after the mastectomy, I am worried that I can't feed my baby because I don't have the breasts

Theme 2: Perceived Negative Psychosocial Response after Mastectomy

This theme captures aspects of the psychological response underpinning participants. They included feelings of fear, emotion, worry, and anxiety. The experience of having incomplete body parts was especially emphasized by many participants.

For instance, a 53 years-old woman who underwent a bilateral mastectomy depicted that:

Table 1. Demographic Characteristics of Women Interviewed about Their Lived Experience Regarding Mastectomy due to Breast Cancer, at TASH and Cancer Center, Ethiopia, 2020

IDI	Age	Marital status	Educational status	Religion	Occupation	Number of children	Time since mastectomy	Status of mastectomy
M1	42	Married	Primary education	Christianity	Housewife	> two children	11 months	Unilateral
M2	29	Married	Secondary & above	Christianity	Housewife	One child	2 years	Unilateral
M3	56	Married	No formal education	Muslim	Housewife	>two children	5 years	Unilateral
M4	48	Divorced	Primary education	Christianity	Housewife	>two children	3 years	Unilateral
M5	37	Married	Secondary & above	Christianity	Gov't employer	One child	9 months	Unilateral
M6	65	Married	Primary education	Muslim	Private	>two children	4 years	Unilateral
M7	33	Divorced	No formal education	Christianity	Housewife	no children	3 years	Bilateral
M8	46	Married	Secondary & above	Christianity	Gov't employer	>two children	7 years	Unilateral
M9	38	Married	Primary education	Christianity	Housewife	One child	2 years	Unilateral
M10	28	Single	Secondary & above	Muslim	Gov't employer	no children	1 year	Unilateral
M11	53	Married	No formal education	Christianity	Housewife	>two children	1year	Bilateral
M12	34	Married	Primary education	Christianity	Housewife	>two children	6 months	Unilateral

Keys notes: IDI, Individual In-depth Interview; M, Mother; TASH, Tikur Anbessa specialized Hospital

Table 2. Overview of the Two Categories and Themes among Study Participants

Main Categories	Themes
Category 1: Perceived alteration in physical and psychosocial aspects	Theme1: Perceived alteration in body image Theme 2: Perceived psychosocial response after mastectomy
Category 2: Perceived social support and adapting to life after mastectomy	Theme3: Family's emotional response to mastectomy Theme 4: Perceived support received from a health worker Theme 5. Coping with the lost breasts

Both of my breasts were removed. just now I have no breasts. So, I am feeling an incomplete body

For some women, the removal of the breast could be frightening and disappointing.

A 29-year-old participant expressed her feeling

My breast is my beauty! Now I lost it. After surgery, I didn't understand what would happen but I started to cry. I am very disappointed, it is a frustrating condition

In contrast, some women appreciated their life better than the situation they experienced during the course of the disease. A 33-year-old participant who underwent a mastectomy suggested her idea concerning the disease she suffered from.

Before undergoing mastectomy, I was experiencing severe pain. I couldn't eat food or sleep well. Just now I am feeling normal. I am free from that stressful situation. So, I don't worry about that.

Category 2: Perceived Social Support and Adapting to Life after Mastectomy

Theme 3: Family's Emotional Response to Mastectomy

Removal of the breast had a considerable psychosocial impact on the family of women. However, the majority of participants experienced that they received support from their family, kids, friends, and husbands. One 65-year-old participant with 6 children noted that

When I was at the hospital, my kid was with me. He was supporting me physically, and psychologically. So, I was feeling good when I see him. He did a good thing for me.

Further, Participants shared their experiences concerning the role of their family relationship

A 53-year-old participant described the support of her friend.

When I was at the hospital, one of my friends was encouraging me by saying No matter what you lost, you are living well, because people lose their hands and legs this doesn't mean that you will live in a bad situation

The majority of women expressed a good relationship with their husbands. 29-year-old participant acknowledged her husband for his support during the course of her illness

My husband is a very good man. He suffers from many things with me. He worries about me…. And he has tried his best to give care of me.

Conversely, Participants felt that their situation had impacted both personal and family relationships, in terms of the support that they required and their relationship roles. For instance, a 46-year-old divorced woman highlighted a poor relationship and inadequate support from her husband

when you are in this condition some guys don't want to care for you especially, those women who have no breasts like me. When I was at the hospital, my husband was doing his business with his boyfriends and he was not with me… So, I haven't received appropriate care from him. And Just now we are not living together

Theme 4: Perceived Support Received from a Health Professional

Study participants experienced that they had good communication and relationship with the hospital staff. They acknowledged nurses and doctors.

For instance, a 48-year-old woman shared her experience

I was very satisfied with all the service provided to me. All nurses and doctors were very supportive. There was no problem. Because the hospital has many counselors and experts who have very good experience in cancer treatment. So, we can easily communicate with them at any time we want

Theme 5. Coping with the Lost Breast

Participants described a wide combination of experiences of coping strategies towards their mastectomy. They have planned several strategies to cope with the situation. One of the coping strategies that a woman planned to use is to deal effectively with the difficult condition they are in. some women believed to use convincing as a means of coping strategy.

For instance, a 38-year-old participant mentioned:

I have felt so bad. But just now I have to convince myself. Because if you worry you may encounter another problem and worry is not good, so you have to convince yourself

Other participants incorporated the use of social media as means of coping mechanism. For instance, a 33-years-old woman has shared her experience as:

Sometimes I have days where I don't get anything done. I just use social media like Facebook and Instagram and do absolutely nothing

Although mastectomy affects women in different ways, their reactions to it are dependent on personal attributes. A majority of participants believed that they see their situation as the will of God. A 42-year-old Christian follower woman assertively replied:

Because not only your breast but also you may lose your legs and hands…God doesn't tempt us with evil, it's to test our strength and patience like 'Eyob' the woman added more explanation…this situation happened in the will of God.

For some participants, the absence of breasts led them to more belief in God, regardless of negative feelings. These mixed feelings and perceptions about the situation captured by a 56- years old woman with four kids:

Even if the situation was not good, for me, it is not the time to compete with beautiful ladies, rather it is time to turn my face into my religion. The main thing is my health, let Allah give me my health, that is the main thing I need from my God

As a coping strategy, some women think about and compared their situation with others. One 34- years- old woman with three children expressed her situation by comparing it with the young girls.

There was a young girl who underwent a mastectomy for treatment of breast cancer like me. when I saw her, I felt very bad because she had no kid. Just now, I am an old lady, So, I don't worry about that.

Further, a 48-year-old woman compared with worse conditions by saying

I don't feel bad. Because there is someone who has no eye but he was happy and living with us. So, this is simple for me I have the foot and leg to walk

From several participants' perspectives, an important part of psychological adjustment to living with the absence of breasts was the importance of a positive attitude. This was described as a sense of maintaining positive goals, hope and a positive mindset: They planned to use clothing styles for the fear of social stigma.

For instance, a 46-year-old participant incorporated the use of a sponge during performing activities

I will survive and I can do my job it's just a sponge. So, I will put on a sponge It seems like an actual breast. I Have normal hands and legs, So, I don't need any help from someone else to complete my activities

Further, a 28- year- old woman highlighted that

By nature, my breast was so small. When I first check out the site of surgery, I felt victorious because I had been looking at it many times. This thing kept getting higher and higher (laughs).

Discussion

Incontrovertibly, mastectomy increases a serious psychological and physical impact on women due to permanent surgical alteration of their breasts. In this study, participants described experiences alteration in their body image due to the surgical removal of breasts. Participants described the breasts as a sign of beauty, and identity for them. Further, some women consider it to be a source of milk that is used for feeding a baby. This finding is similar to the previous study which stated breasts are a sense of femininity, beauty, motherhood, and attraction [20].The loss of breasts can change a woman's dressing style and body image because it is the most important feature of womanhood [8]. Similar expressions like feeling half, incomplete, and disabled were mentioned commonly in another study [6, 21]. The difference in perception of the women about their bodies indicates that most women didn't accept their body image after mastectomy due to alteration in their bodies.

The impact of mastectomy is not only described by body image but also has a psychosocial impact on a woman's perception. In the current study, many women expressed different feelings when they heard information about the removal of breasts. The majority of women reacted by crying, feeling bad, and hurt inside. Prior studies related to this issue have reported that many women expressed their emotions negatively and reacted in a bad situation when they heard about the lost breast [11, 22]. Providing the right information to patients has a significant impact on the psychosocial of patients and family as well [12].

Although the removal of the breast had a considerable psychosocial impact on the family of the woman, the majority of women who underwent mastectomy shared their experience regarding the support they received from their families such as kids, husbands, and friends. They noted that they received effective emotional support from their husbands and considered it as the main reason for returning to their normal mental state. It is well-documented that family support is crucial for women

who underwent mastectomy [11, 23, 24]. On other hand, one participant shared a different opinion that she didn't receive effective support from her husband. Women with breast cancer need physical, psychosocial, and emotional support from family and healthcare professionals [12, 24]. This can help them to early recover from their illness and it can also encourage the women to forget the challenge they faced in their life.

In the current study, participants shared their experiences of care and treatment they received from healthcare professionals. Moreover, they appreciated the oncology nurse and doctors. Particularly, the information they received about the risk and benefits of having mastectomy was a crucial for making decisions. Previous research studies have shown that healthcare professionals can play a significant role in providing counseling and reassurance for women with breast cancer [23, 25]. Most importantly, women with breast cancer need physical, psychological, and emotional support from multidisciplinary healthcare professionals [25, 21]. Therefore, all healthcare professionals especially, nurses have a professional responsibility for providing health education and counseling for a patient who underwent surgical treatment.

The current study found that the majority of women make use of various coping strategies including convincing, self-acceptance, destruction, social engagement, religious practices and lifestyle adjustments. This finding is consistent with several studies conducted on the lived experience of women who underwent mastectomy due to breast cancer [21, 20, 26]. This issue might be that women gradually accepted the reality and used such coping strategies for living a better quality of life. Moreover, coping strategies are characterized by viewing or thinking of different ways to solve a problem [26]. Therefore, no single action is used as a coping mechanism, but a combination of behavioral and cognitive skills is used to manage a stressful condition like the removal of breasts. All concerned bodies especially healthcare professionals should encourage patients by arranging continuous follow-ups to provide health information and counseling.

In conclusion, this study demonstrated that the removal of the breast had a considerable physical and psychosocial impact on the perception of women. To overcome the challenge, many women highlighted that they received support from various sources, used various coping strategies, and accepted the situation they faced. However, they need comprehensive care including physical, psychological and emotional support from family, society and healthcare professionals.

Strengths and Limitations

The current study is the first to thoroughly explore the lived experience of Ethiopian women after mastectomy due to breast cancer. This study provides significant information on the lived experiences of women after mastectomy. However, our study has some limitations: first, we used only an in-depth- interview with a limited number of participants. Second, the study was conducted only in one hospital, however, In Ethiopia, advanced cancer treatment like mastectomy is offered only in TASH. Hence, it is hoped that this study finding will contribute to improving the gap elaborated by study participants and it shows many directions for future research.

Author Contribution Statement

This paper is the result of joint research, and all authors made a significant contribution to the work reported. Meron Hailu Teshome, Nigusie Tadele Atinafu and Boka Dugassa Tolera searched the literature, conducted data collection, and data analysis, and wrote results and interpretations. Yohannes Ayalew Bekele have supervised the study, conceptualized the paper, actively participated in data analysis, manuscript preparation, and reviewed the document for publication. All authors read and approved the final manuscript

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This paper is the result of joint research, and all authors made a significant contribution to the work reported. Meron Hailu Teshome, Nigusie Tadele Atinafu and Boka Dugassa Tolera searched the literature, conducted data collection, and data analysis, and wrote results and interpretations. Yohannes Ayalew Bekele have supervised the study, and reviewed the document for publication.

This research is approved by the Institutional Review Board (IRB) of the Addis Ababa University college of health science with a protocol (number Ref: 037/20/ SNM, dated 09/2012 E.C) and nonfunded. No conflict of interest exists between the authors. The datasets used and analyzed during the current study are available without restriction.

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Ethical Approval and Consent

This research was approved by the Institutional Review Board (IRB) of the Addis Ababa University college of health science with a protocol (number Ref: 037/20/ SNM, dated 09/2012 E.C). Before the commencement of the study, both written and verbal consent were obtained from each respondent based on the educational level of participants. The objectives and importance of the study were informed to the participants in accordance with the Declaration of Helsinki. All study participants were informed that their participation in the interview was voluntary and they had the right to withdraw from the interview at any time they wanted. To ensure participants' confidentiality and anonymity, codes, and identification numbers were used in interview questionnaires, audio recordings, and transcriptions. The audio-recorded information and transcript files were stored and kept on a password-protected computer with access limited to the principal investigators.

Conflict of Interest

The authors declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article

Data Availability

The datasets used and analyzed during the current study are available without restriction.

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