

Research Article

# Postmastectomy Experiences of Reproductive-Age Women (15-49), Harar, Ethiopia: A Qualitative Study

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## Abstract

**Background:** Despite contemporary initiatives to raise breast cancer awareness, mastectomy as a surgical therapy for breast cancer may have a detrimental impact on a woman's life. Intervention to address the variety of challenges encountered in their personal and family lives postmastectomy is the other side of therapy. **Purpose:** The aim of this study was to examine the experiences of reproductive age (15-49 years old) women's lives after breast surgery for breast cancer. **Methods:** This qualitative study was conducted at a tertiary cancer center in Harar, Ethiopia, between February and March 2023. Study setting, and participants selected using the purposive sampling technique and interviewed individually using a semi-structured interview guide with the assistance of a voice recorder. The data were transcribed verbatim and analyzed using a thematic approach. **Results:** Five main themes emerged from the data: body image changes, relationships with husbands and sexual life, health risks, silent stigma and perception of sinfulness by society, and coping with life postmastectomy. **Conclusions:** Following a mastectomy, women face various challenges emanating from their own perceptions, their husbands, and society. The study's findings are helpful in advancing knowledge of a variety of challenges encountered postmastectomy and coping strategies. It is essential to actively incorporate psycho-emotional and husband-supportive rehabilitation into their care, creating community awareness to solve misconceptions, and additional multi-perspective research.

## Keywords

Postmastectomy, Breast Cancer, Dire Dawa

## 1. Introduction

Despite continued medical advancements, breast cancer continues to be the second most common and lethal cancer in women globally [1]. Africa has the highest death and incidence rates for breast cancer, particularly in sub-Saharan African nations [2]. Likewise, the bulk of the affected ladies

in Ethiopia are relatively young, which is a concern for Ethiopia and the communities in the research area [3-6].

Despite contemporary initiatives to raise breast cancer awareness, mastectomy as a surgical therapy for breast cancer may have a detrimental impact on a woman's body image

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due to cultural context, social taboos, and patriarchal structure [7-9]. As a result, in addition to the physical side effects of the illness and its therapies, they often have mental issues [7, 8, 10]. Additionally, one of the main causes of delayed presentation and the stigma attached to mastectomy continues to be fear of the procedure [7].

Mastectomy has significant effects on women's psychology related to body image and sexual function because many women's breasts are viewed as sexually attractive [8, 11-15]. So far, studies reveal different coping mechanisms which are employed by women who have mastectomy, including positive rational acceptance, sociocultural coping mechanisms, and support groups, which may help them lessen their anxiety through the sharing of information [15-17].

Women can improve their body image by participating in an effective psychological rehabilitation program and being aware of their efficient coping mechanisms [16-18]. Concerns about the quality of postmastectomy care must be addressed because mastectomy in women of reproductive age is widespread [8, 11, 12, 19, 20]. The mastectomy is also increasingly popular as a surgical option for treating breast cancer in Ethiopia [3-6, 19]. However, both nationally and in the research region, there is a dearth of information regarding worries about the living experiences of women post-mastectomy. Thus, the purpose of this study was to investigate the experiences of reproductive-age (15-49) women who had undergone a mastectomy due to breast cancer. This may assist in producing data that may address the concerns of patients who need mastectomy at a young age and identify crucial elements of postmastectomy care intervention.

## 2. Methods

### 2.1. Study Setting

The study was conducted at the Hiwot Fana specialized university hospital (HFSUH) oncology center in Harar city, which is located about 526 km away from Addis Ababa, the capital city of Ethiopia. HFSUH is a teaching hospital at Haramaya University that delivers wider healthcare services to approximately 5.2 million people in the catchment area. It has different service areas, including the chronic disease outpatient department (OPD), emergency OPD, medical, surgical, pediatric, psychiatry, gynecology, obstetrics wards, intensive care unit (ICU), and oncology centers.

### 2.2. Researcher and Interviewer Characteristics

All five authors hold master's degrees in different health fields: three in maternity and reproductive health and two in maternity and neonatal nursing. The principal researcher (AM) provided overall leadership to the work. The research team consisted of two females and three males with experience in teaching at public universities, qualitative research studies, and community services in urban and rural areas.

The research teams had no prior relationship with the participants, and participants were unaware of the researchers. The interviewers, three women with first degrees in clinical psychology, were selected from Harar city. They all spoke local languages (Afan Oromo and Amharic) and had experience in qualitative interviews.

### 2.3. Research Design

The study was a qualitative, semi-structured interview that involved individual women who had undergone breast surgery due to breast cancer. This methodology was chosen because it does not assume a specific mindset and allows for personal narratives to evolve into general ideas and themes.

#### 2.3.1. Sampling Strategy

Both the study setting and study participants were selected using a purposive sampling technique. Participants were selected based on information obtained from the oncology center after describing the purpose of the study and confidentiality security. Participants were eligible to participate in the study if they were between 15 and 49 years of age, had undergone mastectomy for breast cancer in the year 2022 and more than three months just to get adequate post-surgery experiences, and had an alive husband at the time of the interview (to provide informed consent for women age between 15 and 18). However, those who were severely ill and unable to communicate at the time of the data collection period were excluded.

#### 2.3.2. Data Collection Methods

An interview guide was developed from a review of the literature [8, 11, 12, 20]. Audio recording was also used. The interview guide is available in the appendices (appendices I and II). Participants contacted through phone, and voluntary participants noted and identified their living kebele along with community health extension workers help. Then participants were informed of the purpose of the interview and audio recordings and that every piece of information they provided would remain confidential (their identities and answers would remain confidential) and would be used for research purposes only by the principal author and interviewers. All interviews were conducted individually at participants' home compound by local language and lasted between 40 and 55 minutes. The interviews were conducted between February and March 2023.

#### 2.3.3. Ethical Considerations

Study participants were interviewed after obtaining ethical clearances from the Hiwot Fana specialized university hospital (HFSUH) oncology center. Two consent forms were signed per participant prior to the interview. One form was handed to the interviewers, and the other remained with the participant. All information obtained was kept confidential

during all stages of the study. The collected data were used only for the purpose of the study.

### 2.3.4. Data Analyses

The data analysis method used in this study was Maguire and Delahunt's six-step approach: 1) developing familiarity with the data through reading and reflection; 2) generating initial codes; 3) searching for themes; 4) reviewing themes; 5) defining themes; and 6) reporting themes [21, 22]. The data were transcribed verbatim, and content analysis was used to code the data. During the data analysis, the authors read the transcripts line by line to identify codes. The codes were then collapsed into themes, and the themes were linked to literature, and finally, a point of view was created. Transcripts were analyzed; recurrent, dominant, and divergent narratives were identified. Transcripts were segmented into quotes bearing meaningful concepts, which were then categorized and labeled. These were further organized into themes and subthemes on the basis of similarities and differences between contexts and phenomena. The iterative process of coding and fine-tuning allowed for the refinement of theoretical constructions through the linking or integration of categories around core themes. The initial coding was done by one of the PIs, and the fine tuning was done by supporting researchers, both with experience in qualitative data analysis. To reduce projection and thematic leading, researchers who conducted the analyses were not involved with the interviews. Postmastectomy experiences, and coping strategies were included based on a single mention, and the document was thoroughly reviewed using the COREQ (Consolidated Crite-

ria for Reporting Qualitative Studies) check-list.

### 2.4. Trustworthiness of the Data

Trustworthiness involves the following factors: 1) credibility (in preference to internal validity), 2) transferability (in preference to external validity or generalizability), 3) dependability (in preference to reliability), and 4) conformability (in preference to objectivity [23]). Thus, to enhance trustworthiness, the pilot interview guide was tested two weeks before the actual interviews with the two participants. Two days of training were provided to the interviewers regarding procedures, how to approach participants, interviewing and discussing sensitive issues, and using voice recordings. All interviews conducted in the local dialect were translated into English and transcribed verbatim; content analysis was used to code the data. The collected data were stored on a secure and password-protected computer by the corresponding author and co-authors. No names or specific identifiers were used in the data processing, analysis, or dissemination of research results. Participants' responses were anonymous on tape.

## 3. Results

Fourteen women were involved in the interview over a two-month period. Participants' ages ranged from 40 to 48 years old. Except for three, eleven had one breast surgery, and all were married [Table 1].

**Table 1.** Demographic characteristics of participants, Harar, Ethiopia, 2023.

Variables	Category	Frequency and percentage
Age (in completed years)	40-45	5 (35.7)
	>45	9 (64.3)
Residence	Urban	8 (57.1)
	Rural	6 (42.9)
Marital status	All married (have husband)	14 (100%)
Education level	No formal education	2 (14.3)
	primary level (1-8 <sup>th</sup> )	7 (50)
	high school (9-12 <sup>th</sup> )	1 (7.1)
	Diploma	4 (28.6)
Occupation	Housewife	3 (21.4)
	Merchant	11 (78.6)
Religion	Muslim	2 (14.3)
	Orthodox	5 (35.7)
	Protestant	7 (50)

Variables	Category	Frequency and percentage
Number of children	1-3	9 (64.3)
	>3	5 (35.7)
Time since mastectomy	3-6 months	5 (35.7)
	>6 months	9 (64.3)
Breast surgery	Only one breast	11 (78.6)
	Both breast	3 (21.4)

### 3.1. Themes

Five main themes emerged from the data, namely body image changes, relationships with husbands and sexual life, health risks, silent stigma and perception of sinfulness by society, and coping with life postmastectomy.

### 3.2. Body Image Change

Removal of the breast had a substantial negative impact on participants' perceptions. These include displeasure with appearance, perceived loss of womanliness, feeling less sexually good-looking. A participant stated that "I feel dissatisfaction when I see the removed breast; you know, no one explained to me about the life changes after the removal of that breast... Due to this, I am dissatisfied with my body generally." The other one said, "I previously had hope to have at least five children; now I have only three females and no male. I lost hope for my body and future birth. I am so displeasure with myself".

They also explained that they feel dissatisfaction and lack self-confidence while seeing their surgical scars. A participant narrated, "Due to some depression, when I look at the breast scar, I avoid looking myself in the mirror, feeling less sexually attractive. You now men like compressing our breasts, which is natural, so I lack self-confidence". Besides, another participant stated that "I feel that I am not sexually attractive to my husband; my confidence was lower after my breast was removed".

### 3.3. Relationship with Husband and Sexual Life

The majority of participants believed that breasts were foci for sexual arousal, and after mastectomy, it became difficult to become sexually aroused. Participants explained that they experienced decreased libido after mastectomy. They also revealed that they face challenges in their perceptions of their husband, thinking that their husband thinks that the woman is not sexually active. Because of such perception, they again worry that their husband will associate with other women for his sexual interests. A participant narrated,

"Breast surgery makes me sorrowful thinking that my husband will associate with other women to satisfy his sexual interest; mine has already died." Another participant stated that "after my breast surgery, my husband decreased his sexual connection with me. I also do not have sexual urges, and as a result, I worry for both of us".

### 3.4. Health Risks

Some participants disclosed that after mastectomy they face STIs (sexually transmitted infections) because their husbands started hidden sexual relationships with other females. A participant narrated, "My hope is becoming black; after breast surgery, I have been infected with HIV/AIDS since my husband went away and had sexual relations with other women that I do not know, including at bars." Likewise, the other one narrated, "After breast surgery, obviously, my husband became imprudent; I mean, he started drinking and having sexual relations illegally with other females; more than three people informed me. After I heard this, I took a test and became positive for HIV infection."

In addition, some participants revealed that they face insomnia challenges postmastectomy. A participant stated that "beside lacking pleasure in my life, I suffer from insomnia".

### 3.5. Silent Stigma and Perception of Sinfulness by Society

Participants disclosed the silent stigma and perception of sinfulness by family and society. They disclosed that after mastectomy, they face societal challenges, including near families, considering women who have undergone mastectomy as sinful people. They also disclosed families and societal silent stigma due to families and societal perception that mastectomy women have cancer and can transmit it. Then they followed the stigma secretly. There is a community fear of the word "cancer." This follows stigma and considers mastectomy women sinful or the breast cancer, and the mastectomy is due to the woman's sinfulness.

A participant narrated, "Many people consider me to have cancer, although surgery is done, and perceive it as conta-

gious, although they do not say it orally, in familial and societal activities that marginalize me obviously, for example, in a wedding, birth date.” The other one stated that “I feel bad very most when my neighbors murmur considering my breast removal as a result of my sin. My neighbors have told me this many times to other societies; I have heard many times.”

Besides, another participant said, “People in my village say the word “cancer” makes them shake, including my family. Although surgery is done, they still consider me cancerous and limit my familial and societal activities.”

### 3.6. Coping with Life Postmastectomy

Participants disclosed some mechanisms to help cope with postmastectomy life.

### 3.7. Disclosing the Mastectomy

Some participants revealed that it was undisclosed as a coping mechanism. A participant stated that “to avoid people asking questions about what happened to me, I avoid public disclosures like breastfeeding and swimming.” The other one said, “Just to keep my children’s psychology, I avoid exposing myself in front of them or mirroring myself in front of them”.

### 3.8. Filling the Mastectomy

A participant narrated, “To protect my children's psychology, I put a sponge in place of my removed breast.”

The other stated that “I use an artificial breast in place just to avoid people’s questions; they ask, what happened to you? Such questions make me depressed more than the breast surgery.”

### 3.9. Acceptance and Religious Practice

Some participants use acceptance and religious practice as coping mechanisms. A participant stated that “since this is God’s decision, what can I do?” Another one said, “Once the breast is gone away, I think Allah has a plan to save my life; if it were not, I may die, so pray to my Allah, and due to this, when I feel sad, I pray and listen to religious thoughts.”

### 3.10. Psychotherapy

A participant narrated, “After my breast surgery, I experienced lack of hope, sadness, and suicidal thoughts. After a while, someone suggested I go to a clinical psychologist in a hospital. Then I joined that and got psychotherapy. After that, I feel good.”

## 4. Discussion

This qualitative study examined the postmastectomy expe-

riences of reproductive-age women (15-49) who had gone mastectomy due to breast cancer. The findings revealed that women experience a variety of psycho-emotional and health challenges after their mastectomy for breast cancer, including body image changes, relationships with husbands and sexual life, health risks, silent stigma, and perception of sinfulness by society. The impact of these challenges on their personal lives underscores the need to actively incorporate psycho-emotional and husband-supportive rehabilitation into their care. The themes identified in this study may be useful in developing a psycho-emotional and husband-support rehabilitation model for young women after mastectomy. The findings explored after mastectomy challenge women's body image. Studies affirm mastectomy alone has been associated with significantly higher psychosocial indisposition in terms of body image [7-9]. Mastectomy is also associated with significantly emotional problems [7, 8, 10]. This implies health care professionals must explore the role that can play in assisting new patients regarding body image as an effective coping mechanism. From the data, after mastectomy, women also face various sexual challenges. Earlier studies also evaluated this; mastectomy caused major negative impacts on sexual functioning or sexual relationships [12-15]. This implies intimacy and sexual relations are aspects of patient and spousal education and counseling that must be given adequate attention. The psycho-emotional and sexual relationship illness of mastectomy on young women should therefore serve as an additional motivation for improving women’s emotional therapy services after mastectomy.

As per the findings, postmastectomy women face new health risks like STIs (sexually transmitted infections) because of their husbands. This implies that although women are the focus, it is important to carefully incorporate husbands into psycho-emotional and sexual issue counseling.

Likewise, this study examined that postmastectomy some women are facing insomnia, which affects their daily activity due to drowsy feelings at daytime. By highlighting the surgical consequences of mastectomy preoperatively, surgeons may better set realistic patient expectations regarding both aesthetic and functional outcomes after breast cancer surgery [24]. This suggests further clinical research on the relationship between mastectomy and sleeping pattern and needs critical attention for intervention. The men’s experiences postmastectomy regarding their sexual perception, experience of emotional distress arising from their wives’ altered bodies, complex coping behaviors, and closed communication also our suggestion to be researched well. Interventions involving only the woman have been considered suboptimal. It is therefore important to include couple counseling on sexual issues as part of the rehabilitation process.

Until so, the provision of adequate information to men may help overcome these challenges.

Besides, postmastectomy, women face challenges related to family and societal misperceptions that lead to stigma and

psychological pain. Therefore, it is essential that husbands, families, and communities be given sound awareness about the condition through mass media or community education programs to solve such challenges. The study also examined women's mechanisms of coping with life postmastectomy, including disclosing the mastectomy, filling the mastectomy, acceptance and religious practice, and psychotherapy. Studies also revealed women use different coping strategies postmastectomy, like rational acceptance and supportive groups, which could help them reduce their worry through information exchange [15-17]. Awareness and information exchanges are coping strategies required to improve their body image and reduce their worry [16-18]. This implies effective coping strategies, a psychological rehabilitation program, and being aware of their positive coping strategies have been shown to have some benefit. This study also shows postmastectomy women using different coping tactics, including sponges and artificial breasts with a breast holder in place, acceptance, religious practice, and being unexposed to people, like during swimming. The religious inclinations of several participants also suggest important roles for faith leaders in the rehabilitation process. Furthermore, this study explored psychotherapy as a new coping mechanism after mastectomy, which was reported to reduce their psychological and emotional worry and increase their hope in life. This finding can be further explored and used to develop interventional programs. Thus, the findings of this study have implications for society, healthcare practices, and future research. Health care leaders and staff need to consider mastectomy women in health care services, including addressing misconceptions, psycho-emotional counseling for both women and their husbands, and what to do as a coping mechanism. Societal implications include the need to address community awareness to clear misconceptions ("breast cancer is contagious to men or the next generation") and husband and social support. Furthermore, future research needs from different perspectives (husband, health service providers, and community) to dig up further evidence.

#### 4.1. Study Strengths

The study design enabled in-depth inquiry into the experiences of women after their mastectomy. To the best of our knowledge, this study is the first to use a qualitative approach to explore the experiences of women after their mastectomy and their competing strategies in the study region. This study identified coping strategies in addition to their worrying life experiences postmastectomy. The study used a diverse participant (from urban and rural dwellers). The accuracy of the data was improved by the use of primary data as well as experienced interviewers.

#### 4.2. Study Limitation

The study only included participants' perspectives and did

not assess husbands' and healthcare service providers' perspectives, which was a limitation of this study.

## 5. Conclusions

Following a mastectomy, women face various challenges emanating from their own perceptions, their husbands, and society. The study's findings are helpful in advancing knowledge of a variety of challenges encountered postmastectomy and coping strategies. It is essential to actively incorporate psycho-emotional and husband-supportive rehabilitation into their care, creating community awareness to solve misconceptions, and conduct multi-perspective research.

## Abbreviations

STIs	Sexually Transmitted Infections
HIV	Human Immunodeficiency Virus
AIDS	Acquired Immunodeficiency Syndrome

## Acknowledgments

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## Author Contributions

**Aminu Mohammed Yasin:** conceptualization, data curation, formal analysis, funding acquisition, investigation, methodology, project administration, software, resources, supervision, validation, visualization, writing the original draft, writing review, and editing

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**Neima Ridwan Abdu:** Data curation, formal analysis, funding acquisition, investigation, methodology, project administration, software, resources, validation, writing the original draft, writing review, and editing

## Ethics Approval and Consent to Participate

Ethical approval was obtained on January 20, 2023, from the Health and Research Ethics Committee of Hiwot Fana specialized university hospital (File-HFSUH-019/Jan/2023). Written consent was obtained from the oncology center, and informed written consent was obtained from all study participants. All protocols were carried out in accordance with the relevant guidelines and regulations of Helsinki.

## Declaration

We confirm that the manuscript has been read and approved by all named authors and that there are no other persons who satisfied the criteria for authorship but are not listed. We further confirm that the order of authors listed in the manuscript has been approved by all of us.

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The author (s) received no financial support for the research, authorship, and/or publication of this article.

## Data Availability Statement

The datasets collected and analyzed for this study are available from the corresponding author and can be obtained upon reasonable request.

## Conflicts of Interest

The authors declare no conflicts of interest.

## Appendix

### Appendix I: Preamble

Thank you so much for meeting with me today and agreeing to participate in this interview. I want to remind you that what you say here is confidential and will not be linked back to you or your families or identify you in any way. I am recording this interview so that I can transcribe it. This means I will type out the words said in this interview into a secure document for analysis. There will be no identifiers on the transcripts. The de-identified transcripts will be accessed by other members of the research team to perform the analysis. The purpose of this interview is to explore your postmastectomy experiences in order to better understand and help with interventions in the health care services. We are here to learn from you, so anything you have to share is welcome. There are no right or wrong answers.

### Appendix II: Semi-structured Question Guide

Good morning or afternoon... Thank you once again for your willingness to do our interview. Can I start the interview?

Can you please explain what goes on in your mind when you look at yourself in the mirror?

How have your relationships with your husband been since you had breast surgery?

What has been your experience with your spouse after your breast surgery?

What things are bothering you that you have not had the opportunity to talk about and that you wish to tell your doctor or someone who cares to listen about?

We really appreciate your time and insight. Thank you once again.

Do you regret having breast surgery?

What do you do to avoid worrying about breast surgery?

We have finished. Anything you want to say... Is there anything else that you think we should know-----?

Thank you very much!

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## Research Field

**Aminu Mohammed Yasin:** Health and Medical sciences

**Ahmedin Aliyi Usso:** Health and Medical sciences

**Leyla Abrar Bedru:** Health and Medical sciences

**Hassen Mosa Halil:** Health and Medical sciences

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