

# **LIVED EXPERIENCES OF POST MASTECTOMY WOMEN AT AIIMS, JODHPUR**

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Master of Science in Nursing  
(Medical Surgical Nursing- Oncology Nursing)

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## **DECLARATION BY CANDIDATE**

I hereby declare that the thesis entitled “Lived experiences of post mastectomy women at AIIMS, Jodhpur” is a bonafied work carried out by me under the guidance of Mrs. Vandna Pandey, Assistant Professor (Medical-Surgical Nursing), College of Nursing, AIIMS, Jodhpur, Dr. Puneet Pareek, Additional Professor and Head, Department of Radiation oncology, AIIMS, Jodhpur and Dr. Ashok Kumar, Associate Professor (Medical- Surgical Nursing), College of Nursing, AIIMS, Jodhpur. No part of this thesis has formed the basis for award of any degree previously.

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## **LIST OF ABBREVIATIONS USED**

WHO- World Health Organisation

ICMR- Indian Council of Medical Research

FICCI FLO- Federation of Indian Chambers of Commerce and Industry Ladies  
Organization

TRAM flap- Transverse Rectus Abdominus Musculocutaneous flap

## ABSTRACT

**Introduction:** Women breast have biological function to lactate, also socially and culturally seen as sensual, and the essence of her femininity. In the both developed and developing countries, breast cancer is the most constantly occurring non-cutaneous cancer among women. There are numerous literatures in the western countries regarding the experiences of post mastectomy women, but unfortunately, this topic has barely explored in India. Now a day, nurses not only give physical care but also provide education and counseling to resolve emotional conflicts and develop coping strategies.

**Objective:** The main objective of the study was to explore the lived experiences of post mastectomy women.

**Method:** A phenomenological study was conducted on post mastectomy women at radiation unit of AIIMS Jodhpur. Total of 14 women were recruited through the non-probability convenience sampling technique based on data saturation, and the data was collected using in-depth interview schedule in a period of 2 months after obtaining permission from institution ethical committee. Interviews were firstly audio-recorded and transcribed, and then themes and sub-themes were extracted.

**Result:** Women verbalized a range of experiences after the mastectomy. The data was analysed using the Colaizzi's framework (1978) and ATLAS ti. 9 scientific software. This revealed that lived experiences of post mastectomy women, can be divided into five main themes which are Body image changes, Physical impacts, Emotional impacts, Treatment impacts and Coping and support sources.

**Conclusion:** Our findings highlight that mastectomy as a surgical treatment may negatively affect a woman's body-image. Thus it is highly recommended to address individual women psychosocial needs and preferences before undergoing for mastectomy in the education sessions by physician involving nurses along with them and also proper knowledge about reconstructive procedures should be provided to improve their body image. The counseling sessions should be conducted at least two weeks after the mastectomy on a particular day every week by the professional counselor or nurses should be given this responsibility after arranging proper continuing or in-service education programs, so that they can help such women to cope with their life situation effectively.

**Keywords:** *body image, breast cancer, coping sources, lived experiences, post mastectomy, women.*



## TABLE OF CONTENTS

<b>Chapter No.</b>	<b>Title</b>	<b>Page No.</b>
<b>I.</b>	<b>Introduction</b>	
	• Background of the study	1-5
	• Need of the study	5-8
	• Aim of the study	8
	• Statement of the problem	8
	• Objectives	8
	• Operational definitions	9
	• Delimitations	10
<b>II.</b>	<b>Review of literature</b>	11-18
<b>III.</b>	<b>Methodology</b>	
	• Methodology flow chart	19
	• Research approach	20
	• Research design	20
	• Variables under study	21
	• Study setting	21
	• Target population	21
	• Sample and Sampling technique	22
	• Sample selection criteria	22
	• Description of tool	23-24
	• Validity of the tool	24
	• Ethical considerations	24-25
	• Pilot study	25
	• Data collection procedure	25-27
	• Rigor	27-29
	• Plan for data analysis	30
<b>IV.</b>	<b>Analysis and interpretation</b>	
	• Result	31-38
	• Description of themes and subthemes	39-80
	• Discussion	81-87
<b>V.</b>	<b>Summary, Conclusion, and Recommendation</b>	
	• Summary of findings	88
	• Limitations of the study	89
	• Implications	89-92
	• Recommendations	92
	• Conclusion	92-94
	<b>References</b>	95-99
	<b>Annexures</b>	100-151

## LIST OF TABLES

Table No.	Title Page	Page No.
1.	Frequency and percentage distribution of post mastectomy women and demographic variables	32-33
2.	Table for themes and subthemes	38

## LIST OF FIGURES

Figure no.	Title	Page No.
1.	Schematic presentation of research methodology	19

## **LIST OF ANNEXURES**

- Annexure Ia: Tool for the data collection (Hindi)
- Annexure Ib: Tool for the data collection (English)
- Annexure II: List of experts for tool validation
- Annexure III: List of experts for validation of themes and subthemes
- Annexure IV: Permission letter from institutional ethical committee
- Annexure Va: Informed consent form (Hindi Version)
- Annexure Vb: Informed consent form (English Version)
- Annexure VI: Bracketing
- Annexure VII: Table for detailed characteristics of post mastectomy women
- Annexure VIII: Transcripts of interview

# **Chapter I-**

# **Introduction**

## INTRODUCTION

*"Optimism is the faith that leads to achievement; nothing can be done without hope."*

*Helen Keller*

## BACKGROUND

The non-communicable diseases have emerged as major health concern worldwide due to improved longevity, changing lifestyle and better control of infectious diseases, mainly in developing countries. After cardiac diseases, cancer has emerged as an important cause of morbidity and mortality in India.<sup>1</sup> Cancer is a vast group of diseases which occurs and starts in almost any organ or tissue when there is an uncontrollable and abnormal cell growth going beyond their usual boundaries to invade various neighbouring parts of the body and/or spread to other organs.<sup>2</sup> This word 'cancer' can bring out the exorbitant fear among every person in the world. According to World Health Organisation (WHO), it is the second leading cause of death globally, and found responsible for approximately 9.6 million deaths in 2018. Globally, about 1 in 6 deaths is due to cancer.<sup>3</sup> It was estimated that India had 1.16 million new cancer cases in 2018, as per the report by the WHO, which also mentioned that 1 in every 10 Indians will develop cancer during their lifetime and 1 in 15 will die of this disease.<sup>4</sup>

Women breast have biological function to lactate, also it is socially and culturally seen as sensual, the mark of her womanhood and the essence of her femininity.<sup>5</sup> For the most people, it is a token of femininity and an precious

organ for child rearing.<sup>6</sup> It is considered as a main feature of woman's identity in many cultures and also represents beauty, motherhood, and feeding organ for infants.<sup>7</sup>

Breast cancer is a disease which begins in cells of different parts of the breast and grows out of control.<sup>8</sup> In the both developed and developing countries, it is considered as most constantly occurring non-cutaneous variant of cancer in women.<sup>5</sup> As per the WHO, the incidence of breast cancer is rising in the developing countries because of increase in life expectancy, increase urbanization and adoption of the western lifestyles.<sup>9</sup> The frequency of this cancer's occurrence is more in the menopausal females than younger ones<sup>10</sup>, impacting 2.1 million women each year, and also causes the greatest number of cancer-related deaths among women as reported by WHO.<sup>11</sup> Also in 2018 this organisation estimated that 627,000 women died from breast cancer that is approximately 15% of all cancer deaths among women and as already known, breast cancer rates are higher among women in more developed regions but rates are increasing in nearly every region globally.<sup>12</sup>

Carcinoma of the breast is the most common cancer among women in many regions of India and has overtaken cervix cancer, which was the frequent cancer a decade ago.<sup>13</sup> The Indian Council for Medical Research (ICMR) mentioned in their news in 2019, that there are 1.5 lakh new breast cancer cases in India, out of which 70,000 succumb every year.<sup>14</sup> Now it has ranked first in Indian women among all cancers with mortality 12.7 per 100,000 women and age adjusted rate as high as 25.8 per 100,000 women. Data reports from many latest national cancer registries were compared for

incidence and mortality rates. It was found in various cities of India, that the age adjusted incidence rate for breast cancer women was highest in Delhi i.e., 41 per 100,000 women, then Chennai (37.9), and followed by other districts like Bangalore (34.4) and Thiruvananthapuram (33.7).<sup>15</sup> According to the government's National Cancer Registry Programme, the number of breast cancer cases in India is expected to increase to around 180,000 by 2020 from 134,000 in 2015. As per the latest Call for Action report by EY and FICCI FLO (Federation of Indian Chambers of Commerce and Industry Ladies Organisation) India ranks after China, US and the African region in incidence of breast cancer.<sup>14</sup>

Cause of the breast cancer is no single or specific; rather, there is a combination of many factors like genetic, hormonal, and probably environmental which may allow the formation of breast cancer in any women. These various causes can involve early menarche, nulliparity, primipara after 30 years of age, and late menopause but as minor risk factors. It is considered that all these factors can cause the prolonged exposure to estrogen because of menstruation thus increasing more risk of breast cancer. The main gene i.e., BRCA-1 mutation is concerned with the development of breast and ovarian cancer, whereas a mutation in the BRCA-2 gene has been identified as linked to breast cancer only. There are many ways which are optimal for preventing breast cancer like 30 to 60 minutes of exercise per day at a moderate intensity. Also breastfeeding which decreases its risk because of limited exposure to endogenous estrogen and also prevents the return of menstruation. We can manage the stress caused by cancerous condition



through the use of various activities such as meditation, prayer, or involvement in support groups, which may act as protective factor.<sup>16</sup>

Breast cancers can occur anywhere in the breast tissue, but most commonly found in the upper outer quadrant as the most of the breast tissue is located there. Generally, these cancerous lumps are nontender, fixed, and hard with irregular borders. Most of the women mainly complaints of diffuse breast pain and tenderness while menstruation which is usually associated with benign breast disease and does not indicate the cancer. While marked pain at presentation, however, may be linked to breast cancer in the successive stages.<sup>16</sup>

Surgery has been found to be an inevitable part of breast cancer treatment. There is use progressive breast conservation since 1970s, nevertheless majority of females choose to undergo mastectomy now a day's along with or without axillary clearance.<sup>5</sup> Talking about various surgical operations for breast cancer cure, the most prevalent was modified radical mastectomy (63%), while breast conserving surgery (36%) was the second most often used.<sup>10</sup> Modified radical mastectomy is removal of the entire breast tissue, along with axillary lymph nodes while the pectoralis major and pectoralis minor muscles remain intact.<sup>16</sup>

The women experience number of changes after undergoing most frequently used mastectomy, as it is considered as an invasive and aggressive surgery which can result in traumatic effects on women's health and life.<sup>10</sup> Every individual woman may have multiple meanings about the loss of a breast after mastectomy and also it has a drastic impact upon their body image which can

trigger conflicting emotions in them.<sup>7</sup> As the number of breast cancer females are increasing, hospitals require to provide quality nursing care, so that we can increase their satisfaction.<sup>17</sup> So it is one of the highly necessary and essential responsibilities of the nurse to provide the professional psychosocial support for the post- mastectomy women.<sup>7</sup>

## **NEED OF THE STUDY**

In the past two decades it was found that in India, the breast cancer incidence has peaked sharply and number of its cases has projected in the 2020 year are 179,790 which form about 10% of all the cancer cases.<sup>18</sup> As per the report of Times of India in 2013, the number of breast cancers in India is not only increasing by the day but more and more young patients are also falling prey.<sup>19</sup>

Women experience different types and amount of pain or discomfort after the mastectomy surgery.<sup>20</sup> Mastectomy that is a breast removal cause the loss of self-worth which is not seen as an effect of the surgical removal of any other tumour in females. They no longer feel beautiful and feel the great loss of personal charm. This leads to a decreased self-esteem which contributes to an attitude of introversion, withdrawal, insecurity, shyness, confinement, and/or social inhibition. Emotional distress, which cause a sense of separation from one's own body and a disturbed sense of femininity are also observed amongst many breast cancer women who have undergone mastectomy.<sup>21</sup> According to the study conducted at Brazil to understand the experience of young women diagnosed with breast cancer and mastectomized. The findings

revealed that this diagnosis can laden women with bewilderment and emotional pain, while neglecting that young women can also land in such condition.<sup>22</sup>

There are numerous literature in the western countries regarding the experiences of post mastectomy women, but unfortunately, the topic of lived experiences of post-mastectomy women has been barely explored in India. The lack of investigation and exploration regarding this topic is may be due to stigmatization with the breast cancer and breast being involved in this cancer is seen as very private part in India and people rarely discuss diseases related to this part. There is a need for more studies to be done to explore the lived experiences of post mastectomy women for breast cancer in India and more attention is required on the role of nurses to assist post-mastectomy women psychologically, spiritually and physically to cope up with their conditions.

In a study at Nigeria conducted to explore the experiences of young Nigerian women after mastectomy for breast cancer. The findings revealed the pschycological needs and preferences about treatment should be taken into consideration for young women of breast cancer. They found certain themes which are useful in planning the treatment protocols and care after the mastectomy as per their experiences.<sup>6</sup> One another study which was carried to explore the lived experiences of married Pakistani women, after 2 years of mastectomy reported that after the diagnosis with breast cancer, some certain coping measures are very helpful for these women in coping with their life situation, which provides ideas for formation of various support groups for

proper communication and exchange of information and improve their mental health.<sup>23</sup>

Many females after mastectomy for breast cancer experience physical loss of one or both breasts in addition to the loss of the significance attached to this organ. Breast removal therefore encompasses multiple losses, including loss of identity, physical attractiveness & completeness, sense of womanhood, status as a woman in community, self-esteem, and even loss of future.<sup>24</sup>

The experiences of women with breast cancer and their quality of life after mastectomy have been studied in number of quantitative studies, which translate their subjective experiences into objective quantified data. Though, there are only some qualitative studies from western countries, which examine the experiences of post-mastectomy women for breast cancer, their life conditions and expressing their experiences in reference to health care professional and caregiver's perspective. But no previous study has addressed this issue in India.

The detailed explorations of post mastectomy women experience may provide best evidence about specific areas of their life which have more problems. And health care provider specially nurses can understand their perception towards their illness and treatment modalities and thus can plan individualized appropriate interventions. Nurses play an important role in providing care to every kind of patient with any disease including breast cancer patients also and as there is increasing number of mastectomy treatment for the cure of such cancer, the hospitals need to improve their quality of nursing care, which could lead to increased satisfaction in them. Now days, the role of nurse has

extended from giving physical care to providing education and teaching to patients along with counseling for resolving their various emotional conflicts related to treatment and disease. Hence, they may help such women to develop skill and various kind of coping strategies, there by introducing more sense of gratification to such women.<sup>25</sup>

Therefore, it is important for them understand the experiences of post mastectomy women, as this could assist in identifying the stressors, and the various coping sources of these women. Additionally, considerable level of knowledge could be increased along with bridging the gap in the body of literature. This could further help nurses to support post- mastectomy women. The findings of this study also have theoretical implications with regard to research and education, in addition to practical and administrative implications.

### **AIM OF THE STUDY**

The aim of this study was to reveal the meaning and concept the experience of post mastectomy women.

### **STATEMENT OF PROBLEM**

Lived experiences of post mastectomy women at AIIMS, Jodhpur.

### **OBJECTIVE**

- To explore the lived experiences of post mastectomy women.

## **RATIONALE OF THE STUDY**

Fewer studies have done to reveal the meaning and concept the experience of post mastectomy women in India. These are more common in western countries as there is no stigmatization about discussing the breast related issues and diseases like in India. So this study can provide theoretical knowledge for the development of appropriate nursing care to mastectomized women and give better conditions to cope with changed life. Also it emphasizes the importance of active participation of nursing professionals in providing human care to these women and their family members in order to adapt to their new images.

## **OPERATIONAL DEFINITIONS**

- **Lived experiences-** It refers to a representation of the experiences of women after at least 1 month of mastectomy who were diagnosed with breast cancer by taking in-depth interview with the help of semi- structured open ended questionnaire.
- **Post mastectomy women-** It refers to those women > 18 years of age, who were diagnosed with breast cancer and had undergone mastectomy at any hospital at least 1 month ago, and coming to AIIMS Jodhpur for follow up procedures or chemotherapy.

## **ASSUMPTIONS**

- Post mastectomy women may have unpleasant experiences.
- Sharing of experience to others may reduce emotional distress and promote feeling of well-being.

## **DELIMITATIONS**

The study is limited to-

- The women who were diagnosed with breast cancer and had undergone mastectomy at least 1 month ago.
- The women who had undergone mastectomy irrespective of the hospital, either at AIIMS Jodhpur or at any other hospitals of Jodhpur and were coming for regular follow up at Radiation unit of AIIMS, Jodhpur.

## **SUMMARY OF THE CHAPTER**

The chapter describes the background of the study, need, problem statement, objectives, operational definition, assumption and delimitation of the study.

The next chapter will deal with a review of the literature.

# **Chapter II**

## **Review of**

## **Literature**



## REVIEW OF LITERATURE

Review of literature was done to assess in-depth information regarding the lived experiences of breast cancer survivors and post mastectomy women and further exploring the research questions, design and the research methodology.

**Wasia Hamid et al.** used Graneheim and Lundman's principles in 2020 to investigate "Lived experiences of women suffering from breast cancer in Kashmir: a phenomenological study". They used snowball and theoretical sampling techniques for recruiting 12 women and conducted face-to-face in-depth individual interviews and found two main themes: challenges encountered and coping strategies. Their findings showed significant influence of breast cancer diagnosis on women and experience it as most traumatic event of their life; however, as time passes, they start accepting the reality and cope with their illness with various methods.<sup>22</sup>

A qualitative study was conducted by **Olalekan Olasehinde et al.** on "Life without a breast: exploring the experiences of young Nigerian women after mastectomy for breast cancer" in 2019 and they interviewed post mastectomy women aged 45 years or younger recruited through purposive sampling at a Nigerian teaching hospital. They used an unstructured interview guide and discovered six major themes which were decision for mastectomy, postmastectomy transition, body image changes, relationship with husband and sexual life, coping with life postmastectomy, and social support. They highlighted the significance of taking into consideration of individual patient's

psychosocial needs and preferences when discussing treatment with young women which can be helpful for planning treatment protocols and postmastectomy care.<sup>6</sup>

The qualitative descriptive exploratory study carried by **Laila Hussain et al.** “Exploring lived experiences of married pakistani women post-mastectomy” in 2019. They recruited 12 participants at outpatient oncology clinic, for interview by purposive sampling from a tertiary care hospital in Pakistan. Audio-taped interviews were transcribed, and then four themes and sub-themes were obtained which were: from history to diagnosis, worries, coping strategies, and recommendations. The results elicited the importance of effective coping strategies for these women. They strongly recommend that support groups should be the formulated, to assist such women to decrease their uneasiness via proper exchange of information.<sup>23</sup>

An interpretative phenomenological analysis was conducted by **Silvestri, A.** on “A holistic approach to care for women struggling after mastectomy” at University of London in 2019. She conducted an idiographic exploration through semi-structured individual interviews. Three major themes and nine sub-themes obtained: the ‘Ill self’, the ‘vulnerable self’ and the ‘coping self’. The results explicitly show the strong recommendation to create a strong professional network of support between counselling psychologists and other relevant healthcare professionals and need of form a holistic treatment plan based on individual client needs and facilitate sensitive communication between them.<sup>24</sup>

**Avital Gershfeld-Litvin** attempted to explore the “Women’s experiences following mastectomy: loss, grief, and meaning reconstruction” in 2018 at Tel Aviv-Yaffo academic college, Israel. Through Denzin’s interpretive interactionism approach he analysed the interviews of eighteen women, aged between 26–80 years after being mastectomised out of which half choosed immediate breast reconstruction. He revealed three central themes: diagnosis, mastectomy, and living without breasts. The main finding is acknowledging loss is important to experience grief. Also focus should be there on counseling for women to cope with breast cancer.<sup>25</sup>

At Washington University in St. Louis, School of Medicine USA, **Faustine Williams and Stephen C. Jeanetta** carried a qualitative study on “Lived experiences of breast cancer survivors after diagnosis, treatment and beyond” in 2018. Through purposive sampling, they recruited interviewed 15 participants from two Missouri cancer centres. Three major themes obtained which are factors from the diagnosis and treatment management impacting survivorship, relationship and support system and implication of survivorship. Findings revealed frustration due to diagnosis and body changes. Coping strategy were support from family members as well as their friends. However, most of them felt abandoned after completion of treatment phase.<sup>17</sup>

“A qualitative study on experiences and needs of breast cancer survivors in Karnataka, India” was investigated by **Sushma Marita Dsouzaa et al.** in 2018. They recruited and interviewed 17 breast cancer survivors who have completed cancer treatment six months ago using purposive sampling

technique. Interviews were first transcribed and then translation was done to develop codes and themes. The findings reported that breast cancer survivors have certain informational or counseling needs regarding breast reconstruction surgery and supportive needs like help in household activities, finances and emotionally.<sup>26</sup>

It was emphasised by **Terry Cheng et al.** that healthcare providers help women to see breast reconstruction as a justified way to restore their body and sense of self in their qualitative study “Restoring wholeness: Women’s embodied experiences in considering post-mastectomy delayed breast reconstruction” in 2018. They conducted telephonic semi-structured interviews of eight women using purposive sampling. The data analysis revealed that decision-making in such women was mainly based on embodiment, they formed four embodiment-related themes: living with an altered body, rebuilding the body and self, taking charge to reclaim the body and self, and losing a sense of self. Other psychosocial factors, however, may compete with embodiment motivations were the major findings of this study.<sup>27</sup>

At Vocational school of health services and school of health sciences, Turkey, **Sema Kocan and Ayla Gursoy** in their qualitative study on “Body image of women with breast cancer after mastectomy”. In 2016 they highlighted the negative statements about appearances by women. They conducted semi-structured interviews of twenty post-mastectomy women in second week after mastectomy and extracted four main themes: meaning of the breast, mastectomy and me, my body image and body image changes, and social

life. Their findings revealed mastectomy surgery had negatively affected woman's body and self-image.<sup>10</sup>

**Michelle S Barthakur et al.** used descriptive phenomenology to explore the "Experiences of breast cancer survivors with oncology settings in urban India: qualitative findings" in 2016. In-depth interviewed collected from 15 women. There is a need to develop patient-centred care services instead of using the doctor/disease centred approach was the major finding through which cancer care in India can be improved quality wise.<sup>28</sup>

**Thayse Gomes de Almeida et al.** in 2015 used Heideggerian framework and interviewed seven women of age between 18-35 years in their phenomenological study "Experience of young women with breast cancer and mastectomized" at Universidade Federal de Alagoas. Maceió, AL, Brazil. Three major themes were obtained: The experience of being diagnosed with cancer; the experience of undergoing treatment in search of a cure for cancer; the experience of overcoming cancer. They concluded that being-in-the-world with breast cancer can laden women with anguish and bewilderment.<sup>29</sup>

**Dr Geeta Patel-Kerai et al.** used Interpretative phenomenological analysis (IPA) to "Exploring the lived experience of breast cancer diagnosis and treatment amongst gujarati speaking Indian women" at University of the West of England, Bristol, UK in 2015. They interviewed five gujarati-speaking Indian women and elicited three main themes: making sense of the cancer, importance of support and body image concerns. They find out that language

barrier and knowledge regarding breast cancer along with their culture greatly influences such women. Providing culturally competent care and support to black and minority ethnic women with limited English proficiency was the implications of their study.<sup>30</sup>

Van Manen's thematic analysis approach was used by **Esmat Mehrabi et al.** in 2015 for their qualitative phenomenological study "The Lived Experience of Iranian Women Confronting Breast Cancer Diagnosis". They gathered data via semi-structured, in-depth interviews from 18 women using purposive sampling and obtained two main themes "emotional turbulence" and "threat control". The major finding was that emotional problems of women are not necessarily resolved; they may continue and gradually engender positive outcomes.<sup>31</sup>

Based on philosophy of Husserl at University of Stellenbosch, South Africa, **NE Stecher et al.** carried descriptive phenomenology study 'Experiences of women in survivorship following mastectomy in the Cape Metropole' in 2014. They interviewed seven women and emerged three general themes: Psychological impact of breast cancer diagnosis and treatment, the impact of an altered body image and concern for family and reliance on them for support. The findings showed that there is stigmatisation in culture yet thus need for the teaching services for such women along with their families to get more support from them in coping with life situation.<sup>5</sup>

A phenomenological study conducted by **A. Joulaei et al.** on “Living with breast cancer: Iranian women’s lived experience” in 2012. The semi-structured interviews were taken from 13 women aged between 34 and 67 years. Nurses can help women in confronting the consequences of the changes associated with the illness was the finding of the study.<sup>32</sup>

To have an idea about awareness regarding breast cancer women perceptions of their care and treatment needs in 2012, a qualitative study was conducted by **Fatma Cebeci et al.** “Life experiences of women with breast cancer in south western Turkey”. They conducted in-depth interviews of eight women individually who were undergoing chemotherapy in an ambulatory unit with the help of semi-structured questions. The results of tape-recorded data revealed three major themes needs, living with losses, and changes which puts a question about enhanced need of health care providers and educators regarding their awareness of difficulties faced by such women in their lives.<sup>33</sup>

**Lisa R. Rubin and Molly Tanenbaum** recruited thirteen lesbian and/or bisexual post-mastectomy women in 2011 for their qualitative study “Does that make me a woman?: breast cancer, mastectomy, and breast reconstruction decisions among sexual minority women”. This study finding suggested that various factors influenced decision making like sexual, gender, and political identities and orientations but experiences with physicians who encouraged reconstruction and the stigmatization of illness in relation to social, profession and romantic context was also a central concern. Findings

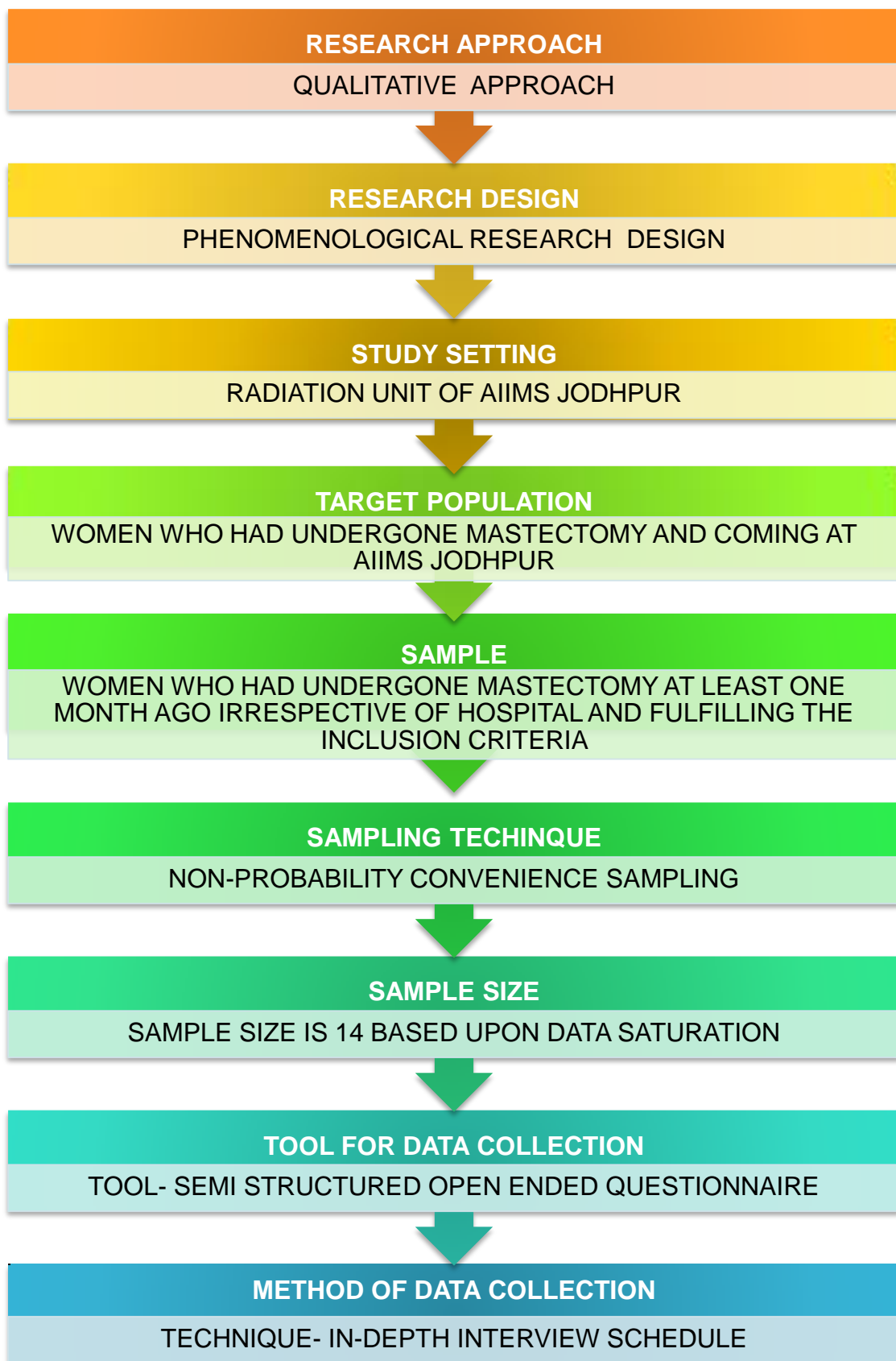
of this study are interpreted through feminist disability, medicalization, and existential frameworks.<sup>34</sup>

At private hospital in Perth, Western Australia **Olivia Hill and Kate White** carried a qualitative study “Exploring women’s experiences of TRAM flap breast reconstruction after mastectomy for breast cancer” in 2008. They recruited ten women using purposive sampling including five after immediate breast reconstruction and other five after delayed breast reconstruction. Semistructured interviews were analyzed which revealed recurring three major themes: losing a breast matters, adjusting to a changing body image, and redefining normality. The findings elicited that nurses provide physical care to women postoperatively, in addition to education and psychosocial support. This study provides greater insight into the holistic experience of women undergoing TRAM flap breast reconstruction to practicing nurses.<sup>35</sup>



# **Chapter III**

## **Methodology**



**FIGURE 1:-SCHEMATIC PRESENTATION OF RESEARCH DESIGN**

## **RESEARCH METHODOLOGY**

This chapter deals with the research methodology adopted to carry the present study. It gives a detailed description of research design, research setting, population, sampling technique, sampling criteria, data collection tool, content validity, ethical consideration, pilot study, procedure for data collection, rigor, and plan for analysis.

### **RESEARCH APPROACH**

Qualitative research approach was used in this study. It is based on understanding a research query regarding people's beliefs, opinions, experiences, concepts, attitudes, and interactions by involving non-numerical data collection in the form of audio, text or video and analysing it. This can be helpful in formation of new ideas for research and getting deeper insight into any problem.<sup>36</sup>

### **DESIGN**

After considering the objective of the study, phenomenological design was used to investigate the phenomenon under study. This design has its roots in philosophy, psychology and education, which attempts to extract the most pure and untainted data.<sup>37</sup> The definition of phenomenology as given by the Creswell, 2013 states that:

*“Phenomenology is an approach to qualitative research that focuses on the commonality of a lived experience within a particular group. The fundamental*

*goal of the approach is to arrive at a description of the nature of the particular phenomenon.*<sup>37</sup>

## **VARIABLES**

- Demographic variables: Age, Religion, Education, Occupation, Marital Status, Total number of family members, Total number of children, Breast feeding practices, Family planning method, Monthly family income, Family history of any cancer, Months passed since mastectomy, Other health associated problems.
- Research Variable: Lived experiences of post mastectomy women at AIIMS, Jodhpur.

## **STUDY SETTING**

The current study was conducted at Radiation unit of AIIMS, Jodhpur in which there is a 12 bedded radio-onco day care where patients come for chemotherapy sessions which is a one of oncological treatment modality. It runs from Monday to Saturday from 8 am to 4 pm with an average of 35 patients attending this unit everyday for chemotherapy as well as radio therapy.

## **POPULATION**

The study population included the women who had undergone mastectomy and coming at AIIMS Jodhpur for follow up procedures and chemotherapy.

## **SAMPLE**

Women who had undergone mastectomy for the breast cancer, at least one month ago and fulfills the inclusion criteria were selected as a sample.

## **SAMPLING TECHNIQUE**

In this study non -probability convenience sampling technique was used. In this the selection of units from the population is based on their easy availability and/or accessibility.<sup>38</sup> This sampling works well with participants who need to be recruited from the particular clinical setting or from a specific organization.<sup>39</sup>

## **SAMPLE SELECTION CRITERIA**

### **Inclusion criteria**

Study includes:-

- Women who had undergone mastectomy for breast cancer at least one month ago.
- Women who were more than 18 years ago.
- Women who were able to speak and understand Hindi language.
- Women who were willing to take part in the study.

### **Exclusion criteria**

- Women who had undergone breast reconstruction after the mastectomy.

## **SAMPLE SIZE**

The sample size was estimated based upon data saturation. The data was collected through in-depth interviews until any new data can be obtained from recruiting new participants in the study rather than predetermining sample size.<sup>39</sup> Data saturation was obtained after 12 interviews but being on safe side, the researcher took 2 more interviews so that no new data may left after complete data collection. So, the final sample size 14 was taken for this study.

## **METHOD OF DATA COLLECTION**

In-depth interview method was used for data collection with the help of a self-structured open-ended questionnaire to explore the lived experiences of post mastectomy women based on the review of research and non-research literature and opinion of experts.

## **DEVELOPMENT AND DISCRIPTION OF TOOLS**

A self-structured open ended questionnaire was formulated for the study. It was prepared after a brief review of the research and non-research literature and opinion of experts.

The self -structured open ended questionnaire consists of two parts *i.e.* Part 1 and Part 2 (**Annexure-Ia & Ib**).

**Part 1:** This part consists of 13 questions that deals with demographic profile of participant women such as Age, Religion, Education, Occupation, Marital Status, Total Number of Family Members, Total Number of Children, Breast Feeding practices, Monthly income of family, Any family planning method

used, Family history of any cancer, Months passed since mastectomy, and Other Health Associated Problems.

**Part 2:** This part consists of 9 open ended questions which are based upon the aim of exploring the lived experiences of post mastectomy women.

### **CONTENT VALIDITY OF THE TOOL**

The validity of the open ended questions for semi-structured interview was established by the opinion of the 9 panel of experts (**Annexure-II**) and necessary modifications were done on the basis of suggestions of experts.

#### **Suggestions for the tool were**

- To keep a single question at one time.
- Do not add with “AND” to split the question.
- Minimize the number of questions for easy analysis of the data.

### **ETHICAL CONSIDERATION**

Ethical consideration for the current study was

- Ethical approval (**Annexure IV**) was obtained from the Institutional Ethical Committee of AIIMS, Jodhpur.
- Certificate reference number- AIIMS/ICE/2020-21/3001
- Written informed consent (**Annexure Va and Vb**) was obtained from each woman participant involved in the study after giving proper explanation of

the purpose of the study. They were informed at starting that they can leave the study at any point of time during the interview.

- Informed consent was also developed in Hindi language.
- Confidentiality and anonymity of the subjects and the data collected was maintained throughout the study.

## **PILOT STUDY**

A pilot study is a trial study which is done before research is finalized, to check the feasibility of the study after obtaining the formal approval from the concerned administrative authority. For this study, pilot study was carried out from 31st August to 12th September 2020 at radiation unit of AIIMS, Jodhpur after taking permission from the institutional ethical committee before the data collection. The purpose of the study was explained and women were assured about confidentiality. The data was collected through interview after taking informed consent from the 3 post mastectomy women coming at AIIMS, Jodhpur and fulfilling the inclusion criteria. The interviews were taken from the women participants with the help of semi-structured interview guide and after explaining that interviews will be audio-recorded and will be used by the researcher for research purpose only and this study was found feasible.

### **Changes after pilot study**

- In pilot study, it was found that one more question can be added in the open ended questionnaire regarding willingness for undergoing breast reconstruction among post mastectomy women.



## **PROCEDURE FOR DATA COLLECTION**

- The formal permission was obtained to conduct the study from the concerned authorities of the institute.
- Data was collected from 28 September to 6 November 2020.
- After explaining about the purpose of study, written informed consent was obtained from participants who fulfill inclusion criteria of the study.
- Confidentiality of the data was ensured to all participants as they were assured that the information would be kept confidential and it will be used for study purpose only.
- Participant women were asked if they agreed to share their experiences after mastectomy. They were informed that the interview will be audio-recorded and only will be used for research purpose.
- Interviews were taken after taking their formal agreement.
- Flexible timings were used for the data collection according to the convenience of the post mastectomy women coming at AIIMS Jodhpur.
- The interviews were conducted in a calm and quiet place to avoid distraction and to provide comfort to the participants. Each interview took approximately 20-25 minutes. All interviews were taken from post mastectomy women undergoing chemotherapy except two who were waiting for CT scanning.
- The interviews were conducted in Hindi language.
- The researcher first collected data related to demographic variables. Then interview was started with general and open- ended question as per the semi- structured interview schedule from each study participant.

- The in- depth interview was initiated and audio tape recorded when the participant women were ready to speak.
- At the time of interview field notes were also taken by the researcher and follow-up questions were asked whenever necessary, to clarify the doubts and information collected.
- Various techniques of interview were used by researcher as required during the data collection.
- After the completion of the each interview, opportunity was provided to each participant women to clarify their doubts and to share information which was not included in the semi structured interview.
- Total 14 interviews were collected for this study based on data saturation.

## **RIGOR**

Rigor of the study was done to increase the trustworthiness of the study. The **Lincoln and Guba's framework (1985)** gave four criteria for enhancing the trustworthiness of the data which are as follows: Credibility, transferability, dependability and conformability.<sup>39</sup>

**Credibility** refers to the confidence in 'truth' of the data and findings. The findings should be compatible with the experience of the participants. Credibility was maintained by recruiting the participants in the study who are willing to participate and helped to acquire the main phenomenon under the study. Also observation, memo writing, interactive and reflective questioning was used. Each interview was audio- recorded and using these recordings individual transcription was made which confirmed that all the information was

captured accurately. Beside this, few visits to the research area was done prior to actual interviews were taken to make good relations with participant women and make them comfortable to share their experiences as researcher is a post-graduate student in oncology nursing and posted in radiation unit mainly day care center as a part of clinical postings.

**Transferability** refers to the potential for extrapolation, which is the degree to which result of research can be applicable or transferred to other groups or settings. It was maintained by providing sufficient description necessary for each theme and subthemes by the researcher. The findings from the participants were stated along with the direct quotations under the theme with participant number and quotation number. This enables the readers to compare the result in context of their own setting. Also data was collected from the post-mastectomy women coming at main tertiary hospital AIIMS Jodhpur, irrespective of hospital in which they had undergone mastectomy in order to examine probable different responses among these women.

**Dependability** refers to the stability or reliability of the findings over conditions and time. This means the findings of inquiry can be repeated if were replicated with same (or similar) participants in the same (or similar) context that is consistency of the findings in similar circumstances. The researcher conducted an audit trial which included all the raw data and explanation about research process and how themes and subthemes ere extracted from the data were explained to another peer researcher who were

familiar with study design and context of the study setting. Also the Panel of experts had consensual agreement on the findings of study (**Annexure- III**).

**Confirmability** refers to objectivity, that is, the potential for congruence between two or more independent people about the data accuracy, reliability, relevance or meaning. It represents the extent to which findings of the study are shaped by the response of the participants not by the researcher's personal interest, motivation and bias. It was done approaching three participant women after secondary data analysis and they confirmed that the findings were suggestive of the statements they given during the interview. Also audio recordings were checked at various stages of data analysis by the supervisor to ensure congruency of transcriptions.

#### **Problem faced during the study**

- It took time and advanced planning to take interview from the post-mastectomy women, as first their records were seen and on particular day of their chemotherapy or CT scanning, interviews were conducted.
- One woman was reluctant to answer the questions.
- Due to Covid- 19 women had fear of talking much with health care personnel and sometimes were not audible properly because of mask.
- Some of the questions were misinterpreted by the women, so timely explanation was given them.
- Lack of awareness among women regarding the research was also a hurdle. Questions were being raised by women about anonymity and confidentiality. A lot of time was offered before obtaining the consent.

## **PLAN FOR DATA ANALYSIS**

The Colaizzi's framework (1978) was used for thematic analysis. The data was transcribed through verbatim and the themes and sub themes were extracted from the statements of study participants.

Bracketing was done before the data collection through peer review and self-review technique of bracketing **(Annexure- VI)**. Data analysis done in this study with the help of scientific software called ATLAS.ti. 9. Free trial license was obtained and latest ATLAS .ti. 9. was used to analyze the data.

## **SUMMARY OF THE CHAPTER**

The chapter described the methodology used in the study which consists of research design, variables, setting, population, sample, sampling techniques, data collection, pilot study, procedure for data collection, and plan for data analysis. Total 14 interviews were taken. Rigor of the data was maintained at various stages of the study by the researcher to enhance the trustworthiness of the data. The next chapter dealt with the analysis and interpretation of data.

# **Chapter IV**

## **Analysis, Interpretation, and Discussion**

## **ANALYSIS, INTERPRETATION AND DISCUSSION**

This chapter presents the analysis and results of the recent study. The data collected was first transcribed and then thematic analysis was done. The findings of the study are discussed with the findings from other studies in the discussion section of the chapter.

### **The objective of the present study is**

- To explore the lived experiences of post mastectomy women.

### **THE DATA AND FINDING HAS BEEN ORGANIZED AND PRESENTED IN THE FOLLOWING SECTIONS**

**Section 1:** Description of demographic variables of post mastectomy women. It contains a following table.

Table 1: Frequency and percentage distribution of demographic variables

**Section 2:** Use of Colaizz's framework. It includes the following table:

Table 2: Themes and subthemes of the study

# SECTION1. DESCRIPTION OF DEMOGRAPHIC VARIABLES OF THE SUBJECTS

**Table 1: Frequency and percentage distribution of post mastectomy  
women and demographic variables**

N=14			
S.No.	Demographic variable	f	%
<b>1.</b>	<b>Age</b>		
	a. 18-30 years	1	00.71 %
	b. 31-45years	9	64.00 %
	c. 46-60 years	3	21.42%
	d. 60 years and above	1	00.71 %
<b>2.</b>	<b>Religion</b>		
	a. Hindu	11	78.57 %
	b. Muslim	3	21.42 %
<b>3.</b>	<b>Educational status</b>		
	a. Illiterate	2	14.28 %
	b. Primary	8	57.14 %
	c. Diploma	1	00.71 %
	d. Graduation or above	5	35.71 %
<b>4.</b>	<b>Occupation</b>		
	a. Homemaker	11	78.57 %
	b. Professional	2	14.28 %
	c. Self employed	1	00.71 %
<b>5.</b>	<b>Marital status</b>		
	a. Married	12	85.71 %
	b. Unmarried	1	00.71 %
	c. Widow	1	00.71 %
<b>6.</b>	<b>Family income</b>		
	a. 10 thousand or below	3	21.42 %
	b. 11-20 thousand	8	57.14 %
	c. 20 thousand or above	3	21.42 %
<b>7.</b>	<b>Family members</b>		
	a. Five or less	10	71.42 %
	b. More than five	4	28.57 %
<b>8.</b>	<b>Total children</b>		
	a. No child	3	21.42 %
	b. Two or less	4	28.57 %
	c. More than two	7	50.00 %



<b>9.</b>	<b>Breast feeding</b>		
	a. No feeding	3	21.42 %
	b. Good	9	64.28 %
	c. Poor	2	14.28 %
<b>10.</b>	<b>Family planning</b>		
	a. Yes	6	42.58 %
	b. No	8	57.14 %
<b>11.</b>	<b>Family cancer history</b>		
	a. Yes	3	21.42 %
	b. No	11	78.57 %
<b>12.</b>	<b>Mastectomy months passed</b>	12	85.71 %
	a. 1-5 months	1	00.71 %
	b. 6-12 months	1	00.71 %
	c. More than 1 year		
<b>13.</b>	<b>Associated problem</b>		
	a. Yes	7	50.00 %
	b. No	7	50.00 %

---

**Table 1 depicts** the frequency and percentage distribution of postmastectomy women and demographic variables. It was found that about 64% post mastectomy women were falling in the age groups of 31 to 45 years followed by 45 to 60 years age group which was 21.42% (n=14), only 0.71 % were above 60 years of age.

Results showed that most of the women, 78.57 % belongs to Hindu religion while 21.42 % women were Muslims. More than half that is 57.14 % women were educated up to primary level followed by illiteracy in 14.28 % women and then 35.71% women has higher education level i.e., graduation and more. Most of the women i.e., 78.57 % were homemaker and were married i.e., 85.71%, while only 0.71% that is one woman was unmarried and one was widowed. More than half of women (57.14%) were having family income

between 11-20 thousands. Half of the women (50.00%) have more than 2 children and only 21.42% women have no child. More than half of women had good breast feeding practices. Only 42.58% women used family planning methods and only 21.42% women had some history of cancers in the family. Majority of women, 85.71% had undergone mastectomy within the last 5 months. Half of women expressed some kind of associated problems like hyperthyroid, DM & HTN etc.

## **SECTION 2: USE OF THE COLAIZZI'S FRAMEWORK**

The data was analysed using the Colaizzi's framework (1978). Researcher familiarized herself with the scientific software ATLAS.ti.9. through online tutorials. Thus, qualitative data was analyzed in two steps: Data preparation and thematic analysis.

### **I. Data preparation**

#### **Transcription of data**

Bracketing was done before the data collection through peer and self-review technique. Interviews were transcribed into verbatim after listening to the audio recorded interviews. Efforts were made to keep the originality of the words spoken by the participant women. Participant women were given code so that the anonymity of the participants can be maintained (**Annexure VIII**).

### **II. Thematic analysis**

This study used the following various steps of thematic analysis:

- **Familiarization with the data:** To obtain a deeper insight of the phenomenon, the researcher immersed herself into the data by reading the interview transcript of each woman repeatedly.
- **Identifying the significant statement:** The researcher identified all the statements from the data that have significance to the phenomenon under study.
- **Formulating the meaning:** Firstly the bracketing was done to remain stick to phenomenon of study and then codes were generated on the basis of different thoughts, ideas and meanings from careful consideration of significant statements. Codebook was generated and was further imported to ATLAS. ti 9 scientific software for the data analysis.
- **Clustering the themes:** The codes were categorized into themes and subthemes on the basis of similarities or relationships among them. Themes were more connected to the research question whereas subthemes were more associated with the group of codes that emerged from the significant statement.
- **Developing an exhaustive description of the phenomenon under study:** Themes, subthemes and codes were reviewed repeatedly and a hierarchical category was made which is called thematic map analysis. The researcher wrote complete and exhaustive description of the phenomenon involving all themes after primary data analysis.
- **Producing a fundamental structure:** The findings from the data analysis are so vague that it is necessary to provide a fundamental structure to it. The codes, subthemes and themes were refined through the process of secondary data analysis and the essence of each theme were identified

and captured. Themes were finalized and it was reviewed from the various experts.

- **Seeking verification of the fundamental structure:** One of the important aspects of the Colaizzi's framework is confirmation of the findings with the participants. The researcher went back to the participants and confirmed the findings of the study. The participants agreed with findings. Certain modifications were done based on the suggestions of experts and participants.

## RESULTS

Objective of the study was to explore the lived experiences of the post mastectomy women coming at AIIMS Jodhpur. Analysis of the data revealed that lived experiences of post mastectomy women, can be divided into five main themes. Each key theme was further divided into several subthemes in order to provide a broader, more complex understanding of the meanings that were reconstructed in light of these events. These five themes and twenty two subthemes were emerged after the thematic analysis. The themes are written in bold text and subthemes along with them in plain text.

- The first theme is **body image changes** which consist of various subthemes: altered self-image, impaired dressing sense, sexual inactivity, social isolation, shift to parent's home and unwillingness for reconstruction.
- The second theme is **physical impacts** which include subthemes as prickling pain, enormous swelling and tenseness, hand movement restrictions, and limited household work.

- The third theme is **emotional impacts** which include subthemes like early morning depression, worries about children future, God's will and their luck and fear of death and future
- The fourth theme is **treatment impacts**. It has various subthemes like Weakness/ ill self, disease recovered and saved life, enhanced financial concerns, and satisfaction with hospital.
- The fifth theme is **coping and support sources** which consist of subthemes like belief / praying God, adequate husband and family support, adequate social support and positive attitude.

#### **Reference of quotations in qualitative data**

- The interviews with the participant women were audio recorded and later transcribed into verbatim. Each theme and subtheme is described separately along with the supporting quotations from the participants.
- The reference of quotations is mentioned by participant number and the quotation number of the participant. (for example P1 ¶ 12 means participant 1 and 12<sup>th</sup> quotation of the whole transcription) as per the transcript exported to analyse the data in the ATLAS. ti. 9, the scientific software for the qualitative data analysis.
- Quotations from the participants create a connection between the data, interpretation and the result of the study.
- No modifications were done in the quotes while transcribing the data to maintain the essence of the statement.

**Table 2: Themes and subthemes of the study**

<b>S. No</b>	<b>Themes</b>	<b>Subthemes</b>
1.	Body image changes	<ul style="list-style-type: none"><li>• Altered self-image</li><li>• Impaired dressing sense</li><li>• Sexual inactivity</li><li>• Social isolation</li><li>• Shift to parent's home</li><li>• Unwillingness for reconstruction</li></ul>
2.	Physical impacts	<ul style="list-style-type: none"><li>• Prickling Pain</li><li>• Enormous Swelling and tenseness</li><li>• Hand movement restrictions</li><li>• Limited household work</li></ul>
3.	Emotional impacts	<ul style="list-style-type: none"><li>• Early morning depression</li><li>• Worries about children future</li><li>• God's will and their luck</li><li>• Fear of death and future</li></ul>
4.	Treatment impacts	<ul style="list-style-type: none"><li>• Weakness/ ill self</li><li>• Disease recovered and saved life</li><li>• Enhanced financial concerns</li><li>• Satisfaction with hospital</li></ul>
5.	Coping and support sources	<ul style="list-style-type: none"><li>• Belief / Praying God</li><li>• Adequate husband and family support</li><li>• Adequate social support</li><li>• Positive attitude</li></ul>

## **DETAILED DESCRIPTION OF THEMES AND SUBTHEMES**

### **THEME 1: BODY IMAGE CHANGES**

Body image is the perception of individual about the sexual gracefulness and elegance of their own body in the eyes of themselves and others in the society.<sup>40</sup> The female breast is mostly seen as an organ which symbolises beauty, and womanhood. In addition to providing feminine identity, it is also considered an important part for breast feeding and maternity in the recent times.

Thus breast removal by mastectomy, a one of the therapeutic approaches for breast cancer which results in mutilation of the breasts, can adversely affect a woman's body image and their feelings of self-confidence and femininity. Most of the women felt body image changes after the mastectomy operation as a cure for the breast cancer. They believed that after this procedure their self-image have been altered and has also need to modify their clothing styles. This has caused such physical and emotional changes due to which they have lost interest in sexual activity now and feel to be remaining socially isolated. Some women choose to shift to their parent's home. It also act as significant concern for some women in their decision-making process about mastectomy thus cause delay in treatments. Some women have accepted these body images changes that now they are unwilling to undergo any reconstruction procedure.

#### **Subtheme 1.1: Altered self-image**

In the current study, all women had undergone modified radical mastectomy. Most of the women spoke about negative effect on their self-image after the mastectomy. They recall negative feelings associated with their altered bodies when they look themselves in the mirror. Various words were used by them to describe feelings like loss of femininity, loose body, weird and less than whole or half. The following reports reveal the difficulties encountered after experiencing mastectomy:

*“Upset the andar se, ajeeb se feeling ho rahi tha jaise ek aang kat gaya ho jaise, like matlab istritav khatam ho gaya ho jaise ladies ka to hota hai na ek bhin part hat gaya jaise, bahar aane jaane m bhi thodi dikaat ho gayi, kafi kuch aise khayal aaye the matlab negativity ki taraf ja rahi thi, ab to bhul gayi sabhi cheezein, istritav khatam ho gaya matlab.” (P 1 ¶ 12)*

*“Dekhne m kharab lagta hai, chaat nahi to yeh kitno kharab lage, jagah khali lage chaati ki jagah, chaati nahi hai.” (P 2 ¶ 53)*

*“Jeewan main beta bahot prabhav pada hai beta bahot dukhi hain pareshan bhi hain, dekhtein hain to main ko dukh hota hai. Pareshani to hoti hi hai par ab wohi hai ki ab kuch ho nahi sakta.” (P 13 ¶ 498)*

*“Aaine ke samne kharab lagta hai, chaati nahi hai, kharab ho lagta hai. Aisa hun ki chati nahi hai. Bura to kharab ho lagta hai, halat kharab ho gayi, baal bhi gaya.” (P 2 ¶ 58)*

*“Ajeeb lagta hai, humko sir pe baal nahi hai aaisa lagta hai koi idher bhi aisa hai, body bhi humari loose ho gayi phele to acha tha hum ....patli hui hun operation se. Bimari hone ke baad sharir to thoda looze hota hi hai. Wahan to hum ma'am kabhi karate nahi, humara to chota gawn hai udhar kon wajan karta hai.” (P 4 ¶ 139)*

*“Subah lagta to hai hi madam jo nahi hai to sharir ka hisa, yahan waise hi lagta hai ki apne yahan se hta diya gaya hai. Vichar to yahi aatein hain ki apan bhi to bure lag rahein hain kya karen, kya hua hai apne sath sharir ka ang kat gaya. Maiyene to kya apne dikhne main thoda wo hogya, phele suroop lagte the ab wo to yahan se thoda bhada lagega or kya.” (P 5 ¶ 169)*

*“Shakal to ...hath wath kale ho gaye sab shakal to pata nahi kaisi thi kaise ho gayi. Baal mere bahot dukh hota hai ud gaye sare, yeh jali leti hun sara din. Yeh bandh ke rakhti hun sare din. Acha ni lagta mujhe khud ko. Iski wajah se to lagta to hai to jab ek cheez nikal jati hai to kam to lagti hai lekin ab theek hai. Bhagwan ki marzi hai yeh to.” (P8 ¶ 307)*

*“Andar aise hi vichar atta hai ab aisa hi rahega hamesha ke liye ab to wapis bna nahi jayega, dusra to aisa ka aisa bnega nahi.” (P 7 ¶ 272)*



One participant pointed out that she has left to look at the mirror because of the altered self-image.

*“Aayine ke samne hi nahi jate, hum to sahi bta dete hain. Ek to baal nahi hain or ab jab baal nahi to kya sawarna kya sajana, koi cream laga li chere pe ek bimdi laga li bas isse jayada koi kaam nahi. Acha nahi lagta, wahi hai.” (P 13 ¶ 505)*

*“Bura hota hai kab kitni achi tayar hoi abhi kuch ni tayar rehti simple rehti hun mera beta bhi mujhko bolta hai mummy aap kaise tayar honge kab tayar honge wapis aap aise kab banoge achi sadi pehen kar. Main pehenugi beta wo din jaldi hi hai. Aap ache tayar nahi hote ho aap kab theek honge m ka ho jaungi.” (P 6 ¶ 224)*

In this study the limit of altered self-image was also dependent or based on the ongoing treatment and their particular side effects that women had experienced. One of the important aspects of the altered self-image was the loss of hairs due to chemotherapy which also negatively affected the woman's self-image. Many participants expressed that they felt worse about the lost hairs which created more tension than breast removal, as now eagerly waiting for their regrowth after completion of whole cycles of chemotherapy and they need to hide their baldness by wearing a cap or stalls to protect their self-esteem and image in the society. In the Indian scenario, women are accepted and praised more in long hairs than in the short hairs or boy cuts. They also dealt with this issue positively by reassuring themselves that the hair loss would be temporary. Therefore, the majority of them experienced difficulty while going through the phase of alopecia due to chemotherapy.

*“Subah uthke lagta hai, maine yeh ek kho diya matlab. Aaine m dekh ke lagta hai thoda change ho gayi m khud hi matlab thoda change lagti main khud hi, ek kho diya maine or chahre m badlav aa gya mere or baal gaye to is wajah se to jayada hi feel hota hai ki maine yeh kho diya.” (P 3 ¶ 94)*

*“Aaine ke samne lagta hi hai apna sharir ka aang gaya, apni kya galti thi aise bhagwan ke samne jo yeh aisa hua apne sath. Or to kya batayein. Baal to utar gaye sare.”(P5 ¶ 178)*

*“Han wo baal chale gaye the tab to bahot rona aaya tha or abhi ho raha hai ki kab aayenge to wapis kab honge baal wgera. Jayada to iski tension nahi thi usse jayada merko baloon ki tension ho gayi. Ab isko (Breast) ko dekh ke to aisa hi lagta hai ek chala gya to feel hota hai.”(P 7 ¶ 272)*

*“Kabhi kabhi lagta hai, rona bhi aata hai (sobbing) lekin phir sochati hun ki theek hai. Han aati to hai bra mere bahu bhi keh rahi thi, wo keh rahi mummy tension mat lo sab khetein hain theek ho jaoge. Ghar wale bhi, bahar wale bhi, sare rishtedaar bhi sab boltein hain. Baal sare ud gaye mere to (sobbing), baal mere bahot ache the. Han sab kahtein hain baal aajayenge.” (P 8 ¶ 302)*

One of the participants pointed out that she feel bad when seeing relatives with normal body.

*“Feel hota hai sabko dekhti hun bhabhi ki dekhti hun, main aise hun wo sab ache se ghume rahe phir rahenge hain (sobbing).”(P 6 ¶ 214)*

*“Aaine ke samne wo to yeh to cheez nikali hai to wo to theek hai. Wo baal utar gayein hain aise lagega to ajeeb sa to.” (P 10 ¶ 381)*

One woman said that they had delayed the treatment just to avoid the altered body image and they were mentally not ready for the mastectomy.

*“Isme mahsoos kiya tha, matlab choti se gilti ho gayi h, khafi time to dikhaya nahi, kyunki usse phele mere periods wegera band ho gayee the, 2-3 mahine, phir merko thodise gilti mahsoos hui , dekhaya doctor ko, idher udher, 2-4 doctor ko dikhaya, to sabne kaha operate karao, us wakat maine karwaya nahi tha, phir jyada hi problem hone lagi to phir maine dikhaya Deepak Bhandari ko, Raj dhani hospital m, unhone usko biopsy ki, usko send kiya, to diagnose hua breast cancer.” (P 1 ¶ 4)*

*“2016 m maine biopsy karai thi phir uska aya tha phir wapis jake Ahmedabad m test karaya tha PET scan wagera to sab normal tha, han PET scan, to us samaye decision liya nahi usko htane ka, doctor ne suggest to kiya tha lakin*

*wahi hai ki dimag se tayar nahi ho pa rahe the is cheez to htane ke liye to aise maine do saal delay kar diya, phir mera 2018 m wapis usme swelling se aane lagi breast m, phir wapis treatment start karwaya, doctor hain Dharma ram poonia unhone kafi merko divert kiya tha kuch ni hota hai karwao phir unhin se maine operate karwaya tha complete.” (P 1 ¶ 11)*

*“Surgery ke bare m, surgery to karani padti hai agar matlab jayada nukhsan de to usko hatana better rekhta hai, wo bhi maine kafi time tak avoid kiya uske 2 do saal tak.” (P 1 ¶ 30 – 31)*

### **Subtheme 1.2: Impaired dressing sense**

An improper fitting of clothes was the most negative impact of mastectomy. Statements indicated that after removal of the breast women experienced a negative body image and preferred to adjust their way of dressing. Most of the women expressed that they want to wear loose-fitting clothing and also they have lost interest in grooming as now they are not able to wear their previous clothes with the same grace as were able to wear before mastectomy.

*“Dekhna to kya, na to pahne odhne ka craze raha, matlab jo kapde apan pahentein hai to fittings nahi baythti hai, ek ajeeb se feelings hota hai matlab ki ek hisa kam ho gya (sobbing), kya btayein ab aapko.” (P 1 ¶ 24)*

*“kapde pahnene m matlab ache se apan toper pehen lete hun na itna mehsoos nahi hota baki, kutra phenti hun to aise khicha hua rehta hai ki koi log dekhenge to merko bolenge, to feel to hota hi hai na phir.” (P 3 ¶ 94)*

*“Ab mere to kapdoon m bhi pareshan ho jati yun aati nahi hai kuch kuch kapde. Swelling ho jati hai.” (P6 ¶ 209)*

*“Abhi to nahi lagati, ki kabhi jayein aayein to mere to itni saree padi hai, theek ho jaungi to phenugi. Phele to laga ki ab, achi bhali body hai, itani achi thi. Aap ache ho, shadi wadi pahente ho to ache lagte ho yeh lagte ho, nazar bhi to rehti hai, kisi ki lag gayi hogi. Kahin jati aati thi ache se shadi wadi to bas khete the aunti g ki aap ache lagte ho. Aapka seena wagera acha hai, fiting*

*achi rehti hai blouse ki, jimke kam hota hai unko lagta hai yeh hai. Han matlab achi thi. Abhi to kher pad wagera aane lagi gayein hain. Sab kahtein hain theek ho jao to pehen lena bas. Mere pass shadiyan hain, mujhe shoak hai shadi wadi phenne ka bahot main hai nai nai shadi phenu. Abhi to nahi pehn pa rahi 6 maheine se, phele pehenti thi jati thi.” (P 8 ¶ 295)*

Participants also showed their concerns about inability to wear their brassier due to post-operative pain and filling their brassier with clothing. Using the modified brassier make them feel weird but still need to do so while going outside in the society. The following are quotes as told by women about this practice:

*“Bra abhi to nahi pehenti, yahan se pehene hi nahi ja rahi yahan se tanke hain. Dard hota hai.” (P 10 ¶ 388)*

*“Nahi jaise wo to main Bombay se actually wo jo hota hai wo main wahan se leke aayi thi bra m dalne ka wo main wahan se purchase karke aayi thi. Bola tha doctor ne kafi dekhlo ki aise bahar nikalo ya matlab apki radiation ho jaye uske baad m agar continue pehno to wo habbit m ho jayega to ni lagega. Nahi abhi maine use nahi kiya. Ab dekhtein hain bahar nikalna hota hai to karna hai, wo thoda sa ajeeb lagta hai.” (P 11 ¶ 428)*

*“Han pahentein hain na. Phir na phene to ajeeb lagta hai. Abhi to sports wali phen rahin hun kabhi to sadhna wali phen letin hun.” (P 12 ¶ 471)*

*“Waise doctor ne to keh diya chahe yeh bra pehn sakte ho, udher m rumal wegera dal leti hun bra pehen leti hun.” (P 7 ¶ 268)*

### **Subtheme 1.3: Sexual inactivity**

Another significant aspect of the body-image is that breast removal has negatively affected sexual relationship of women with their husband. Women felt that they have lost sexual interest after mastectomy. However, these women were happy about knowing that their husbands have become even more supportive at this crucial time.

*“Sharirik sambhand nahi, bas itna hi rehta, acha ni lagta abhi unko bolti hun ki ab mera ek hisa bhi chala gya tohhi feel hota hai, unko kuch nahi feel hota magar mujhe feel hota hai, mujhko acha nahi lagta megar wo mujhse bahot pyaar kartein hain. Kuch nahi ignore kartein hain har cheez ko magar m kamjoor pad jate hun unke samne. Thoda bura lagta bura hota hai kaise zindagi thi kaise ho gayi.” (P 6 ¶ 217)*

*“Sharirik sambhand nahi hai abhi to filhaal, bilkul nahi hain, yeh dikkat hone se. Dikkat to kuch nahi.” (P 9 ¶ 343)*

*“Operation ke baad kuch ni koi sharirik sambhand nahi.” (P 14 ¶ 535)*

Woman expressed that they felt tension after surgery and due to disease condition and also afraid that chemotherapy they are taking, can have negative effects on the husband.

*“Sexual relations nahi, surgery ke karan nahi, matlab abhi bhi to tension to thodi bahot rehti hai sabko, hain isliye tension hai to.” (P 11 ¶ 422)*

*“Nahi nahi sharirik sambhand ab nahi bnate. Nahi wo bnaye hui wase bhi mein bnati nahi thi or uske baad se na tabiyat theek bhi nahi rehti thi aisa hai.” (P 12 ¶ 463)*

*“Sharirik sambhand nahi, yeh chemo chal raha hai na to doctor se puchna tha phele to. Abhi to mere tabaiyat hi theek nahi hai, thakan bhi hai. Nahi doctor ne ni mana kiya, phucha hi nahi humne. Or nadein bhi kachi haina kahin lag na jaye.” (P 10 ¶ 380)*

Woman reported that they are not able to make sexual relations because after their disease confirmed they have shifted to parents home away from husband.

*“Han abhi to admi rehta hi nahi ....isliye nahi bnaye.” (P 4 ¶ 138)*

*“Nahi is operation ke baad nahi. Main to yahin hun madam jab se, wo bhi wahan hai merko dikha ke wapis ghawn chale jayein hain.” (P 5 ¶ 175)*

#### **Subtheme 1.4: Social isolation**

Certain feelings of isolation from others can be reflected in post mastectomy women, as they imagine about reaction of society towards their changed appearance which cause more pain and suffering in them. In this sense, majority of women expressed ashamed feeling when going out, about their loss of breast in addition to, loss of hairs due to chemotherapy. As a result, they limited their social activities and have started to avoid social functions or programmes.

*“Kahin aane jaane dikaat to or kahin program wagera attend ni kar pate, sharam ke mare jayada tar ghar pe hi, kafi time ghar pe hi rahi hun, lagbhag 4-6 mahine rahi, phir mere bhai ne unhone kafi himat dilai ki nahi aap jao aao, bahar niklo karo tab wapis shuru kiya.” (P 1 ¶ 12)*

*“Abhi m bahar gayi ni, aisa lagta hai ki m bahar jaungi koi bolenge kya hua achanak ...yeh.” (P 3 ¶ 94)*

*“Samaj m aana jana, thoda ajeeb si feeling aati thi, kapda bhi lagane padta tha matlab yeh feeling se gayi nahi m kabhi bahar. Saal bhar maine koi function attend nahi kiya, uske baad thoda sa karne lagi.” (P1 ¶ 17)*

*“Bahar nahi nikalti matlab kabhi kabar kaam hota hai bachoon ka to bas. Abhi matlab aane ke baad Bombay se aane ke baad main nahi nikalti bahar, surgery hone ke baad to bilkul hi nahi, chemo ke doran to main nikalti thi or abhi jaise kuch lana ho. Nahi yeh cheez mind m nahi hai, actually kya wo bilkul bal bhi nahi hain chemo se sab chale gaye to thoda sa lagta hai yaar yeh laga ke jao. Aisa koi must kaam ho to nikalo, jaruri nahi hai to nahi nikalte hain.” (P11 ¶ 423)*

*“Baal bhi chale jati hain, usse bhi matlab yeh mehsoos hua ki kahin aane jaane m sharam mehsoos hoti hai.” (P 1 ¶ 36)*

*“Nahi maam, kahin ni nikalti, ghar ke alawa to bas yahan hospital aati hun. Aise hi nahi jati bas yun hi.” (P7 ¶ 261)*

*“Nahi wase jate to nahi bahar theek hai koi bahar milta hai do ghadi humko btala leta hai ya koi apne yahan pe rehta hai padosi to btala leta humko. Jaise apan bahar to kate nahi or jaise bahar khade gate pe khade ho jata hai to koi bol leta hai to batla letein hain thodi der. Ya koi apne ghar ka ki rehta aram puchne ke liye to unse bol letein hain. Nahi apni to hai na aise hi humari aadat ghar par rehne ki hai. Hum bahar jate hi nahi hain. Main to mujhe soak bhi nahi hai bahar phirne ka shopping wagera karne ka main to ghar par hi mast rehti hun bas.” (P 12 ¶ 462)*

*“Bahar nikale ka tension wo to hai hi abhi bhi hai matlab thoda kuch...wo to ab jo cheez hai nahi uske liye to kya kare saktein hain. Per ab bahar nikalna to waise bhi nahi hai, matlab abhi to matlab bahar nahi nikalna hota nahi theeke. Ab yahan doctor ke jana hota hai. Uske alawa nahi (sobbing)...I know mere jaise hain or bhi....maine dekha tha sabke chemo chal rahi hain isliye.” (P 11 ¶ 414)*

*“Log to hume ki kehtein chaati nahi hai. Keh log to gaawn thi phele Jodhpur ni jaun. Log kahe chaati nahi hai. Chaati kaat de. Bura hi bole acha kena bole.” (P 2 ¶ 55)*

*“Akele bhi rehti hun jayadatar apne sapne ke bare m bhi sochtein hun ki mujhe apna pura karna tha bich m hi yeh aa gya.” (P 6 ¶ 217)*

One woman expressed that she never go outside the house because she feels that going outside and roaming can lead to more pain at the operated region.

*“Nahi hum ghar se bahar hi nahi jate, kidher jate aisa humko lagta kahin for jayenge kesa ho jayenge aisa bahar bhi nahi nikalte. Humare pass koi as jata hai baju m mahila, humare bache ghar pe hi rehte , time pass karte uske sath. Nahi chakkar nahi aata aise hi lagta hai ki jayada wapis dard ho jata hai isliye.” (P 4 ¶ 133)*

One woman also expressed that she don't like to talk with anyone, even she don't like to talk with her husband and small kid as feels weird and has developed very negative attitude after the mastectomy, now wants to live alone.

*“Apne husband se bhi door hoti hun unse bhi baat nahi karti, wo boltein hain kuch ni hai yeh sab to bhi nahi karti (sobbing). Maan ajeeb sa ho jata hai ki bhai nahi kisi se bhi koi baat karne ka koi maan nahi hai.” (P 6 ¶214)*

*“Mera bacha bhi aata to usko door rakhti thi ki, kyunki m usko le nahi pati thi, ab usko leti hun, wo bar bar mere pass aata hai, dino bachoon ko. Hota hai takleef kabhi zindagi m , nikal jayega yeh bhi waqat.” (P 6 ¶214)*

*“Pati se batein karna chod diya, abhi chemo ke baad mera man kisi se kyunki wo sab poochte the kaise hua kya hua phir wo neend aati nahi thi. Dimag me rehta tha kaise hua kya hua.” (P 6 ¶216)*

*“Sabko yahi bolti hun himmat se karna, rona to sirf akeli mein subke samne nahi rona, rone se yeh thoda man bhi halka ho jata hai. Baat cheet kartein hain log hamari feeling btayein aisa hoga waisa hoga woh suggestion detein hai aise karna wasie karna wo bahut bura lagta hai aap humko suggestion mat do humko sub pata hai kaisa hoga.” (P 6 ¶230)*

After mastectomy, one woman expressed that she is unable to fulfill her duties.

*“Abhi haal nahi jate logon ke ghar, do teen maheine yeh dikkat hone se chuti hai. Aise to lagta hai ki kaisi dikhungi, loog kya bolenge.” (P 9 ¶342)*

### **Subtheme 1.5: Shift to parents home**

Most of the participants expressed that they have started to live in their parents' house, even if married after the disease or mastectomy, so that they can have more rest and proper care they can get from mother, sister-in law and brothers.



*“Abhi main apni mother ke sath rehtein hun mere sasural jate rehtein hain.” (P 3 ¶ 95)*

*“Kaam to bahot hai hai lekin kya karen, main yahan bathi hun, wo kahwe ki bahi tu yahan aayegi kuch kaam karegi to tere jayada dikkat hojayega to tu rest kar jaldi theek hoja isliye.” (P 5 ¶ 168)*

*“Main idhar mere bhabhi ke pass hi hun. Wo (husband) apne ghawn m wahan bache bhi to hain na isliye.” (P 5 ¶ 175)*

*“Main thi nahi sasural m abhi bhai ke yahan aai hui hun 3 mahine ho gaye ghar jaye hue. Gaye nahi wapis bache bhi yahin hain nana nani ke saath. Sasural m wahan karene wala nahi hai na itna koi. Jethani hai megar wahan ek to finance ki bhi dikkat hai sasural m, yahan acha hai maike m to dikkat nahi hai.” (P 6 ¶ 212–213)*

*“Nahi sab mere family or mieke wale uthatein hain sab (treatment finance). Mere bhai peher wale, mere husband ki salary itani nahi hai na. Yahan to kya business hai to phir thodi sale ho jati hai achi. Kartein hain wo bhi help kartein dono.” (P 5 ¶ 219)*

*“Log to aache- pache gaawn jaun koni, Jodhpur main hi bethi hun (Parents house). Log to hume ki kehtein chaati nahi hai. Keh log to gaawn ki phele Jodhpur ni jaun. Log kahe chaati nahi hai. Chaati kaat de. Bura hi bole acha kena bole.” (P 2 ¶ 55)*

### **Subtheme 1.6: Unwillingness for reconstruction**

Most of the women decided not to have breast reconstruction as they were not concerned about their physical appearance and also because of various other reasons like lack of proper knowledge, financial problems and going through another painful invasive operation.

*“Nahi mera bhai to bolta hai ki wapis surgery karwange ahemdabaad m lakin mujhe nahi karwani mera maan nahi hai bilkul. Koi log boltein hain ki achi ni*

*rehti khuzali rehti hai pareshani Hoti hai. Aap mat karwao. Kuch boltein hain alag alag comments kartein hain. Abhi tak to kuch socha nahi iske bare m.”*  
**(P6 ¶ 22)**

*“Ab to nahi wo actually kya doctor se bina puche to kuch nahi. Yeh ichha le nahi dimag m yeh pata hai ki hoti hai surgery jo bhi aap keh rahein hai pad dal ke to uske alawa mind m aaaya nahi na maine pucha bhi nahi iske bare main.”* **(P 11 ¶ 429)**

Some of the women were afraid about the side effects of the reconstruction operation.

*“Reconstruction ke bare m socha tha per maine kaha hi temporary wo cheez hoti hai, uske side effects to hotein hain na phir.”* **(P 1 ¶ 27)**

Some women expressed that its time for their daughter's marriage and only small time is being remaining in their life.

*“Nahi maam ab to ladkiyan badi ho rahi hain to unki shadi karni hai wagera isliye. Yeh bhi kah rahen hain ki jyada jaroori nahi hai ,hum wahan bhi jake aaye the Gupta ji ke number diye the brace ke liye wahan bhi jake aaye to ek bra milti hain na wo to wo panch hazar ki aati hai to inhone kaha dekhenge terko kharidani hai terko pehnana hai to m dila dunga. Waise doctor ne to keh diya chahe yeh bra pehn sakte ho, udher m rumal wegera dal leti hun bra pehen leti hun.”* **(P 7 ¶ 268 )**

*“Ban jati hai? Nahi kya karna thodi se to umar hai, 70 saal ki to ho gayi hun main. Aage jo pad wagera aatein hain wo pehen lungi. Han karne wala bhi koi nahi hai abhi phir kya karna. Thodi se zindagi hai kya karna hai.”* **(P 8 ¶ 310–311)**

*“Nahi abhi to bas bachon ki shadi karani hai....uska koi vichar nahi hai.”* **(P 13 ¶ 511)**

One woman expressed that she already has spent lots of money for the treatment and going for another operation is not possible for them.

*“Nahi madam ab jo hai wahi sahi, ek to abhi ilaaz ka kharcha pura nahi hota aur...iske liye ek or operation krana padega to wo to nahi ho payega....kya karein madam..ab jo hai wo hi sahi.” (P4 ¶ 142)*

One woman expressed that she has very little knowledge about this so she would not like to go for it.

*“Chest ki jagah ab bnana to kya chahungi, jaisa hai na usme bhi kafi kya hua na usme bhi rehti hogi bnane m kya pta iske baren m itna knowledge nahi hai isme kya hai kya nahi hai filhaal jo bhi hai to filhaal theek hai.” (P12 ¶ 470)*

## **THEME 2: PHYSICAL IMPACTS**

Most of the women shared their feelings regarding the physical impacts after the mastectomy. They mainly emphasized on pain, enormous swelling and tenseness surrounding the axillary region and hand movement restrictions. These impacts have limited their capability to perform activities at home and outside and thus require help from others to complete the tasks.

### **Subtheme 2.1: Prickling Pain**

Some women expressed that they feel pain from the deep inside like aunts crawling. They said that the region where stitches have been made after the breast removal surgery i.e., mastectomy, cause more and more deep pain from inside. This pain tends to increase more while moving hand for any work.

*“Han dard hota tha andar hi chtiyaan chityaan se chalti thin. Isliye dheere dheere dheere theek ho gaya.” (P8 ¶ 298)*

*“Abhi bhi dard hai, tanke jaise aaye na andar, andar hi andar or bhi jayada dard ho raha abhi, jaise yeh operation kiya hua hai tanke diye hue hain andar andar dard karta hai abhi bhi, khichav bahot jayada karta. Yahan se leke yahan tak pura kiya hua hai, bada kiya hua hai operation.” (P3 ¶ 91)*

*“Operation ke ek maihine, wahi pe treatment pandra bees din chala yahin pe. Han dard to hota hi hai baki or koi jayada kuch nahi, nahane dohne main dikkat to thi.” (P 13 ¶ 500)*

*“Phele wo darad bahot karti or pache harda toot gayi yun matlab kamjori aane lagi, mere dard hai. Kaise hoyega kaise nahi hoyega aise. Soojan nahi hui, dukhati jada. Hath chalane par dukhati. Nahana dhona bahot kam kam. Pache wo to nikalti (gaye ka dudh), pache baad m gaye or wo sab bech diya, jayada dard hone laga.” (P 14 ¶ 534)*

Some women acknowledged that sometimes they feel movement whenever any liquid drink being consumed by them like prickling and burning sensation at the operated site.

*“Han yahan dard hai, sujan wo to hai hi hai abhi hath pura upper ho nahi raha hai. Aise aise taniz rehta hai. Aise tana hua hai. Uske ander jaise wo sar sar pani kaise chalta hai, waise waise chalta hai khoon, jaise paar pane ko koi khoon wagera hai. Ander se hi aise pani jaise tar raha hai na. Han pani petin hain jab bhi mahsoos hota hai, aise bhi sar sar chaltein hain chubtein hai, jalan se hoti hai matlab.” (P 10 ¶ 375)*

*“Badlav yeh jaise koi kaam karti nahi sar sharir karti nahi, hilti hilti hai lagta hai, pani bhi peeti hun to thoda lagta hai jaise andar jata hai na. Pani pitein hain to jaise lagta hai yahan pe idher. Koi bhi cheez pitein hain to aise yahan hoti hui jati hai niche niche maloom padta hai. Nahi dard to nahi hota lekin maloom padta hai ki yahan niche tak ja raha hai, mehsoos hota hai.” (P 8 ¶ 306)*

One woman shared her feeling that pain was coming slowly slowly along with some tenseness in the axillary region.

*“Dard, ruk ruk ke dard tha, yahan pe (showing axillary region), jaise khichav ho raha tha or ruk ke dard ho raha tha phir.” (P 3 ¶ 90)*

Some women were agreed that they feel mild pain which caused difficulty in hand movement and they felt heaviness in the upper thorax at operated site.

*“Is hath m hota hai thoda dard, aisa thoda thoda idher se aata hai or wo wala to..humko aise lagta hai wo operation hone ke baad wo aisa hua, to thoda ajeeb lagta hai, aaisa aisa kartein to humko aise lagta hai ki kya hai idher hi aisa kyun rehta, dekho aap idher waisa rehta hai na operation karne ke aad thoda humko ajeeb lagta hai, ek to aisa wo ekdam sahi hai per idhar operation ke baad aisa hua hai saaf ho gya hai isliye humko thoda lagta hai kuch raha nahi hai.” (P 4 ¶ 131)*

*“Dard wo dukhta hai thoda bahot, dukhta hai aise. Nahi yahi pe yeh twacha hi dukhti jahan operation hua ho.” (P5 ¶ 168)*

*“Thoda dard aise to mehsoos hota hai, sujan yahan pe aayi thi or dard itne din to yahan darad hota tha, yahan do dedh mahene tak, aaj kal to thoda bahot kam hota hai dhere dhere. Wo dard to khoob tha, nahi bath to nahi raha tha lekin wo dard karta yahan pe, yahan bhari bhari lagta. Hath hilane main dikkat aati thi, dikkat to ab bhi aati hai, yahan tak aise or yahan se aise.” (P 9 ¶ 337)*

## **Subtheme 2.2: Enormous Swelling and tenseness**

Swelling after the breast removal surgery i.e., mastectomy occurs due to lymphedema when too much lymph collects in operated area of the body as a side effect. Mostly the operated arm, hand and breast or torso areas are affected because the few axillary nodes are also removed along with affected part. In some women it can appear during the months or even years after treatment ends.<sup>41</sup> Most of the women emphasized the appearance of swelling mainly in the upper arm which cause limited activity of that particular hand along with the pain.

*“Mere mainly yeh hath ki dikkat thi, yahan pe swelling jyada aa gayi thi upper arm m. Uske liye maine excercise centre bhi join kiya tha, physical therapy bhi li thi or usko jo belt phentein hain. Bas mainly mere hath ki problem jayada thi.” (P 1 ¶ 15)*

*“Na doctor ne kaha tha ki isko jyada se jyada use m lo, exercise karo, kaam karo lakin ho hi nahi pata tha, yahan pe ikadam swelling sa ho jata, kada ho jata, dukhne lagta.” (P 1 ¶ 16)*

*“Yahan to sojan aaya, sojan atheich hi hai hath main. Atte bhi hai, niche bhi hai atee atee. Atee sojan hai or hath main hath dard karta hai or thoda bahot sojan rehti hai hathoon m.” (P 2 ¶ 52)*

*“Soojan hoti hai hath m iski liye mane kuch ni pehna. Ab mere to kapdoon m bhi pareshan ho jati yun aati nahi hai kuch kuch kapde. Swelling ho jati hai.” (P6 ¶ 209)*

Some women expressed the feeling of tenseness and heaviness of the operated site due to accumulation of the excessive lymph, which require further treatment to remove the fluid to relieve heaviness or tightness.

*“Han yahan pe na khichav sa hone laga pani bhar gaya. Ye hai na phool gaya. Yeh itna hoke phool gaya.” (P 8 ¶ 298)*

*“Uske baad m phir teen char din tak yeh aise khikav raha.” (P 8 ¶ 298)*

*“Kabhi kabhi khichav hota hai. Do baar pani nikala to, han yahin nikala AIIMS main. Han sujan yeh aa rahi hai ab to kam ho gayi hai, issi hath m aai thi, yeh hai yahan pe. Han wo btai na exercise, ab to nahi karti phele btai thi karti thi. Han abhi phele hath m bhi dard tha ab to theek hai hath to. Phele tha ab to theek hi hai. Aise modti to dard hota that to, ab unhone bola hai exercise karo.” (P 8 ¶ 298)*

*“Nahi jaise koi hath upar karti hun na thoda sa yahan khichav hota hai baki to sara kaam kar leti hun m or wajan uthane ka to waise bhi abhi mna kiya hua hai.” (P 7 ¶ 265)*

*“Nahi sujan aai to nahi lekin thoda bharipan rehta tha yahan pe thoda akdaa hua rehta tha pura bharipan yun bhari thoda kicha hua.” (P 12 ¶ 456)*

Lymphedema usually develops gradually, and can be felt as unusual sensation, such as tingling or numbness that comes and goes before any visible swelling occurs.<sup>41</sup> Some women shared that they feels numbness only at the operated site.

*“Nahi sujan to nahi hai thoda sa sunapan rehta hai yahan pe, sun kartein hain na yahan pe operation karte wakat sun kartein hain, to wo abhi tak sun hai yahan pe, ab to ghar ka kaam bhi kar lete hun main.” (P7 ¶ 256)*

### **Subtheme 2.3: Hand movement restrictions**

Another important physical impact of the mastectomy is the restrictions of hand movement. Most women pointed out their difficulty in moving their hand against gravity above the heart level, for which they did various exercises as prescribed by the physician and also felt difficulty due to carrying drains with them for at least 20 days after the surgery.

*“Uske baad is hath m bahot dikkat aai, uthne mein takleef aai yeh itna bhi nahi ho pata tha kyunki yahan ki sab nashein nikali thi niche ki, khichav hota tha, kamjori uthne bathne m dikkat, dard hota tha.” (P 6 ¶ 209)*

*“Matlab jaise yeh hands to yeh pura upar abhi bhi nahi uthta hai or yahan se matlab piche se yahan aake heavy heavy lagta hai ki kuch heavy hai to bola tha doctor ne ki ab wo to long time rahega. To wo ab jaise ab sone m problem hoti thi jaise matlab 20 days to wo bottle carry karne padti thi surgery ke baad wo 24 hours matlab bottles carry karni to woh or usme matlab sone m bahot problem hoti thi, matlab karwat badalne m , kya aap so nahi pate the. Abhi bhi hoti hai jaise uthne m sone m to wo uncomfortable to hai hi hai.” (P 11 ¶ 416)*

*“Wahi hai matlab thoda sa jaise yahan se yeh hua hai to bas wahi hai hath uthane m jo difficulty ho rahi hai thoda improvement ho raha hai jaise standup hoten hain to thoda sa abhi bhi bend rehta hai. Exercise btai thi wo chal rahi hai.” (P 11 ¶ 424)*

Some women expressed that before it was impossible for them to taking the hand above but they have started some hand movements.

*“Hath upper nahi hota tha ab thoda hone lga hai.” (P 3 ¶ 91)*

*“Abhi to ho jata upper hath, phele nahi hota , abhi to doctor sahab exercise karne ki bola ek to aise bola uper uthana ek wo wali side or ek aise ghumana.” (P 4 ¶ 132)*

*“Han hath hilane m dikkat, hath ko bola exercise bhi karo, hilate raho to main hilati hun hath. Us time m bta diya pura hilaoge hath. Han hath ko hila pa rahi hun. Phele to hoti thi dikkat, isko thoda kam hilati thi, ab to nahi oti nahati bhi khud hi.” (P 5 ¶ 168)*

#### **Subtheme 2.4: Limited household work**

Household work is something daily chores like sweeping, preparing meals, washing dishes, doing laundry, cleaning bathrooms and dusting. Some of the women revealed that they were not able do the housework and field work as before and thus felt depressed and as half a person.

*“Ghar ka kaam to hove koni hath to, karun koni abhi to. Kapda to thoda operation hone ke baad thoda change karein main nahi karoon, mera ladka ladki karein.” (P 2 ¶ 52)*

*“Nahin main to bahot karta tha main yeh kar lun, lakin main kar nahi pati thi. Kamjori aa jati thi to. Jaise main khanna pakka lun or merko aisa lagta main kapde dhoo lun. Yahan per main jhadu pocha kar lun. Lakin main kar nahi pati thi. Mujhe apne aap ko bahot kamjori mahsoos hoti thi. Or thodi apne aap ko mera ab swasth bhi rehna chahti thi ki main ab thoda na apne aap pe control karun abhi kaam na karun to main aage ke liye sahi rahonge.” (P 12 ¶ 466)*

*Kuch nahi hota, nahi kar sakte hum. Khatoon m mazdoor log dekhte hain tu abhi kya karte ek aadmi kya kare majdoor ke sath mai katttai buaai to karna padta ma'am boo to diya usko katna hi pade. (P 4 ¶ 133 – 134)*



*“Nahi main to karti nahi kaam ab to khaer hath main dard ho jata hai.” (P 8 ¶ 306)*

Some women acknowledged about the limited occupational work due to various physical symptoms they had felt after the mastectomy.

*“Right hand tha to kuch kam hota nahi tha, ajeeb sa lagta tha, ki aisa hi kuch, main teachers hain to board per likhne ka kaam hota hai, 3-4 mahine to gayi ni chuti le li thi, ji swelling aa gayi thi hath m isse kaam hota ni tha, board pe likha ni jata tha, copy m kuch likha ni jata tha. Ghar ka kaam kuch ni hota tha mujhse.” (P 1 ¶ 15)*

*“Silai karti hun m lakin mere saas keh rahi hai ki do teen maheine abhi kar mat beta phele doctor se puch ki phir aake karna. Han abhi silai nahi karti hun. Khana bhi mere saas bnane nahi dete hai ki phele doctor se mil ke aao phir puch lo kya karna hai kya ni karna baki sara kaam mere saas kar leti hai.” (P7 ¶ 265)*

*“Silai wagera wo toh kahan kar paungi abhi. Abhi to bahot thakan hai.” (P10 ¶ 385)*

*Han silai ghar ghar ki kar leti hun. Han khud ke mere parivar ke ho gya, baki paision ke liye ni karti hun. Ab to wo bhi nahi ho pa raha. (P 5 ¶ 171)*

Some women expressed that now they have started to do some work i.e., a limited light work at home like serving food.

*“Thoda bahot kaam bhi kar letin hun halka fulka kaam. Halka fulka kaam jaise dhooth ubaal letin hun chaan ke rakh diya. Thoda sa or kaam khaana paros ke de diya kisi ko aise kaam. Nahi nahi wo rakhi hai roti wali rakh rakhi hain wo to hamare. Jadhu pooche wali rakhi hai. Han bahu bhi hai hmari yun to per rakhi hui hai nokrani.” (P 8 ¶ 301)*

*“Thoda abhi kar leti hun waisa kuch nahi hai. Mere actually iske sath ovary ka bhi hua tha, to waise wo boltein hain ki bhai one month tak matlab jaise heavy*

*cheez kuch uthne nahi hoti hai , ya niche baithana hai to ab hogya one month to main thoda bahot niche baithati hun, matlab wo bhi sirf snan karne ke liye just.” (P 11 ¶ 417)*

*“Yeh to wajan bhaar ka kaise hoga, halkka halkka kaam hoga or to hoga nahi.” (P 9 ¶ 347 )*

### **THEME 3: EMOTIONAL IMPACTS**

Various treatment methods of breast cancer including mastectomy has a great adverse impact on the patient's mental health like hopelessness, mood disorders (depression, anxiety, and anger), changes in body esteem, relapse of the illness, and death.<sup>42</sup> Thus the removal of breast as a treatment modality can cause a risk to such women emotional as well as physical integrity. Feelings of depression, anguish, uncertainty and fear are most experienced by the women from the moment they are being told to undergo mastectomy and further taking cycles of chemotherapy as per their reports. Most of women felt early morning depression by seeing their body. Also they had worries about their children future and marriage. Some women acknowledge that the condition in which they are today is all due to God's will and their luck. Many women expressed certain uncertainty and fear of future along with fear of death, recurrence and severity of disease in upcoming time.

#### **Subtheme 3.1: Early morning depression**

Mastectomy may have various consequences like disappointment, frustration, enormous sadness and fear. Through participant women's speech, it could be understood that, even if they are well known with the essentiality of this surgery for their health, even they experienced long period of gloominess due to the loss of their breast. As a result, most of women experienced early morning depression as reported below:

*“Han subah uthe lagta tha kabhi kabhi, jaise kabhi kabhi to aisa lagta yah Allah merko utha lete isse acha to, mere saas sasur mere liye bahot rohe ki nahi beta tu kya kah rahi hai, nahi ki Allah sab acha karenge. Unhone merko himmat bhadai, mere pati ne, mere bachon ne.” (P 7 ¶ 260)*

*“Subah uthke acha nahi lagta dukh wali feeling aati thi, aisa to abhi tak bhi aati hai, feeling to aati hi hai ek hisa kata hua hai to ab dusra bhi aisa ho gya hai to or bhi jayada....” (P 1 ¶ 16)*

*“Subah subah han han bahot lagta hai, bahot kharab lagta hai mere chati koni koni mane bahot lagta hai. Dard bhi karta hai or chaati ni lagte, jani kitna bura lage. Yun kharab lage. Kharab bahi chaati nahi hai. Ni hai to kai hai hum kya kare sakaan. Buraaijh hai bahi chaati nahi hai bura lagta hai. Kitno kharab lagta hai.” (P 2 ¶ 53)*

*“Han shuru shuru main lagta tha, raat ko bhi lagta hai ki bhagwan ne kya diya sazaa de di aise hi. Mujhe to kabhi bukhari bhi nahi aaya abhi itane sare chakkar lag gaye. Kabhi kabhi lagta hai, rona bhi aata hai (sobbing) lekin phir sochati hun ki theek hai.” (P 8 ¶ 302)*

*“Subah uth ke acha ni lagta. Hota hai, aaine m jati hun to ekdum plain dikhta hai to acha ni lagta, feel bhi hota hai kya hua, kaisa hogya sharir.” (P 6 ¶ 214)*

Most of women reported their emotional response by sobbing at their condition after the mastectomy.

*“Kaya kartein Ma'am bahot takleef hai (sobbing) kisko bol de hain madat kar rahein hain.” (P 4 ¶ 130)*

*“Jeewan main beta bahot prabhav pada hai beta bahot dukhi hain pareshan bhi hain, dekhtein hain to main ko dukh hota hai. Pareshani to hoti hi hai par ab wohi hai ki ab kuch ho nahi sakta.” (P 13 ¶ 498)*

*“Koi badlav mujhe dikhta nahi hai, bas yeh hai ki pareshani thodi rehti hai, dekhtein hain to thoda dimag pareshan hota hai baki aisa or kuch nahi hai jo ho gaya usko kya sochna, humara to manna yahi hai.” (P 13 ¶ 504)*

*“Royein bhi tadfein bhi (sobbing), ab kya kare saktein hain. Aap se phele bhi kayi logon ne pucha main jab bhi ki thi surgery tab bhi ek bhaiya the wo bhi Odisha ke the, ab jo bhi kuch puchte mujhe mere aansu ke alawa mujhe kuch nahi niklta, wo kehte jaise main roti to wo kehte the ....mere husband bhi khade rahe kehte ni isse kuch ni puchna.” (P14 ¶ 514)*

### **Subtheme 3.2: Worries about children future**

Worries about some conditions can make a person more anxious and embarrassed. Some of the women revealed their worries about providing good future to their children and get them married, as they were unknown about the results of their treatment.

*“Han main theek ho jaungi. Theek hota hun, kaam aise karta hun, ladka ladki ki shadi karta hun.” (P 2 ¶ 71)*

*“Future ke bare m sochti hun, yeh clear ho jaye treatment pura ho jaye apni study karungi acha future banugi, bachon ko bhi acha future dunggi, or parents ki liye bhi kuch na kuch to baneige na or yeh bhi hai self dependent banugi, kisike samne hath na falun.” (P 6 ¶ 222)*

*“Yahi ki bas ab jo bache ke honge wo apne hi hain main ladkon ki bhi tension nahi karti hun bas ladkiyon ka shochti rehti hun shadi ke bare m wegra. Apne bare m to jaise yahi sochun ki apan ki aadhi to chali gayi adhi ab bachon m chali jayegi bas yahi waise bachon ki shadi hogi phir delivery unki wegera unko sambhalana padega ladkiyan hi hain teeno isliye ab hai na saal bhar toho gya mere ladkiyon ki sagai ho gayi dono ki.” (P 7 ¶ 275)*

*“Ab beta bas yahi sochna hai mere bachoon ki shadi ho, ladkiyon ki abhi shadi nahi hui hai. To yeh sochtein hain acha ghar baar de unko, cheeze set ho jayein mere zindagi ka kya hai. Agar yeh sahi ghar pe chali gayin to mera bhi jeewan thoda tension main hai free ho jayega.” (P 13 ¶ 517)*

One woman's speech clearly showed her worried and anxious feeling about small kid still requiring breast feeding and she had to leave him at this time due to this mastectomy operation.

*"Mujhe bahut bura laga mera bacha bahot chota hai. Dus mahine ka hai usko feeding choda ke aayi." (P 6 ¶ 202)*

*"Kinta time ho gya inse door hue huye, ghar chod diya, bachon ko chod, sabse door ho gaye ek pal ke liye. Acha nahi lagta mujhe abhi kuch bhi, bilkul nahi bas. Akele bhi rehti hun jayadatar apne sapne ke bare m bhi sochtein hun ki mujhe apna pura karna tha bich m hi yeh aa gya." (P 6 ¶ 217)*

### **Subtheme 3.3: God's will and their luck**

God's will is the plan of God for the life of a person and the luck is a belief that the things happen to the person because of chance whether positive or negative. Some women expressed that will of Allah/ God is the reason for their current situation and also see their luck as an important factor.

*"Galat hi hai lakin kya karein isme apne nasib main likha hoga wo to hoga bhagwan bhi kya karen. Han bhagwan ko haath jod leti hun yahi hai bas." (P 5 ¶ 177)*

*"Mehsoos to....bura lagta hai. Logon se ghulna milna shuru karenge iske baad, wo dikkat to aayegi ki kaise dikhenge lakin kya karein majboori hai, bhagwan ki deen hai." (P 9 ¶ 346)*

*"Subah uthke nahi usko dekhte the ki ab aise hi yeh tai karta hai na, nasib m apne yahi likha hua hai to rub ki marzi hi thi jo karega bahtar karega, acha hi karega." (P12 ¶ 460)*

*"Yeh salah dungi, salah main yehi kehna chahungi ki hai na sabse phele to usper nirbhar rehna wo apne aap asani karta jayega. Bas jo yeh hai na jo doctor or jo Allah ne jo hai na naseeb jo Allah ne likha hai or jo doctor ne kaha hai wo to apne ko karna hai hai." (P 12 ¶ 475)*

Some women expressed guilt of their past sins and see this current situation as result of some bad works in their previous life.

*“Bhagwan ke bare m bahot, ki bhagwan sabo ni yahan aawe sabko theek karna, merko bhi karna. Bhagwan bus zindagi jo de ache de, bus khush rakhein. Bhagwan ko manti hun barobar. Ye to humare karmo ki saza hai, bhagwan to kya karein.” (P 14 ¶ 537 – 538)*

*“Uske baad yahi hai beta ki jo bhagwan karta hai uske aage kuch hota nahi. Doctor log to mainte nahin hai. Mainte ho tum log ? ...bhai bahot se doctor nahi mante. Kyunki bhagwan ki aab duniya main agar ek sutra hai to bhagwan hi hai wo jo kartein hain wahi hota hai. Ab humne koi paap kiye honge phichle janam main to ho sakta hai uska bhog humko bhogna pada hai ki nahi. Abhi bhi maan hi rahein hai.” (P13 ¶ 502)*

*Phir AIIMS m hi doctor se kya baat hui inhone wo merko bhi bataya nahi ki main ghabhrati to merko chupa ke rakha inhone. Phir baad m na maine apne aapko ko na rabke hawale kar diya tha ki nahi jo kare wo behtar hi hoga. (P 12 ¶ 452)*

Some women expressed anguish that what was there mistake and why all these things happened to them only and why god planned these things for them?

*“Operation ke baad 2-4 maheine yeh sab nahi ho pa raha tha, kabhi kabhi lagta hai aise maan m ki aisa hamare sath hi kyun ho raha hai, humse aise kya galati ho gayi kabhi kabhi hota hai. Abhi bhi hota hai lakin maan ko samjhane wali baat hai ki boltein hain jo hota hai ache ke liye hota hai, kya pta isme bhi ho kuch.” (P 1 ¶ 19)*

*“Aaine ke samne lagta hi hai apna sharir ka aang gaya, apni kya galti thi aise bhagwan ke samne jo yeh aisa hua apne sath. Or to kya batayein. Baal to utar gaye sare.” (P 5 ¶ 178)*

Some women shared that it's all in the hand of god. The plans he had made for us we have to live the life accordingly and we can't do anything.

*“Aane wala samaye main to kya hoga madam, kitna apna sharir sath dega utna hi kaam karega or kya. Ab wo to bhagwan rakhenge waise rehna hai apne kya hai. Bhagwan rakhega waise hi revenge madam jaise kaam apne se hoga wo kare lenge nahi hoga to nahi karenge.” (P 5 ¶ 188)*

*“Yahi sochtein hun ki theek hojaungi to theek hai nahi to theek hai jaisa bhi hoga bhagwan ki marzi hai. Khetein to yahi hain ki theek ho jaoge chemo band ho jayegi to theek ho jaoge. Ab dekho bhagwan ki marzi hai. Han yahi soch rahi hun theek ho jaungi to theek hai, nahi to bhagwan ki marzi hai jo bhagwan karega wahi hai.” (P 8 ¶ 316)*

*“Ab jaisa ho gya ho gya. Aisa lagta hai sahi to ho jayenge hum. Sahi ho jayein kuch dua kuch dawa se.” (P 3 ¶ 107 – 108)*

#### **Subtheme 3.4: Fear of death and future**

Another important emotional impact after being operated for breast cancer is women's experience of some fears and uncertainties of future. These include the fear of death and recurrence of disease. They have become emotionally weak and experienced the propability of dying from this disease, as discussed in the following thematic quotations:

*“Mother ki to death ho hi gayi thi or phirse wahi cancer stress, mere mother ki 16 m hi death hui thi January m or merko Nov m hi diagnose hua tha matlab phir wahi, family tension m aa gayi , nahi lagta ilaz wagera.”(P 1 ¶ 7)*

*“Kitna time lagega, wahi to. Bache ko bhi chod ke aai, bachungi ki nahi bachungi. Kuch nahi pata tha.” (P 6 ¶ 206)*

*“Kabhi khabi to dar lagta hai ki bhai ab ghar pura sambhati, ab m aise ho gayi to ab ghar nahi sambhala jayega.” (P 14 ¶ 551 – 552)*

*“Yeh hota hai mehsoos hota hai ghar m teen death ho gayi thi, mere uncle ki death ho gayi thi chemo ke doraan, second mummy ki ho gayi, third patient main hun bas ab yeh icha hai ki kisi ko koi bimari na ho pure parivar m, humare parivar m teen member ki death teesari m hi hun matlab do ki death ho chuki hai.” (P 1 ¶ 18)*

One woman pointed out the fear of recurrence of the condition in the future.

*“Iske bare m sochati hun ki bhai kya hoga aage, wapis to nahi hojayegi magar bhulne ki bhi koshish karungi. Future ke bare m nahi sochungi past bnake isko bhul jaun. Han aisa kuch pal aya tha zindagi m jo puri zindagi hil gayi mere, nikal hayega yeh bhi wakat.” (P 6 ¶ 223)*

Still after the mastectomy that is a treatment surgery for the breast cancer, women also experienced doubt and uncertainty about the future as observed in the following speeches:

*“Yahi sochun ki future kaisa hoga, future m kaise sambhalungi sab kuch, bache ko, husband ko, ghar ko. Wo kaise hoga.” (P6 ¶ 221)*

*“Aane wale samaye ke bare m to main sochte hi nahi hun ab, present m hi jetein h, nahi future ka bilkul nahi, filhaal to m itani negative ho chuki hun ki merko to kal ka bhi bharosa nahi hai. Negativity bahot aa gayi hai.”(P1 ¶ 33)*

*“Jab ek ghar m bathe rahtein hain na to mentality change hone lagti hai, negativity aane lagti hai, to m aksar thoda thoda bahar nikalti hun, baagiche m jana .....matalab apne aap ko busy kar lena matlab taki us cheez se ...vichar negativity aati hai ki ab kya hoga (ane wala samaye) aise waise isse acha hai ki upper hi chale jayein.” (P 1 ¶ 19)*

*“Sochtein to kani hain, soche jitrun hi hai. Sochta to kaya, bimari ki hui. Kaise aayi bahar. Aage bhai adi bimari mat aajaio.” (P 2 ¶ 71)*

*“Han dar lagta hai yeh dikkat ka hi or to madam kya hai. Yeh dikkat hone se lagta hai madam or to kya hai. Bhooj bhar ka. Yeh wajan bhaar ka or koi dikkat ho kaam karne main. Or to dar kis cheez na nahi lagta, yeh pareshani*



*ka hi. Or to kya hai madam ab yeh phele jitna kaam bhi nahi hoga, har cheez ki dikkat aayegi or to kuch dikkat nahi.” (P 9 ¶ 356)*

*“Kuch hai to sharir ke anusaar hai. Sharir sahi hai to sab sahi hai. Wo to lagta hi hai. Abhi to dard hai bahot jayada. Kab theek honyege, phir kaisa hoga aisa.” (P10 ¶ 395)*

#### **THEME 4: TREATMENT IMPACTS**

Treatments that women underwent for the breast cancer and their side effects as experienced by them have a significant impact on their lives. Most of women also expressed the weakness all over the body as an important impact of past and ongoing treatment on their life. They were not particularly concerned about the body changes experienced as a result of treatment. Instead, they gave more emphasis on their life being saved from the deadly disease after the removal of breast and recovery from the disease. They also felt that as per their elderly age, body related changes are not so important and don't bother them much. Some women experienced the enhanced financial concerns for their post-mastectomy surgery and ongoing chemotherapy treatment as belongs to middle class families. Some women also expressed the satisfaction with the care provided in the current hospital and suggested others to come here for their treatments.

##### **Subtheme 4.1: Weakness/ ill self**

Weakness is a decreased power in one or more muscles of any part of the body. Most women felt weak and lack of strength for some time afterwards as a side effect of the mastectomy. Moreover, the severity of these effects depends mainly on individual and disease stage or metastasis. In this study some of the women felt weakness after the mastectomy as expressed in the following quotations.

*“Operation kara to mujhe koi na bas thodi kya hai na mujhe karzori bahot hoti thi. Jaise main na 5 -10 min khadi kya ho zati thi na to na jahir se baat hai ab mere bache to the hi nahi, ghar m akele rehti thi.” (P12 ¶ 454)*

*“Operation ke baad chakkar aate the matlab sharir m khoon nahi tha, kamjori or chakkar bahot aate the or main Jaipur se aage thi 7 point tha blood. Mere sharir m blood tha na 7 point tha bilkul, safade thi bilkul. Kam tha doctor sahab ne bola kamjori is wajah se hui hai ki khoon chush gayi hai pura andar hi andar.” (P 3 ¶ 90)*

*“Nahin main to bahot karta tha main yeh kar lun, lakin main kar nahi pati thi. Kamjori aa jati thi to. Jaise main khanna pakka lun or merko aisa lagta main kapde dhoo lun. Yahan per main jhadu pocha kar lun. Lakin main kar nahi pati thi. Mujhe apne aap ko bahot kamjori mahsoos hoti thi. Or thodi apne aap ko mera ab swasth bhi rehna chahti thi ki main ab thoda na apne aap pe control karun abhi kaam na karun to main aage ke liye sahi rahonge.” (P 12 ¶ 466)*

Administration of chemotherapeutic agents as an oncological treatment modality is characterized by various side effects which occur due to damage of tumor cells along with rapidly growing healthy cells in the organism. Thus ill feeling and weakness from ongoing chemotherapy was reported by most of women.

*“Bhi ni ho pata, jaise ghar ka kaam hai, itani weakness aa gayi hai, ab kahin aana jaana bhi nahi hota hai or ek hi jagah baithe rehna, is therapy ki wajah se mera bohut jayada kamjore aa gayi hai, na koi khana pina bahata hai kuch bhi ni hota aisa, chakkar wagera ana.” (P 1 ¶ 23)*

*“Phir bhi mera juice wgera ana hota hai rasoi m hai koi soup wagera bnana ho to to thoda m karti to mera saans bhul jata, dhadkan teez ho jati, kamjori hoti thi, mujhe wapis hai na bed m sona padta, soup bna to lete lakin mujhe kamjori bahot hoti thi, seena bhool jata, dhadkan teez ho jati. Paron m jaan hi nahi rehti itani kamjori rehti. Nahi abhi to is wakat nahi ho rahi lekin ghar pe to*

*chalti phirti rehti hun na thodi to mujhe ahsaas hota hai kamjori ka bahot jyada.” (P 12 ¶ 455 – 456)*

*“Yeh hai ki paaron ki wajah se main bhagwan ki puja nahi karte pati hun, jayada chaltein hain to ek to huphan ek to kamjori hai is samaye, chemo vemo lgatein hain, kuch khane pine dete nahi hain. Kacha na khao yeh na khao wo na khao ab roti khayein, roti se chaltein...challenge nahi to roti pache gi kaise to usme thodi kamiyaanaayi hain.” (P 13 ¶ 503)*

#### **Subtheme 4.2: Disease recovered and life saved**

Post mastectomy women's feelings and thinking showed many differences. Some women expressed that they feel grateful as being still alive and life is more significant than the loss of a breast and considered it as lifesaving. They accepted their loss of breast as there was no other option of cure. They believed that removal of the breast has removed the cancer and helped in recovery from the disease and saved their life. They expressed that if they would think about breast conservation then they might have lost their life, thus underwent for mastectomy surgery as a possible cure, as described below:

*“Merko to acha hi lagta, phele jaise hi hai shareer to kam nahi hai. Acha hi lagta hai, wo to bimari to nikal gayi kya karna ab.” (P 14 ¶ 542)*

*“Nikalwainge phir, bimari se to bachein kya karna. Wo to laga per kya karen madam zindagi se jayada or thodi na hai, bachein hain chote chote, unki dekhbaal ho. Dikhne ke chakkar m apni zindagi se chale jayein to unke piche wale ke kon rakshak.” (P 5 ¶ 165)*

*“Bimari to kumhich karna chahun. Hum kaye kar sakun, bimari to hata de doctor ne.” (P 2 ¶ 65)*

*“Bhai m to yahi kahun ki dard ho raha to us samaye to lage bahi nikal diya to acha hi hai, aise kehti hun.” (P 14 ¶ 548)*

*“Sahi to kya kiya majbori hai to karwani padi, jaan bachane ke liye hi kiya hai. Acha dikhav rahte to apni jaan se chale jate, to wo.” (P 5 ¶ 191)*

#### **Subtheme 4.3: Enhanced financial concerns**

Oncological treatment can make any person worried about finances as these modalities are expensive even with insurance. Most of the women found arranging money was the major concern, as going for mastectomy and paying for the expensive chemotherapy drugs was difficult for them and family and they have to borrow money from others; while some were able to pay for the whole treatment by their own.

*“Kharcha byaaz pe paisa letein hai dusroon ke pass se. Hamare paas toh abhi toh koi income to char mahine phele aati nahi khati badi ki. Wo aata to mazdooron ko dena padta kya karein. Bima karaya hai, pura to humare husband ko maloom nahi. Han ek bima kara rakha hai.” (P 4 ¶ 136)*

*“Nahi madam ab jo hai wahi sahi, ek to abhi ilaaz ka kharcha pura nahi hota aur...iske liye ek or operation krana padega to wo to nahi ho payega....kya karein madam..ab jo hai wo hi sahi.” (P 4 ¶ 142)*

*“Wahi laga rahein hain. Ab wo kaise kar rahein hain merko to itana bhi nahi bataya operation main kitna kharcha hua, wo to bole tu theek hoja kahin se bhi laun, kaise bhi lagaun wo mera kaam hai. Paise se sambhandhit merko koi bhi problem nahi hai. Merko kuch problem matlab batate nahi ki tu tu bas tere to swasthye theek hona chahiye bas. Bima nahi karaya hoga. Karya hua to hoga mam shayad unke pass hi hoga puchna padega.” (P 5 ¶ 176)*

*“Chemo ka itna budget hai hi nahi or doctor sahab ne bola ki itna chemo lagega 13 baar, 13 chemo lagega phele 6 baar laga, ab to jayada date badh gayi hai iski to hamara budget hai nahi, tax cut jata hai or apan 15:57... Han bima kara rakha hai...jiska merko jayada pata nahi hai.” (P 3 ¶ 100)*

*“Bima nahi to, kharcha ko ghar ka hi uthata hai, kuch chaye mahina hogya kahan hi karta hai majdoori bahar.” (P 9 ¶ 345)*

*“Humko to dukh to hua, aisa tension aa gayi ki hum kya karenge humare pass paise nahi operation kaise karenge, bache chote chote humare ma'am. Late hua bacha isliye chota wala 12 saal ka hai.” (P 4 ¶ 120)*

*“Nahi sab mere family or mieke wale uthatein hain sab (treatment expenditure). Mere bhai peher wale, mere husband ki salary itani nahi hai na.” (P 6 ¶ 219)*

#### **Subtheme 4.4: Satisfaction with hospital**

Satisfaction is a feeling of fulfilment of one's wishes, expectations and needs from the particular thing. Some women expressed their satisfaction regarding the care being provided to them in the current hospital setting. Also they admired the communication of the staff with their patients. They expressed their willingness to recommend others also to take treatment here in this hospital for the breast cancer.

*“Abhi AIIMS m ilaaz lene ke baad thodi positivity aa rahi hai kyunki jo mere ye first therapy lagi na isse mere kafi farak pada lakin mere, abhi do saptah delay ho gye to wapis problem banane lagi phele covid ke chakkar m phir mere WBC kam thi 2 saptah delay ho gaye.” (P 1 ¶ 33)*

*“Main to sabko yahi salah deti hun ki AIIMS hospital sabse better hai or yahan pe sab kuch check karwana sabko yahi kahti hun ki bas mere ladki ka yahan ilaaz baith gya. Ladki ko wo pf malaria ho gya tha to usko do teen bar dusre hospital legye wahan farak nahi hua uske bahot suj gayi thi, gurdoon m kharabi ho gayi thi. Manish Chaturvedi ji hain na yahan pe doctor unka ilaaz kiya tha ab theek hai isko do baar dialysis hui chori ladki ke yahan pe hi hui thi sab 10 din admit hui yahan pe. Lakin wo kya hai ki merko himmat dedeta hai Allah matlab m tension nahi karte hun Ma'am sab yahi kehtein hain (smiling).” (P 7 ¶ 271)*

*“Nahi bas m to sabse yahi kahungi ki bas kisi ko breast cancer hai to yahan pe check karwane or yahan pe ilaaz karwayen kyunki yahan per merko sab kuch suwidha wagera sab acha laga. Yahan pe sab jaise aap ke jaose koi bhi aatein hain na to yahan pe sab tasali se baat kartein hain jaise koi to hotein hain dhant dete hain yahan pe sab tasali se hi baat kartein hain dante nahi hain.” (P 7 ¶278)*

*“To Palampur wale doctor ne bhi kaha tha ki nahi pura nikalna, to us samaye na bura feel hua, roi bhi thi. Phir sab ne mana kar diya ki nahi Palampur m nahi karana matlab hamare relation m jitane bhi the unhone sabne mana kar diya nahi Palampur m nahi karana. Palampur m doctor sahi nahi, AIIMS m jaake karwao, AIIMS main behtar rahega. Sabki raai mashware ke baad hum AIIMS m aaye.” (P 12 ¶451)*

## **THEME 5: COPING AND SUPPORT SOURCES**

Coping is the way of solving any personal and interpersonal difficulties in an individual's life by using his consciousness, so as to bear the stress and minimise the emotional conflicts occurring as the consequence of those difficulties while support sources can be a place, person or thing which can provide psychological and physical assistance to a person.<sup>43</sup> The fifth main theme refers to those sources which helped the women participants to deal with the life obstacles come after the mastectomy. Women coped by using several ways to decrease the sense of loss. One was to praying and belief in God that provide them some peace of mind and relaxation. They admired the adequate support that they get from family and society. Especially they expressed the support they get from their spouse in dealing with all the abnormalities after being operated with mastectomy. Most of the women shared some positive attitude even after losing normal body appearance.

### **Subtheme 5.1: Belief / Praying God**

Belief in God is considered to be a source of support to cope with the experience of cancer as well as its treatments. Most of the women believed that praying and belief in God enables post mastectomy women to feel peace of mind, and relaxation and they love to spend time in doing religious practices.

*“Subah subah uthati hun bagwan ka naam leke phir, bagwan se dua karti hun ki aage bhi kuch na ho. To bagwan ki sewa puja karti hun to acha feel hota man ko thoda sukoon mila hai jaise.” (P 4 ¶ 101)*

*“Bhagwan ki puja se han matlab thoda relax mahsoos hota hai.” (P 1 ¶ 19)*

*“Bhagwan to ghani mane, bhagwan tayin to baitha hain. Han bas manu je bhagwan mare bimari kyun kari. Din m kitni baar subah sanan balkan ne diya vati karta, hum diya vati ni hue, snan huaye ni segery (surgery) pacha. Diya bati karta hain, jal wagera chadhta hun bhagwan jal chadhta hun. Abhi to nahi chadya mahino bhari hum tyaar ready raho karo bhagwan re puja. Bhagwan ke aage hath jodna diya bati bhagwan ko.” (P 2 ¶ 57)*

*“Han kartein to the ghana abhi operation ke baad time fix nahi hota hai to nahi banta isliye aaise hi baghwan ka naam lete. Nahi baghwan ko nahi chod sakte, takleef to humare nasiboon ki kya kare saktein, bhagwan to hath jodna hi jodna, acha lago chaye bura lago bhagwan ko to aise yaad kartein hi hain ki he bhagwan ....” (P 4 ¶ 137)*

*“Bhagwan se prarthna kartein hain bhagwan humko sadha sukhi rakhein. Acha lagta hain puja karke.” (P 9 ¶ 344)*

*“Bhagwan ke prati to shradha hai hi humari. Bhagwan pe vishwas hai hi hai. Han bhagwan ki puja karke shanti mahsoos hogi, aur acha lagta hai.” “Wo to ghar ka kaam to chuta hua hi hai or puja path bhi itani nahi karte pati hun sirf muh se ram ram karo apne. Phele to aur bhi puja path karte the kabhi katha padhte the.” (P 10 ¶ 384 – 385)*

*“Bhagwan ke bare m bahot, ki bhagwan sabo ni yahan aawe sabko theek karna, merko bhi karna. Bhagwan bus zindagi jo de ache de, bus khush rakhein. Bhagwan ko manti hun barobar.” (P 14 ¶ 537)*

Most participants emphasised a certain kind of trust/gratitude for God as their coping strategy.

*“Nahi maam, Allah ka shukar hai kuch bhi dikkat nahi aaye surgery ke baad.” (P 7 ¶ 255)*

*“Han bhagwan ko manti huna, actually isme mere astha hai jo karta hai acha hi karta hai bas, namaz karti hun jab wakat milta hai padh leti hun, 5 time ki hoti hai, operation ke baad kabhi padhtein kabhi nahi regularly nahi ho pata hai, Operation ke baad 2-4 maheine yeh sab nahi ho pa raha tha.” (P 1 ¶ 19)*

*“Han bhagwan ko haath jod leti hun yahi hai bas. Vrat upwas hai wo to kar nahi rahi dawai chal rahi hai isliye. Subah sham agarwati kartein hain. Bhagwan ke upar hi wishwas hai ki jaise rakhega wase rehna hai or kya. Man ko thodi shanti or kya.” (P 5 ¶ 177)*

*“Wo jo usne takleef deta wo shifa bhi wahi deta hai. Takleef bhi wahi dega to shifa bhi wahi dega. Dua bhi usko sunayenge to uske takleef di hai to usme shifa mojude hai. Hamare to na namaaj hoti hai na padhtein hain, jaise humare sajde m ni jate kurse m baith baith ke padh letein hain. Bahot sukoon milta hai. Aisa lagta hai bahot sukoon milta hai jaisa apne sath m apna Allah hai.” (P 12 ¶ 465)*

*“Bhagwan ke prati bahot acha hai. Mera pura support hai mere bhagwan ke liye. Unhone hoke mujhe bachaya. Aaj m thoda sa bhi wait karti to m to mere bachne ka chance kam ho jata. Krishna ko bahot pujtein hain mere krishna. Bhagwan ki puja karke bahot acha mahsoos hota hai, relief milta hai Bhagwan mujhe bahot priya hai. Bahot himat rehte hai mujhe.” (P 6 ¶ 220)*

*“Allah tala hi hai. Nahi m to Allah ka shukar karti hun ki Allah ke merko wapis ache se jaldi se theek kar diya. Shuru se aisa hi raha hai Allah pe wishwas or ab bhi hai. Jaise phele bhi main roze to kam hi rakhti hun kya hai BP wegera ho jati hai roze rekhti hun, to ab m roze nahi rekhti thi kabhi kabar nmaaz padhti hun kuraan sharikh padhti hun, matlab Allah ka sukar karti hun yah*



*Allah tere lakh lakh sukar hai. Yeh bhi rote the mere sunke ki tu chali jayegi mera kya hoga. Bache bhi rote the. Ki tu tension mat karo main tere saath hun baaki to upar wale ki marzi hogi jo kaam aayegi.” (P 7 ¶ 264)*

Women expressed trust in God by leaving everything on Almighty God and taking their decision for them positively and believing those would be in favour of them.

*“Nahi mujhe kuch nahi hua maine kaha jo hua wo dekha jayega bhagwan sab hai hi.” (P 8 ¶ 294)*

*“Yeh salah dungi, salah main yehi kehna chahungi ki hai na sabse phele to usper nirbhar rehna wo apne aap asani karta jayega. Bas jo yeh hai na jo doctor or jo Allah ne jo hai na naseeb jo Allah ne likha hai or jo doctor ne kaha hai wo to apne ko karna hai hai.” (P 12 ¶ 475)*

*“Bhagwan ke upar hi wishwas hai ki jaise rakhega wase rehna hai or kya. Man ko thodi shanti or kya.” (P 5 ¶ 177)*

*“Kya sochtein hain humko kya maloon. Kya aata maloom nahi bhagwan theek kareinge to sab acha hi hoga. Hum to yahi sochte baghwan theek karein humko.” (P 4 ¶ 148)*

*“Unko yehi batana chahta hai ki ache se sochein sab kuch accha hoga bhagwan pe chhod de wo hamare saath bura nahi karega agar hum kisi ke sath bura nahi kiya ho.” (P 6 ¶ 230)*

*“Bhagwan theek hi rakhe sada ke liye. Wo to lagta hai, bura lagta hai lakin majboori hogayi kya karein karna hi padega.” (P 9 ¶ 356)*

## **Subtheme 5.2: Adequate husband and family support**

As the women told their stories, it became evident that support, particularly from their husband and family members, was very important in helping them to deal with their experiences post mastectomy. Particularly immediate family, which include mother, brother, sister-in law etc., were described as direct care provider along with the indirect support in the form of emotional comfort, and

also helped them with their routine activities like taking them to hospital for chemotherapy treatments, assisting in household chores along with other tasks such as bathing, changing dressings and clothes, washing clothes etc., which the women found difficult after surgery. The following quotes narrate some of these experiences:

*“Kaam oo meri ladki o kare kaam, khana bnana, kheti m kaatna, ghar ka kaam karna, padhai bhi karni. 14, 15 bich padhe hain ladki, sab kuch karti hai. Ek ladka hai, ladka bhi karta hai.” (P 2 ¶ 61)*

*“Ghar ka kaam mere ladkiyan karti hain, sara kaam. Abhi main apni mother ke sath rehtein hun mere sasural jate rehtein hain, abhi mother hai wahi karti hain kaam or bhabhi.” (P 3 ¶ 95)*

*“Kapda to thoda operation hone ke baad thoda change karein main nahi karoon, mera ladka ladki karein.” (P 2 ¶ 52)*

*“Mere bhabhi karti hai han wahi nehlati thi, abhi bhi wohi karti hai. Nahi abhi kapde to main khud badalti hun dhoo deti hai wo. Abhi to main khud naha leti hun, phele wo hi nehlati thi wohi dulati thi. Sab wohi banati main to kuch bhi nahi.” (P 5 ¶ 168)*

*“Bhai bhabhi wo uthate the baithate the 10 din tak to phir isko halka halka movement diya mere bhai ne. Ek time khanne m pareshani. Kha nahi pati thi jayada kyunki yahan pe nashoon m takleef ho jati thi. Yahan se thi na to khane khaana bhi slowly , dhere dhere khaana padta tha.” (P 6 ¶ 209)*

*“Ab to kapde khud phen lete hain phele bhabhi karti thi. Phele sab bhabhi karti thi. Nahana dhona bhabhi hi karati thi 10 -15 din tak jab tak yeh hath cover nahi tha na. Ghar ka kaam bhabhi or mummy karti hai.” (P 6 ¶ 212)*

*“Mere saas, mere bache, mere bache hai na badi 18 saal ki ladki hai, mere devrani sab sath m hain na ghar ka kaam karte the. Kapde phenana wo mera aadmi karta tha, badalwate the wo lagi hui thi na wo nalki usko bhi drain karate the roaz, bo sab ye mera aadmi hi karta tha.” (P 7 ¶ 259)*

*“Kaam to bache katein hain. Wo to mere bhanji thi, han wo nehlati dhulati thi.”*  
**(P 9 ¶ 340)**

*“Mere husband bhi pura support detein hain, bhai bhi detein hain. Bhai ka pura acha support hai, dono bhaiyon ka. Do bhai hain aatein hain sath m, treatment wahin karatein hain ek to yahin hain ek jo aata hai or do piche hai bhai bhabhi ka bahot acha support hai har bar himmat detein hain mujhko kuch nahi sab kuch hoga. Yahan lana, tujhko wapis theek karunga, theek karunga bas. Han bhai ka bahot support hai.”* **(P 6 ¶ 216)**

*“Ghar ka kaam mere mummy ne kiya. Naha to khyer apne aap leti thi. Sapta bhar to nahi nahai wo lati karte the wo pipe dala hua tha dus din phele jab to snaan hi nahi ki thi, jab to wo paper aatein hain na gila usse snaan karte the. Phir tanka kholne ke baad khud snaan karti dheere dheere hota kar leti thi. Kapde mummy pehena dete the snan ke baad.”* **(P 10 ¶ 378)**

*“Abhi to nahi hota sabke phone hi aatein hai ghar pe to koi milne ke liye mujhse. Nahi ghar wale to theek hain sab khetein hain nahi theek hojaoge theek hojaoge. Madat to kya apna kaam to khud hi kar leti hun, phir beta karta hai, khane pine ka dhyan hai bahu rakhti hai, ghar per hai abhi, lecturer hai college jati hai ab to chutiyaan chal rahin hain.”* **(P 9 ¶ 303)**

*“Ghar ka kaam phele to main hi karti thi, abhi to maine kaha na, khanna to sister ke yahan se aa jate hai humare or mere liye ek ladki bachi wo kaam karti thi kapade thone ka.”* **(P 12 ¶ 461)**

*“Ghar ke kaam to phir bachoon ne kiya, maine to nahi kiya, bachoon ne kiya. Ghar ka kaam us time to phele to bachoon ne sambhala khafi kuch, phir mere husband ne bhi sambhaala. Sab ne milke bhai is mood ko sahi leaaye.”* **(P 13 ¶ 508)**

*“Ghar ka kaam khana ladka or papa dono baap or beta mil ke bnata hai.”* **(P 14 ¶ 542)**

Some women expressed that their family members helped them to get out of social isolation and provided adequate psychological support.

*“Logo se milna acha hi hai waise to magar mere family wale bahot achhe hai wo mujhe poora support detein hain. Kabhi kamjor nahi karte hai himmat dete hai mujhko puri.” (P 6 ¶ 215)*

*“Kahin aane jaane dikaat to or kahin program wagera attend ni kar pate, sharam ke mare jayada tar ghar pe hi, kafi time ghar pe hi rahi hun, lagbhag 4-6 mahine rahi, phir mere bhai ne unhone kafi himat dilai ki nahi aap jao aao, bahar niklo karo tab wapis shuru kiya.” (P 1 ¶ 12)*

*“Mera bada wala beta mujhko bahot support karta hai. Aap aajana hain operation kra Liya aapne ab aap aa jana Jodhpur se aungi.” (P 6 ¶ 224)*

Many women admired that their spouse supported in many ways like help in bathing, changing bandages and enhancing their courage in coping with their current situation.

*“Nahana dhona wo mere husband karate h, aaj bhi mera kapda mere husband dhotein hain. Mujhko maloom nahi ki hum kaam karte tu aur bhi jyada ho jata to kya karun to isliye humko bolta puri rest pe raho tum humara kapda bhi wo dhota hai humara.” (P 4 ¶ 130)*

*“Wo to sahi dekhtein hain, boltein hain bahi to aaram se rest kar, tere tabiyat theek ho jaye jaldi se jaldi sahi rahe, phir apna kaam bache or ghar waise hai hi.” (P 5 ¶ 171)*

*“Wo to dhyan rakh rahein hain barabar ilaaz karwa rahein jain mera, jaldi theek ho jayein to acha hai. Kuch ni wo to theek ho jaye bahi to acha hai phir or kya. Yahan par bar bar laana lejana, khane pine ka dhyan rahna, dawai wagera time pe dena. Khana to bhabhi g khilati hai. Juice wagera fal fruit aise, jab hua to unhone lake Rakha tha sab kuch khilane ka nahi Inka dekhrekh to acha karen jaldi those theek ho jayein bas.” (P 5 ¶ 174)*

*“Wo to sab kaam kaaj khana bhi Ma'am hamare husband banake bachchon ko khilate, gay bans hai ghar pe uska dudh bhi nikalna padta hai, gobar bhi dalna padta hai sab hamare husband aur bachon ne. Bhabhi operation*

*karvaya to sath m hi thi phir baad mein hum idhar admit hone ke baad 10 bje wo aai or baad mein wapis chali gayi.” (P 4 ¶ 127)*

*“Chemo se ek din phele hi aajatein hain, khoon test karwake sare janchein wanchei karwake kal wo wapas wo chobis khante baad wo injection lagta hai ek kal wo. Teen din chaar din yahan ruk ke, mera ilaaz karwa ke , phir wapis chaye jatein hain aisa.” (P 5 ¶ 175)*

*“Nahi nahne dhone m dikkat hoti thi to husband madat karte the. Han wo pati wati karne mein wo help karte the.” (P 12 ¶ 459)*

*“Pati ke saath sambhand to theek hi hai. Aise to har ghar main thodi thodi to bachoon ko lekar bhi, parivaar ko leke bhi Hoti hai. Isse related koi cheez nahi balki help ki hai hamari.” (P 13 ¶ 500)*

Moreover, some women mentioned that their spouses have become very caring and some said that have become even more supportive than before.

*“Phele se ab jayada ho gya hai, phele thoda kam tha matlab itna nahi tha ab yeh cheez hone ke baad thoda sa jayada ho gya ki nahi yaar.” (P 11 ¶ 424)*

*“Pati bahoot ....khayal raktein hain.” (P 14 ¶ 535)*

*“Mere helper aati hai jaise jhadu poche or khane ka kaam hai toh wo mere mummy karti hai, husband sath rehtein hain, phele se thoda sa supportive to hota hi hai is cheez se , jyada ho gaye hain.” (P11 ¶ 421)*

### **Subtheme 5.3: Adequate social support**

Most participant women stated they received support from others in doing household work like sweeping, washing clothes and sometimes taking bath as well as help from them psychologically as they come for talking and spending some time with them. Women also revealed that surrounding society support them emotionally as well by expressing concerns regarding their health, asking about their health condition and encouraging them about their

decisions to undergo mastectomy which is a positive thing for early recovery from their disease.

*“Tanke khole jab tak to koi bache ya aju baju m aake snan kra dete humko. Phir baad m humara wo hath dard kam hone laga to main dhere dhere karte.” (P 4 ¶ 132)*

*“Khaana sister ke yahan se aata tha khanaa, kaam karne wali kaam karke chali jati thi. Bulate to kisi padose ki ladki wo jhadu kar ke chali jati thi or na kapde wagera sab dhoh diya karti thi.” (P 12 ¶ 454 – 455)*

*“Achein hain, madaat kartein hain mere padosi bahot achein hain, aatein hain baatein kartein thodi der time pass karatein hain.” (P 10 ¶ 382)*

*“Han wo mere saheliyan wegera sab merese milne aa jatin hain mere peher m aa jati hain or yahan sasural m bhi aate hain sab aatein hain sab mere liye dua bhi bahot kartein hain.” (P 7 ¶ 261)*

*“Theek honge aisa boltein hain log, rest karo theek ho jayenge. Aisa nahi hai wo boltein hain theek ho jayenge tension mat lo. Koi aisa acha aadmi ho to thoda bahot madat karta nahi to nahi karta. Koi aisa acha ho to kabhi jhadu nikalna aisa thoda bahot yeh bartan idher udher rakhna aisa.” (P 4 ¶ 135)*

*“Nahi madam abhi to kuch nahi bolte log. Yahi puchtein hain ki apki tabihat kaise hai, aapne operation karwa liya to acha hi hai. Aapke aage bimari nahi badhegi.” (P 5 ¶ 170 )*

*“Mere to achein hi hain sabse main to bahot kam bolti hun, jayada kisi se nahi wo nahi karti, kam bolti hun. Phele se kam bolti hun. Han wo to sab se mere wahwhar acha hai sabse se yahi rehti hun kudi housing board mein rehti hun. Wahan to sab ache log hain to.” (P 8 ¶ 303)*

One woman shared that she gets support from her colleagues in their professional work.

*“Mainly jaise roti bnana, weight huthana hai isme or sabse jayada likhne m problem board pe to bilkul bhi nahi likha jata tha staff co-operate karta, verbally jaise likhne ka Jo copy checking jo kaam hota tha mera sara staff kaam karta tha, only padhane ka kaam m karti thi.” (P 1 ¶ 16)*

*“Mera sabse jayada cooperation mere staff ka or mere matlab bhaiyon ka hi raha hai kaam m. Khanna bhabhi bnati hai.” (P 1 ¶ 22)*

#### **Subtheme 5.4: Positive attitude**

The study also highlighted the positive attitude as a coping strategy helped women to bear the psychological and emotional effects of the mastectomy. Many of them expressed about not thinking much about the past as there is no solution of the thing already happened, and now they have to move on.

*“Per ab wo usko mind m bar bar main leti nahi jo cheez ho gayi jo ho gayi. Ab aage bhadhna hai. Sochne se to kuch hoga nahi ab. Ab solution nahi hai is cheez ka to....”(P 11 ¶ 425)*

*“Abhi bhi hota hai lakin maan ko samjhane wali baat hai ki boltein hain jo hota hai ache ke liye hota hai, kya pta isme bhi ho kuch.” (P 1 ¶ 19)*

*“Yeh to aat-pata sa lagta tha, aise to vichar karne se dikkat aati hai, vichar nahi karti hun, thoda bahot mahsoos hota tha, bhai aise kya ho gya, kya dikkat ho gayi kya nahi hai.” (P 9 ¶ 341)*

*“Waise kuch nahi sochtein hun matlab wo jo normal jaise tha phele continuous chal raha hai wohi Abhi bhi matlab chal raha hai jo bas. Iske bare m abhi kuch socha hi nahi hai.” (P 11 ¶ 434)*

*“Subah uthke aisa kuch nahi tha, jab ek baar yeh ho gaya na ki hogya phir usko kya socho, ghar main bhi kehte sochegi tab theek nahi hogi, yeh wo phir to...”(P 13 ¶ 499)*

*“Main to mujhe soak bhi nahi hai bahar phirne ka shopping wagera karne ka main to ghar par hi mast rehti hun bas. Nahi nahi waisa kuch nahi hai ki aang*

*nahi hai. Yeh to apne hath m thodi na hai. Yeh to chalo yahan ka aang tha, sharir ka or aang hota, nahi hota kisi ke to wo bhi to jeeta hai.” (P 12 ¶ 462)*

*“Aesa to nahi hua, main kya theek ho jaun, kya karna is ek (breast) hi ghani hai or kya karna didi.” (P 14 ¶ 534)*

*“Yahi lagta hai madam theek rahungi to acha hai agar kuch problem ho to fatafat doctor sahib ko dikhana, jaldi se jaldi ilaaz karen aisa.” (P 5 ¶ 188)*

*“Abhi to mere sirf ki achi post pe job karun ab bache bhi bade ho gaye to exam ki tayari karun, bahot achi post pe soch Rahi hun ab wo hoga ya nahi hoga dekhun... Baad m koshish karungi.” (P 6 ¶ 217)*

*“Future ke bare m nahi sochungi past bnake isko bhul jaun. Han aisa kuch pal aya tha zindagi m jo puri zindagi hil gayi mere, nikal hayega yeh bhi wakat.” (P6 ¶ 223)*

*“Aise koi baat ni, jo man m tha wo to bta de. Dard hai wo to sehan karna hi padega.” (P 14 ¶ 554)*

One woman expressed that she doesn't take much stress and everyone says that she is very brave as even in this very stressful condition she keeps smiling.

*“Yahin pe mulakat hui thi ek Ajmer se aaye the ,to unko bhi maine himmat bdhai to aaj tak mera shukar gujaar kar rehe hain ki bhabhi ji aap bahot ache hain aapki itani badi problem ho gayi phir bhi aap khush ho matlab aap tension nahi karte ho maine kaha aap bhi mat kiya karo wo tension kartein the or unse baat hoti hai.” (P7 ¶ 271)*

*“Madam sab yahi khetein hain ki tum tension nahi karti ho itna dukh aa jata hai phir bhi sehnaaz tum bahot achi ho matlab himmat hai aap ke andar. Ab tee. Bache bhi chale gaye hain do ladke ..ladka to hai hi nahi mere ek ladki chali gayi ab.” (P7 ¶ 278)*



## DISCUSSION

The current study was conducted to assess the lived experiences of the post-mastectomy women at the AIIMS Jodhpur. In this section, discussion about the research findings from this study with the current literature available is done.

The **theme ‘Body image changes’** consist of the various subthemes such as altered self-image, clothing adjustment, sexual inactivity, social isolation, shift to parents home, unwillingness for reconstruction.

Most of the women spoke about negative effect on their self-image after the mastectomy. They recall negative feelings associated with their altered bodies when they look themselves in the mirror and this finding is similar with the findings from the study conducted by Sema Koçan & Ayla Gürsoy in which they mentioned about how women see themselves using different words like ugly, scary, horrible, imperfect or half body etc which shows about the negative impact they feel regarding their altered body image.<sup>10</sup>

Study conducted by NE Stecher, MA Cohen, EJ Myburgh et al. supported the findings of this study where they stated about the distressing effect of changed body image after undergoing mastectomy and oncological treatment<sup>5</sup> and also the findings from the study carried by Laila Hussain et.al (2018) in which they stated worries in most study participants about their self-image in all phases mastectomy operation.<sup>5</sup>

Most of the participants stated that they wanted to wear loose-fitting clothing and also they have lost interest in grooming as now they are not able to wear their previous clothes with the same grace as were able to wear before mastectomy. This finding is compatible with the study conducted by Sema Koçan & Ayla Gürsoy in which they mentioned that women after the breast removal felt the need for transform their dressing style so as to cover the new appearance in the society.<sup>10</sup>

Mastectomy has negatively affected woman's sexual relationship with spouse. Women felt that they have lost sexual interest after mastectomy. This finding can be compared with the findings from the study conducted by Olalekan Olasehinde et al. which revealed about the decreased libido post mastectomy.<sup>6</sup>

The findings from the study conducted by Laila Hussain et al. in which they stated how the breast removal has negatively affected their sexual relationship with husband that is similar to findings of this study as woman expressed that they felt tension after surgery and due to disease condition and also afraid that chemotherapy they are taking can have negative effects on the husband.<sup>23</sup>

A study conducted Sema Koçan & Ayla Gürsoy mentioned that mastectomy caused a need to hide their breast loss while facing society and thus limited social life.<sup>10</sup> This finding is similar to the finding of this study in which certain feelings of isolation were reflected in post mastectomy women, as they imagine about reaction of society towards their changed appearance which cause more pain and suffering in them. In this sense, majority of women

expressed ashamed feeling when going out, about their loss of breast in addition to, loss of hairs due to chemotherapy. As a result, they limited their social activities and have started to avoid social functions or programmes.

The **theme ‘Emotional impacts’** consist of the various subthemes such as early morning depression, worries about children future, God’s will and their luck and fear of death and future.

Some of the women revealed their worries about providing good future to their children and get them married, as they were unknown about the results of their treatment. This finding is similar with the findings from the study conducted by Laila Hussain et al. which revealed raising children was one of the worries of participants because of uncertainty of their disease consequences.<sup>23</sup>

Some women expressed that will of Allah/ God is the reason for their current situation and aslo see their luck as an important factor. This finding is similar with the finding of study conducted by Esmat Mehrabi which revealed patients had strong faith regarding God’s will in their disease causation.<sup>31</sup>

In this study another important emotional impact after being operated for breast cancer is women’s experience of some fears and uncertainties of future. These include the fear of death and recurrence of disease. Still after the mastectomy that is a treatment surgery for the breast cancer, women experienced some doubt and uncertainty about the future. This finding is similar with the findings from study conducted by Esmat Mehrabi in which although, some participants were not thinking about their condition in the

starting of interview but when going into more depth, a fair amount of fear was revealed from their expressions.<sup>31</sup>

The **theme ‘Treatment impacts’** consist of the various subthemes such as weakness/ ill self, disease recovered and saved life, enhanced financial concerns and satisfaction with hospital.

Feeling ill and weakness from on-going chemotherapy was reported by most of women this is similar with findings from the study conducted by Thayse Gomes de Almeida et al. in which they expressed chemotherapy made them sick.<sup>29</sup> Also study conducted by Esmat Mehrabi revealed that weakness was one of the important experiences of the women who were taking chemotherapy and also they were afraid about their recovery.<sup>31</sup>

Post mastectomy women’s feelings and thinking showed many differences. Most of them considered mastectomy as lifesaving as they accept the loss of their breasts and expressed that life is more important than breast. They believed that removal of the breast has removed the cancer and recovered them from the disease and saved their life. This finding is consistent with study conducted by Sema Koçan & Ayla Gürsoy in which they mentioned some women find loss of a breast less significant than being still alive and thus grateful for this.<sup>10</sup>

They expressed that if they would think about breast conservation then they might had lost their life, thus underwent for mastectomy surgery as a possible cure. This finding is similar with the findings of study conducted by Avital Gershfeld-Litvin which showed that women taken mastectomy as lifesaving,

as they were feared about death due to cancer. Also, they allowed breast removal to survive.<sup>25</sup>

Most of the women found arranging for the money were the major concern, as going for mastectomy and paying for the expensive chemotherapy drugs was difficult for them and their family and they have to borrow money from others. This finding is similar with the findings from the study conducted by Laila Hussain et al. in which revealed that some of the participants found financial burden has affected their normal daily activities, while some were able to pay for treatment by their own.<sup>23</sup>

**The theme ‘Coping and support sources’** consist of the various subthemes such as belief / praying God, adequate husband and family support, adequate social support and positive attitude.

The fifth main theme refers to those sources which helped the women to deal with the life obstacles come after the mastectomy. Women coped by using several ways to decrease the sense of loss. This finding is similar with the findings from the study conducted by Olalekan Olasehinde et al. which revealed that participants adopted some strategies to cope with psychological problems like self-acceptance, religion and distraction.<sup>6</sup>

Most of the women believed that praying and belief in God enables post mastectomy women to feel peace of mind, and relaxation and they love to spend time in doing religious practices. This finding is similar to the findings from the study conducted by Dr Geeta Patel-Kerai in which participants

described that doing religious activities like praying God supported them and given power to cope up with on-going life problems.<sup>30</sup>

As the women told their stories in this study, it became evident that support, particularly from their husband and family members, was very important in helping them to deal with their experiences post mastectomy. This finding is similar with the finding from the study conducted by NE Stecher, MA Cohen, EJ Myburgh in which they revealed that family and friends were main support sources for most of the participants.<sup>5</sup> Also the findings from the study conducted by Fatma Cebeci et al. in which she revealed that family provided a holistic kind of support including physical, social and emotional aspects at the time of both diagnosis and therapy for breast cancer women.<sup>5</sup>

Most participant women stated they received support from others in doing household work as well as help from them psychologically as they come for talking and spending some time with them. This finding is similar with the findings from the study conducted by Olalekan Olasehinde et.al. in which participants recognised coworkers and church communities as their support system.<sup>6</sup>

The study also highlighted the positive attitude as a coping strategy helped women to bear the psychological and emotional effects of the mastectomy. Many of them expressed about not thinking much about the past as there is no solution of the thing already happened, and now they have to move on. This finding is similar with the findings from the study conducted by Laila Hussain et.al which showed that in order to suffer all side effects of

oncological treatment, fighting back and brave attitude of participants relieved them so much.<sup>23</sup>

One woman expressed that she doesn't take much stress and everyone says that she is very brave as even in this very stressful condition she keeps smiling. This finding is similar to findings from the study conducted by Wasia Hamid in which women deal with their situation with hope for good future and disease recovery that helped them to defeat negative thinking and worries.<sup>22</sup>

## **SUMMARY OF THE CHAPTER**

The chapter presents the data analysis, interpretation, and discussion of the data collected to explore the lived experiences of post mastectomy women. Total 14 post mastectomy women were recruited in the study through non-probability convenience sampling. Collazizs framework (1978) was used for data analysis. The five themes and twenty two subthemes were emerged after the thematic analysis which includes: Body image changes, Physical impacts, Emotional impacts, Treatment impacts and Coping and support sources. This chapter described themes and subthemes in detail and rigor were maintained throughout the study. Findings from this study were discussed with the other studies in the discussion section. Chapter V presents a summary and conclusion.

# **Chapter V**

## **Summary,**

### **Conclusion And**

### **Recommendations**



## **SUMMARY CONCLUSION AND RECOMMENDATIONS**

The chapter gives a brief account of the present study including the conclusion from the findings, limitations, implications of the study and recommendations for future research.

### **SUMMARY**

A qualitative phenomenological study was conducted on “Lived experiences of post mastectomy women at AIIMS Jodhpur.” The objective of the study was to explore the lived experiences of postmastectomy women. The post mastectomy women coming at AIIMS Jodhpur and fulfilling the inclusion criteria were the sample. Ethical permission was obtained from the Institutional ethical committee, AIIMS, Jodhpur. Tool consisted of personal variable data sheet and self structured interview guide to collect the data through audio recorded interview. The interview guide was validated from the 8 panel of experts. Pilot study was conducted using this interview guide where certain modifications were done on the basis of expert’s suggestion. Sample size was 14 based on data saturation. Informed consent was given to each women participant and they were informed about the aim and objective of the study. They were encouraged to ask the questions if wanted. Interviews were conducted and audio recorded at Radiation unit of AIIMS Jodhpur in the period of 2 months. Each interview took 20-25 minutes approximately. The interviews were listened and transcribed into verbatim. Colaizzi’s framework was used for data analysis using the ATLAS. ti. 9 scientific software. Five themes and twenty two subthemes were extracted which includes: Body

image changes, Physical impacts, Emotional impacts, Treatment impacts and Coping and support sources and these were discussed with the findings of the other studies.

## **LIMITATIONS OF THE STUDY**

Limitations pointed out various considerations for the future studies are:

- The limitation of the study is the generalizability of the research findings.  
As the study is limited to radiation unit of AIIMS Jodhpur.
- Due to the recruiting phenomenology as a method of present research, the study is limited to a small sample size.

## **IMPLICATIONS**

The information revealed from this study provide significant implications for nursing practice, nursing education and nursing administration which will help the oncology nurses to provide the quality care to post mastectomy women.

### **Nursing Practice**

The findings from the study suggested that post mastectomy women and their families face numerous problems while and after undergone various cancer treatments. They require effective coping strategies to deal with these problems and changed situations in their life. Some steps should be taken to improve the quality of care provided to them so that they can easily cope with their changed life situations without any bad emotional impact. Counselling sessions can be arranged for post mastectomy women on a particular day

every week after about 2 weeks of mastectomy surgery so that they can share their feelings and various suggestions can be given to solve their problems along with psychological support. Educational or teaching programs can be conducted before the mastectomy procedure for the breast cancer women so as to make them understand fully with this procedure and its consequent changes can be explained to resolve any kind of misconception regarding this in them individually according to their previous knowledge and needs. Also their body image concerns should be taken into the consideration before doing mastectomy operation and accordingly suggestions should be provided about advantages of undergoing this surgery. Also group sessions can be conducted on the frequent basis among such post mastectomy women which can help them to support each other and helping each other in adapting the changed self physically and emotionally.

Ultimate aim of nursing is to provide a good quality care to each and every patient. For this they need to have a more exhaustive understanding of body image concerns among post mastectomy women. Rather than believing on obscure preconceptions about what woman feels according to her age or the phase of life, nurses can understand from each woman her own and personal story about breast removal means to her. As the study findings suggest that they feel various emotional conflicts and body image related concerns after mastectomy which can be resolved with proper nursing interventions. It is highly recommended that physician should involve nurses in the education and counselling sessions of post mastectomy women as they are healthcare professional who spent maximum time with their patients and can better understand their psychological conditions.

## **Nursing Education**

The study findings revealed that nurses are providing good care to their clients with their highly surpassing communication skills. Also findings from the study suggest that post mastectomy women feels emotionally depressed. Therefore, nursing education should involve the curriculum with more topics on the psychological needs of each patient with similar disease problem. Teaching hours can be increased to address the patient psychological needs and regarding practical methods to solve their emotional problems while providing care, during their training period.

## **Nursing Administration**

The findings of the present study indicated that there is lack of proper staff for counselling and educational services for post-mastectomy women in the oncology team who can address the emotional and body image concerns of such women timely. The hospital administration should arrange such staff or nursing personnel can be given this responsibility, for most effective utilisation of such services among the post mastectomy women as they spent maximum time with their clients and can better understand their emotional conflicts. They can also arrange inservice education programmes regarding this problem for nurses to provide quality care to patients. A counsellor can be appointed in the oncology setting of the hospital who can listen their problems or needs of the post-mastectomy women, and help them to adapt effective coping measures to solve their problems and follow up services can be rendered to them at appropriate intervals.

## **RECOMMENDATIONS FOR THE FUTURE RESEARCH**

In the present study the experiences of the post-mastectomy women highlighted some important topics which were hidden and under-diagnosed. Further studies such as mixed method studies can be conducted in similar context in India to develop counselling services and support groups for post mastectomy women.

- Interventional studies can be carried out to assess the effectiveness of individual or group support programs that are already working to support breast cancer women and other educational and counselling sessions for them involving the nurses in decision making.
- Descriptive research can be done focusing on the informational and support needs of the family of post mastectomy women and breast cancer survivors.
- Multi-center study can be done in the similar context.

## **CONCLUSION**

The purpose of phenomenological study design is to explore the lived experiences of post-mastectomy women at AIIMS, Jodhpur. Exploring their experience can give theoretical support to the development of appropriate nursing care for post mastectomy women as this enables nurses to better understand the emotional and body image concerns of each woman following the mastectomy operation and thus help them in adaptation of their changed image in various ways. Colaizzi's framework was used as a framework for the data analysis. Five themes and twenty-two subthemes were extracted after the

data analyses which are: Body image changes, Physical impacts, Emotional impacts, Treatment impacts and Coping and support sources.

Findings of the study revealed that post mastectomy women had body image concerns and due to which they shifted to their parent's home and had lost interest in sexual activities. Also they had isolated themselves socially after this operation. It has caused impaired dressing sense in them, but still most of them were unwilling to undergo reconstruction. They also felt physical problems like prickling pain, swelling and tenseness in the axillary region which has led to restricted hand movement and limited household activities. They had number of emotional disturbances like early morning depression, worries about the future of children and fear of severity of disease and death. Most of them considered their condition as a will of God and their luck. They also felt treatment impacts like weakness in body and enhanced financial concerns. But some of them were satisfied with the care provided and thought that mastectomy treatment has saved their life. They adopted some coping and support from their husband, family and society. And positive attitude and belief in God also provided emotional support to them to cope with their condition effectively.

The findings suggest that mastectomy as a surgical treatment for breast cancer may adversely affect a woman's body-image and appearance. Thus it is highly recommended to address individual women psychosocial needs and preferences before undergoing for mastectomy in the various education or teaching sessions by physician involving nurses along with them. Also proper knowledge should be provided to every breast cancer women regarding the reconstructive procedures which can be performed after mastectomy to

improve their body image. The counseling sessions should be conducted at least two weeks after the mastectomy on a particular day every week by the professional counselor or nurses should be given this responsibility after arranging proper continuing or inservice education programs, so that they can help such women to cope with their life situation effectively.

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# **Annexures**

**ANNEXURE – Ia**  
**TOOL FOR DATA COLLECTION**  
**(IN HINDI)**

**डाटा संकलन हेतु उपकरण/स्रोत (हिंदी)**

**भाग -1**

**जनसांख्यिकीय-प्रपत्र**

कृपया नीचे दिए गए प्रश्नों को पढ़ें और उपलब्ध कराए गए स्थान को भरें।

1. आयु - .....
2. शिक्षा - .....
3. व्यवसाय - .....
4. धर्म - .....
5. वैवाहिक स्थिति - .....
6. परिवार के सदस्यों की कुल संख्या - .....
7. बच्चों की कुल संख्या- .....
8. ब्रेस्ट फीडिंग प्रैक्टिस- .....
9. किसी भी परिवार नियोजन विधि का उपयोग किया है
10. परिवार की मासिक आय - .....
11. किसी भी कैंसर का पारिवारिक इतिहास- .....
12. मास्टेक्टॉमी के बाद कितना समय बीत चुका है? .....
13. आपको कौन सी अन्य स्वास्थ्य संबंधी समस्याएं हैं और यह कितने समय से है?  
.....

## भाग – 2

लीव्ड एक्सपीरियंस ऑफ पोस्ट मास्टेक्टॉमी वोमेन अत एम्स, जोधपुर ।

### विस्तार साक्षात्कार के लिए खुली प्रश्नावली

#### परिचय: (2 मिनट)

मैं आपको सुप्रभात की शुभकामनाएं देती हूं। मेरे शोध में भाग लेने के लिए धन्यवाद। मैं नेहा पाटियाल, कॉलेज ऑफ नर्सिंग, एम्स, जोधपुर से एम.एससी नर्सिंग की छात्रा हूं। मेरे शैक्षणिक अनुसंधान कार्यक्रम के एक भाग के रूप में, मैं इस साक्षात्कार का संचालन कर रही हूं। विस्तार साक्षात्कार के लिए प्रश्न खुली प्रश्नावली होंगे। उत्तर ऑडियो टेप रिकॉर्डर में दर्ज किए जाएंगे और पूरी जानकारी की गोपनीयता बनाए रखी जाएगी और इस जानकारी का उपयोग केवल अनुसंधान के उद्देश्य के लिए किया जाएगा।

#### उद्देश्य: (1 मिनट)

- टू एक्सप्लोर द लीव्ड एक्सपीरियंस ऑफ पोस्ट मास्टेक्टॉमी वोमेन ।

#### प्रश्न:

1. आप कितने समय से स्तन कैंसर से पीड़ित हैं?
2. स्तन कैंसर के बारे में पता चलने पर आपकी पहली प्रतिक्रिया क्या थी?
3. आपने मास्टेक्टॉमी से गुजरने का फैसला क्यों किया?
4. मास्टेक्टॉमी के बाद से आप सभी किन समस्याओं का सामना कर रहे हैं?
5. इन समस्याओं के प्रबंधन में आपकी मदद कौन करता है?
6. क्या आप मौका मिलने पर स्तन पुनर्निर्माण से गुजरना चाहते हैं?
7. स्तन कैंसर के बारे में अन्य महिलाओं के लिए आपके क्या सुझाव हैं?
8. क्या आपको भविष्य के बारे में कोई चिंता या भावनाएँ हैं?
9. कुछ और जो आप बताना चाहते हैं?

#### धन्यवाद सत्र

अपना बहुमूल्य समय बिताने के लिए आपका बहुत-बहुत धन्यवाद। मैं विश्वास दिलाती हूं कि ये साक्षात्कार और आपके सुझाव स्तन कैंसर से पीड़ित रोगियों और मास्टेक्टॉमी से गुजर चुके हैं को पर्याप्त सहायता और देखभाल प्रदान करने में मदद करेंगे ।



**ANNEXURE- Ib**  
**TOOL FOR DATA COLLECTION (ENGLISH)**  
**PART- 1**

**Demographic variables**

1. Age - .....
2. Religion - .....
3. Education - .....
4. Occupation - .....
5. Marital Status - .....
6. Total Number of Family Members - .....
7. Total Number of Children-.....
8. Breast Feeding practices- .....
9. Any family planning method used-.....
10. Monthly income of family - .....
11. Family history of any cancer- .....
12. How many months have been passed since mastectomy?  
.....
13. Any other health associated problems and since how long you are  
having? .....

## **PART - 2**

### **• TOOL TO EXPLORE THE LIVED EXPERIENCES OF POST MASTECTOMY WOMEN**

#### **Open ended questionnaire for In-Depth Interview**

##### **Introduction: (2 minutes)**

I wish you Good Morning. Thank you for participating in my research. I am Neha Patiyal, M.Sc. Nursing student from College of Nursing, AIIMS, Jodhpur. As a part of my academic research program, I am conducting this interview. The questions will be open-ended questions. The answers will be recorded in audio tape recorder and confidentiality of the whole information will be maintained and this information will be used for research purpose only.

##### **Objectives: (1 Minute)**

- The purpose of the study is to explore the lived experiences of post mastectomy women.

##### **Questions:**

1. For how long you are suffering from breast cancer?
2. What was your first reaction when you were diagnosed with breast cancer?
3. Why you made decision to undergo mastectomy?
4. What all problems you are facing since mastectomy?
5. Who helps you in managing those problems?
6. Do you want to undergo breast reconstruction if get chance?
7. What suggestions do you have for other women about breast cancer?
8. Do you have any concern or feelings about the future?
9. Anything else which you wish to tell?

##### **Thanking session**

Thank you so much for spending your valuable time. I assure that these interviews and your suggestions will help in providing adequate support and care to patients diagnosed with breast cancer and had undergone mastectomy.

## **ANNEXURE – II**

### **LIST OF EXPERTS FOR TOOL VALIDATION**

<b>Name of expert</b>	<b>Designation</b>
<b>Dr. Jaya Kumar</b>	Associate Professor Department of Surgical Oncology AIIMS, Jodhpur
<b>Dr. Vasantha Kalyani</b>	Associate Professor College of Nursing AIIMS, Rishikesh
<b>Mr. Anand</b>	Assistant Professor College of Nursing AIIMS, Bhubaneswar
<b>Mr. Nipin Kalal</b>	Assistant Professor College of Nursing AIIMS, Jodhpur
<b>Mrs. Nimarta</b>	Assistant Professor College of Nursing AIIMS, Jodhpur
<b>Ms. Ujjwal Dhaiya</b>	Assistant Professor College of Nursing AIIMS, New Delhi
<b>Mr. Maneesh Sharma</b>	Assistant Professor College Of Nursing AIIMS, Rishikesh
<b>Mrs. Ruchika Heera</b>	Assistant Professor College Of Nursing AIIMS, Rishikesh
<b>Mrs. Rakhi Mishra</b>	Assistant Professor College Of Nursing AIIMS, Rishikesh

**ANNEXURE – III**

**LIST OF EXPERTS FOR VALIDATION OF THEMES AND  
SUBTHEMES**

<b>Name of expert</b>	<b>Designation</b>
<b>Mrs. Gomathi A.</b>	Associate Professor College of Nursing AIIMS, Jodhpur
<b>Mr. Nipin Kalal</b>	Assistant Professor College of Nursing AIIMS, Jodhpur
<b>Mrs. Mamta</b>	Assistant Professor College of Nursing AIIMS, Jodhpur
<b>Mrs. Nimarta</b>	Assistant Professor College of Nursing AIIMS, Jodhpur
<b>Mr. Aashish Parihar</b>	Assistant Professor College of Nursing AIIMS, Jodhpur

**ANNEXURE – IV**  
**PERMISSION LETTER FROM INSTITUTIONAL ETHICAL  
COMMITTEE**



**अखिल भारतीय आयुर्विज्ञान संस्थान, जोधपुर**  
**All India Institute of Medical Sciences, Jodhpur**  
**संस्थागत नैतिकता समिति**  
**Institutional Ethics Committee**

No. AIIMS/IEC/2020/3082

Date: 01/06/2020

**ETHICAL CLEARANCE CERTIFICATE**

Certificate Reference Number: AIIMS/IEC/2020-21/3001

Project title: "Lived experiences of post mastectomy women at AIIMS Jodhpur."

Nature of Project: **Research Project Submitted for Expedited Review**  
Submitted as: **Student Research Project, as a part of Academic Programme**  
Investigator: **Neha Patiyal**  
Supervisor: **Mrs. Vandna Pandey**  
Co-Supervisor: **Dr. Puneet Pareek & Dr. Ashok Kumar**

Institutional Ethics Committee after thorough consideration accorded its approval on above project.

The investigator may therefore commence the research from the date of this certificate, using the reference number indicated above.

Please note that the AIIMS IEC must be informed immediately of:

- Any material change in the conditions or undertakings mentioned in the document.
- Any material breaches of ethical undertakings or events that impact upon the ethical conduct of the research.

The Principal Investigator must report to the AIIMS IEC in the prescribed format, where applicable, bi-annually, and at the end of the project, in respect of ethical compliance.

AIIMS IEC retains the right to withdraw or amend this if:

- Any unethical principle or practices are revealed or suspected
- Relevant information has been withheld or misrepresented

AIIMS IEC shall have an access to any information or data at any time during the course or after completion of the project.

Please Note that this approval will be rectified whenever it is possible to hold a meeting in person of the Institutional Ethics Committee. It is possible that the PI may be asked to give more clarifications or the Institutional Ethics Committee may withhold the project. The Institutional Ethics Committee is adopting this procedure due to COVID-19 (Corona Virus) situation.

If the Institutional Ethics Committee does not get back to you, this means your project has been cleared by the IEC.

On behalf of Ethics Committee, I wish you success in your research.

**Dr. Praveen Sharma**  
Member Secretary

**Member secretary**  
Institutional Ethics Committee  
AIIMS, Jodhpur

**ANNEXURE – Va**  
**INFORMED CONSENT FORM HINDI**  
**सूचित सहमति प्रपत्र (हिंदी)**

परियोजना का शीर्षक: लीव्ड एक्सपीरियंस ऑफ पोस्ट मास्टेक्टॉमी वोमेन अत एम्स, जोधपुर।

प्रधान अन्वेषक का नाम: नेहा पटियाल (एम.एस.सी. नर्सिंग)

नमूना पहचान संख्या :

मैं \_\_\_\_\_ पुत्री/ पुत्र \_\_\_\_\_ निवासी  
\_\_\_\_\_ "लीव्ड एक्सपीरियंस ऑफ पोस्ट मास्टेक्टॉमी वोमेन अत  
एम्स, जोधपुर" नामक अध्ययन जिसकी प्रक्रिया और प्रकृति मुझे मेरी भाषा में समझा दी गई है। मैं इस  
अध्ययन का एक हिस्सा बनने के लिए अपनी

पूरी, स्वतंत्र, स्वैच्छिक सहमति देती हूँ। मैं समझती हूँ कि मेरी भागीदारी स्वैच्छिक है और मुझे बिना  
कोई कारण बताए किसी भी समय अध्ययन से बाहर निकलने के अपने अधिकार के बारे में पता है। मैं  
समझती हूँ कि मेरे और मेरे किसी भी रिकॉर्ड की जानकारी एम्स, जोधपुर, राजस्थान के जिम्मेदार  
व्यक्ति या नियामक अधिकारियों से देखी जा सकती है। मैं इन व्यक्तियों को अपने रिकॉर्ड तक पहुंचने  
की अनुमति देती हूँ।

दिनांक: \_\_\_\_\_

स्थान: \_\_\_\_\_ हस्ताक्षर

यह प्रमाणित करने के लिए कि मेरी उपस्थिति में उपरोक्त सहमति प्राप्त हुई है।

दिनांक: \_\_\_\_\_

स्थान: \_\_\_\_\_ प्रमुख अन्वेषक के हस्ताक्षर

साक्षी 1 साक्षी 2

\_\_\_\_\_

हस्ताक्षर हस्ताक्षर

नाम: \_\_\_\_\_ नाम: \_\_\_\_\_

**ANNEXURE – Vb**  
**INFORMED CONSENT FORM ENGLISH**

**Informed consent form (English)**

**Title of the project:** Lived experiences of post mastectomy women at AIIMS, Jodhpur.

**Name of the Principal Investigator:** Ms. Neha Patiyal (M.Sc. Nursing)

Sample Identification No.

I \_\_\_\_\_ D/o, S/o \_\_\_\_\_  
\_\_\_\_\_ R/o \_\_\_\_\_

\_\_\_\_\_ give my full, free, voluntary consent to be a part of the study “Lived experiences of post mastectomy women at AIIMS, Jodhpur”, the procedure and nature of which has been explained to me in my own language to my full satisfaction. I confirm that I have had the opportunity to ask questions.

I understand that my participation is voluntary and I am aware of my right to opt out of the study at any time without giving any reason.

I understand that the information collected about me and any of my records may be looked at by responsible individual from AIIMS, Jodhpur, Rajasthan or from regulatory authorities. I give permission for these individuals to have access to my records.

Date: \_\_\_\_\_

Place: \_\_\_\_\_ Signature

This to certify that the above consent has been obtained in my presence.

Date: \_\_\_\_\_

Place: \_\_\_\_\_ Signature of Principal Investigator

Witness 1

Witness 2

\_\_\_\_\_

\_\_\_\_\_

Signature

Signature

Name: \_\_\_\_\_

Name: \_\_\_\_\_

## ANNEXURE- VI

### BRACKETING

This bracketing is done before the data analysis so that there is no preconceived notions which may affect the results of my study.

The method of bracketing used for this study is by the **peer review** with my colleagues and writing memos. **Writing memos** is the process where researcher writes whatever comes to his mind and just writes it down.

Researcher personally thinks that the most post mastectomy women had bad experiences about daily living, mainly the young mastectomized women. They may not be able to cope up with their situation and body image, thus frequently feel depressed about themselves. While the older mastectomized women are not much concerned about their body image. Thus both kinds of women use different coping strategies to cope up with their daily ups and downs in mood.

Following are my preconceived notions which I am penning it down on the paper:

- Cancer stigma
- Fear of death
- Inadequate coping strategies
- Anxiety to move outside home
- Frequent crying episodes
- Tension about children
- Disturbed body image

Researcher is also a registered nurse and working in the radiation unit as a student posted for clinical posting as a part of academic requirements. So I have provided care to many post mastectomy women.

Hope, this will not affect my study results and I will be completing my thesis successfully.

Ms. Neha Patiyal

10<sup>th</sup> September 2020.



## Annexure VII

**Table for detailed characteristics of post- mastectomy women**

Patient	1	2	3	4	5	6	7	8	9	10	11	12	13	14
Age (yrs)	38	45	42	47	31	30	35	70	43	37	41	50	58	38
Religion	Muslim	Hindu	Hindu	Hindu	Hindu	Hindu	Muslim	Hindu	Hindu	Hindu	Hindu	Muslim	Hindu	Hindu
Education	MA English	Illiterate	8 <sup>th</sup>	5 <sup>th</sup>	10 <sup>th</sup>	MA Politics	6 <sup>th</sup>	10 <sup>th</sup>	10 <sup>th</sup>	6 <sup>th</sup>	B.Com	11 <sup>th</sup>	MA Hindi	Illiterate
Occupation	Govt. Teacher	House wife	House wife	House wife	House wife	House wife	Tailor	House wife	Asha worker	House wife	House wife	House wife	House wife	House wife
Marital status	Unmarried	Married since 25 yrs	Married since 16 yrs	Married since 30 yrs	Married since 15 yrs	Married since 5 yrs	Married since 20 yrs	Widow	Married since 30 yrs	Married since 20 yrs	Married since 18 yrs	Married since 28 yrs	Married	Married
Family members	5	5	5	6	7	10	7	5	5	2	4	2	5	5
Total children	No	3 (1 boy & 2 girls)	2 (1 boy & 1 girl)	3 (all boys)	3 (2 boys & 1 girl)	2 (boys)	3 (girls) & 3 miscarriage	2 boys (one died in accident)	3 (Boys)	No	2 (1 boy & 1 girl)	No	3 (girls) & 2 abortions	4 (3 boys & 1 girl)
Breast feeding	No	Good	Cerelex feeding after cesarean	Good	Good	Good but 10 months for 2 <sup>nd</sup> child	Good	Good	Good	No	Good	No	Powder milk 1 <sup>st</sup> child	Good
Family planning	No	Tubectomy 14 years ago	No	Tubectomy 12 years ago	Tubectomy in 2015	No	Tubectomy 11 years ago	Tubectomy 30 yrs ago	No	Tubectomy 10 years ago	No	No	No	No
Monthly income	40000	20000	12000	5000	15000	15000	10000	15000	15000	12-15000	30000	12000	40000	10000
Family cancer history	Mother (Lymphoma) Uncle (Stomach)	No	No	Mother (stomach)	No	No	No	No	No	No	No	Grandfather (Liver) Uncle (Neck) Sister (Stomach)	No	No
Mastectomy years passed	2 years	2 months	2 months	4 months	4 months	3 months	5 months	4 months	2 months	2 months	3 months	2 months	8 months	4 months
Associated problem	No	No	Piles	Foot ache	No	Thyroid	No	Diabetes and HTN	No	Gall stone operated 2 yrs ago	No	Allergy	Arthritis	No

## **ANNEXURE- VIII**

### **TRANSCRIPTS OF INTERVIEW**

**Subject Code-Res\_1**

**Interviewer: Aap kitne samaye se stan cancer se pidit hain?**

**Interviewee:** Phele bar 2016 m pta chala breast cancer ka. Isme mahsoos Kiya tha, matlab choti se gilti ho gayi h, khafi time to dikhaya nahi, kyunki usse phele mere periods wegera band ho gayee the, 2-3 mahine, phir merko those gilti mahsoos hui , dekhaya doctor ko, idher udher, 2-4 doctor ko dikhaya, to sabne kaha operate karao, us wait maine karwaya nahi tha, phir jyada hi problem hone lagi to phir maine dikhaya Deepak Bhandari ko, Raj dhani hospital m, unhone usko biopsy ki, usko send kiya, to diagnose hua breast cancer.

**Interviewer: Stan cancer ke bare main pata chalne par aapki pehali pratikriya kya thi?**

**Interviewee:** Mother ki to death ho hi gayi thi or phirse wahi cancer stress, mere mother ki 16 m hi death hui thi January m or merko Nov m hi diagnose hua tha matlab phir wahi, family tension m aa gayi , nahi lagta ilaz wagera, Mumma ki death ilaz ke doraan hi hui thi unki therapy hui thi chemotherapy, nahi unka operation nahi hua tha unka blood m that na, to 4 therapy hui thi.

Brother hi hai or yeh to maine mere bhai se hi discuss kiya tha, mera bhai kafi close h kyunki ladies wagera koi thi ni kyunki shadi hui nahi thi to...

**Interviewer: Aapne mastectomy se guzarne ka fainsla kyun kiya?**

**Interviewee:** 2016 m maine biopsy karai thi phir uska aya tha phir wapis jake Ahemdabad m test karaya tha PET scan wagera to sab normal tha, han PET scan, to us samaye decision liya nahi usko htane ka, doctor ne suggest to kiya tha lakin wahi hai ki dimag se tayar nahi ho pa rahe the is cheez to htane ke liye to aise maine do saal delay kar diya, phir mera 2018 m wapis usme swelling se aane lagi breast m, phir wapis treatment start karwaya, doctor hain Dharma ram poonia unhone kafi merko divert kiya tha kuch ni hota hai karwao phir unhin se maine operate karwaya tha complete. Complete ilaaz liya tha 2018 m or 20 m phirse diagnoses hua. Jahan pe maine radiation karwaya tha wahan pe chaala hua usse ghaw ban gaye kafi, to abhi mere chest pe kafi sare gaw hogye yahan pe or phir jo second breast hai na usme bhi swelling aane lag gayi abhi hai, wapis test karwaye na to usme diagnose ho gya yahan per (second breast).

Upset the andar se, ajeeb se feeling ho rahi tha jaise ek aang kat gaya ho jaise, like matlab istritav khatam ho gaya ho jaise ladies ka to hota hai na ek bhin part hat gaya jaise, bahar aane jaane m bhi thodi dikaat ho gayi, kafi kuch aise khayal aaye the matlab negativity ki taraf ja rahi thi, ab to bhul gayi sabhi cheezein, istritav khatam ho gaya matlab kahin aane jaane dikaat to or kahin program wagera attend ni kar pate, sharam ke mare jayada tar ghar pe hi, kafi time ghar pe hi rahi hun, lagbhag 4-6 mahine rahi , phir mere bhai ne unhone kafi himat dilai ki nahi aap jao aao, bahar niklo karo tab wapis shuru kiya.

**Interviewer: Mastectomy ke baad se aap kin sabhi samasyaon ka samna kar rahein hain?**

**Interviewee:** Mere mainly yeh hath ki dikkat thi, yahan pe swelling jyada aa gayi thi upper arm m. Uske liye maine excercise centre bhi join kiya tha, physical therapy bhi li thi or usko jo belt phentein hain. Bas mainly mere hath ki problem jayada thi. Right hand tha to kuch kam hota nahi tha, ajeeb sa lagta tha, ki aisa hi kuch, main teachers hain to board per likhne ka kaam hota hai, 3-4 mahine to gayi ni chuti le li thi, ji swelling aa gayi thi hath m isse kaam hota ni tha, board pe likha ni jata tha, copy m kuch likha ni jata tha. Ghar ka kaam kuch ni hota tha mujhse. Na doctor ne kaha tha ki isko jyada se jyada use m lo, exercise karo, kaam karo lakin ho hi nahi pata tha, yahan pe ikadam swelling sa ho jata, kada ho jata, dukhne lagta.

Subah uthke acha nahi lagta dukh wali feeling aati thi, aisa to abhi tak bhi aati hai, feeling to aati hi hai ek hisa kata hua hai to ab dusra bhi aisa ho gya hai to or bhi jayada..... mainly jaise roti bnana, weight huthana hai isme or sabse jayada likhne m problem board pe to bilkul bhi nahi likha jata tha staff co-operate karta, verbally jaise likhne ka Jo copy checking jo kaam hota tha mera sara staff kaam karta tha, only padhane ka kaam m karti thi.

Samaj m aana jana, thoda ajeeb si feeling aati thi, kapda bhi lagane padta tha matalb he feeling se gayi nahi m kabhi bahar. Saal bhar maine koi function attend nahi kiya, uske baad thoda sa karne lagi. Saal barabar acha gya 2019 phir wapis problem hone baad m phirse wahi. Abhi chuttiyon m hain 1-2 maheine ho gye.

Nahi insurance to mera kuch nahi kara rakha. Yeh hota hai mehsoos hota hai ghar m teen death ho gayi thi, mere uncle ki death ho gayi thi chemo ke doraan, second mummy ki ho gayi, third patient main hun bas ab yeh icha hai ki kisi ko koi bimari na ho pure pariwar m, humare pariwar m teen member ki death teesari m hi hun matlab do ki death ho chuki hai,

Han baghwan ko manti huna, actually isme mere astha hai jo karta hai acha hi karta hai bas, namaz karti hun jab wakat milta hai padh leti hun, 5 time ki hoti hai, operation ke baad kabhi padhtein kabhi nahi regularly nahi ho pata

hai, Operation ke baad 2-4 maheine yeh sab nahi ho pa raha tha, kabhi kabhi lagta hai aise maan m ki aisa hamare sath hi kyun ho raha hai, humse aise kya galati ho gayi kabhi kabhi hota hai. Abhi bhi hota hai lakin maan ko samjhane wali baat hai ki boltein hain jo hota hai ache ke liye hota hai, kya pta isme bhi ho kuch. Bhagwan ki puja se han matlab thoda relax mahsoos hota hai. Exercise bahar thoda ghumna phirna or jab ek ghar m bathe rahtein hain na to mentality change hone lagti hai, negativity aane lagti hai, to m aksar thoda thoda bahar nikalti hun, baagiche m jana .....matalab apne aap ko busy kar lena matlab taki us cheez se ...vichar negativity aati hai ki ab kya hoga (ane wala samaye) aise wase isse acha hai ki upper hi chale jayein.

**Interviewer: In samasyaon ke prabhandhan main aapki madat kon karta hai?**

**Interviewee:** Mera sabse jayada cooperation mere staff ka or mere matlab bhaiyon ka hi raha hai kaam m. Khanna bhabhi bnati hai. Ghar ka kaam sab kar leti hun mera kaam m khud karti hun, jab surgery hui thi tab mere bhabhi karti thi.

Hard yeh hai ki kuch kaam ho ni pata hai ab..kuch... Bhi ni ho pata jaise ghar ka kaam hai itani weakness aa gayi hai, ab kahin aana jaana bhi nahi hota hai or ek hi jagah baithe rehna, is therapy ki wajah se mera bohut jayada kamjore aa gayi hai, na koi khana pina bahata hai kuch bhi ni hota aisa, chakkar wagera ana.

Dekhna to kya, na to pahne odhne ka craze raha, matlab jo kapde apan pahentein hai to fittings nahi baythti hai, ek ajeeb se feelings hota hai matlab ki ek hisa kam ho gya (sobbing), kya btayein ab aapko.

**Interviewer: Kya aap moka milne par stan punahnirmaan se guzarna chahtein hain?**

**Interviewee:** Reconstruction ke bare m socha tha per maine kaha hi temporary wo cheez hoti hai, uske side effects to hotein hain na phir. Abhi aap dekhoge to mere ghaw hi ghaw hue hai matlab or yeh ghaw mere 4 -5 maheino se hain. Doctor ne kaha uska koi treatment nahi hota chemo hi ilaaz hai tab yeh step uthana pda hume baki isko bhi maine kafi time tak ignore kiya isko, capacity nahi thi wo mentality ho jati hai ki ab nahi karwani chemo bas. Nahi second time hua na yeh wo to maine complete treatment liya na yeh wapis second time hua hai mere. Abhi doctor ne bola ki chemo teen extra lo phir uske bad CT scan hoga uske baad next descion leinge kya karna hai. Nahi m nahi karana chate reconstruction

**Interviewer: Stan cancer ke bare main anya mahilaoon ke liye aapke kya sujhaav hain?**

**Interviewee:** Suggestion to yahi hai ki apni care karo, choti moti bhi problem hoti hai to phele jake batao jaise mere starting m jo monthly cycle the wo gadbad hue the 4-6 maheine rah gaye, those those aate the wo to gharelu ilaaz kar liya le liya or ghar m koi guide karne wala bada bhi nahi tha jaise mummy nahi thi , theek hai m hun teen bhai hain, us wakat m thoda sa active ho jate na is cheez ke bare m to itani badi problem mere m nahi banti. Surgery ke bare m, surgery to karani padti hai agar matlab jayada nukhsan de to usko hatana better rekhta hai, wo bhi maine kafi time tak avoid kiya uske 2 do saal tak.

**Interviewer:** Kya aapko bhavishya ke bare main koi chinta ya bhavnayein hain?

**Interviewee:** Aane wale samaye ke bare m to main sochte hi nahi hun ab, present m hi jetein h, nahi future ka bilkul nahi, filhaal to m itani negative ho chuki hun ki merko to kal ka bhi bharosa nahi hai. Negativity bahot aa gayi hai. Abhi AIIMS m ilaaz lene ke baad thodi positivity aa rahi hai kyunki jo mere ye first therapy lagi na isse mere kafi farak pada lakin mere, abhi do saptah delay ho gye to wapis problem banane lagi phele covid ke chakkar m phir mere WBC kam thi 2 saptah delay ho gaye.

**Interviewer:** Kuch or jo aap kehna chahati hain?

**Interviewee:** Baal bhi chale jatien hain, usse bhi matlab yeh mehsoos hua ki kahin aane jaane m sharam mehsoos hoti hai.

**Interviewer: Aap kitne samaye se stan cancer se pidit hain?**

**Interviewee:** Abhi giya hai, pata padta yeh hospital btata hai, 5-6 maheine ho gaye graphy karaye, phele to Pali gaya phir Jodhpur aaye. Nahi Pali m nahi bataya ganth ka, athaich btaya, chaar panch chah mahena hogya hoga. Chaati ki ganth ka patahi ni padeya wo yeh betni teedha ne tab pata padya. Dukhe nahi hain. Kadi duhi nahi hai. Ganth ka janchein reportein kal bahare bheji pache pata padeya kya bimari hai.

**Interviewer: Stan cancer ke bare main pata chalne par aapki pahali pratikriya kya thi?**

**Interviewee:** Bura laga, sochne laga bimari kaise ho gayi yun.

**Interviewer: Aapne mastectomy se guzarne ka fainsla kyun kiya?**

**Interviewee:** AIIMS main yahan ek tarik ko aya, doctor kahyo operation hai na. Han karwa diya, phele koi sharir main ki koni, operation ke phele matlab yun lagta hai, batlain lagya, yeh laga chaar batlain, ni farak padeo, seger( surgery) hoya, yeh seger hoga, operation hoga, aaye chaar batlain lagaya phelain. Oo botlain khatam hui to wo bola operation karya.

**Interviewer: Mastectomy ke baad se aap kin sabhi samasyaon ka samna kar rahein hain?**

**Interviewee:** Koi dikkat nahi sejer karane ke baad, dard to hui hai abhi aj bhi. Yahan to sojan aaya, sojan atheich hi hai hath main. Atte bhi hai, niche bhi hai atee atee. Atee sojan hai or hath main hath dard karta hai or thoda bahot sojan rehti hai hathoon m. Bahot dard to nahi, normal kare hai. Ghar ka kaam to hove koni hath to, karun koni abhi to. Kapda to thoda operation hone ke baad thoda change karein main nahi karoon, mera ladka ladki karein.

Subah subah han han bahot lagta hai, bahot kharab lagta hai mere chati koni koni mane bahot lagta hai. Dard bhi karta hai or chaati ni lagte, jani kitna bura lage. Yun kharab lage. Kharab bahi chaati nahi hai. Ni hai to kai hai hum kya kare sakaan. Buraaijh hai bahi chaati nahi hai bura lagta hai. Kitno kharab lagta hai. Dekhne m kharab lagta hai, chaat nahi to yeh kitno kharab lage, jagah khali lage chaati ki jagah, chaati nahi hai.

Logon ke sath thna bathna to ho hi ni rahe ho abhi mahena hi hoye operation kare ne, utha bathta ni karu, kadhhi bhi niche ni bathti hun kurse par bathti hun, majah per bathti hun, batha h .....

Log to aache- pache gaawn jaun koni Jodhpur main hi bethi hun. Log to hume ki kehtein chaati nahi hai. Keh log to gaawn ki phele Jodhpur ni jaun. Log kahe chaati nahi hai. Chaati kaat de. Bura hi bole acha kena bole.

Mera pati karta hai. Nahi nikale to kya kare saktein hain.

Bhagwan to ghani mane, bhagwan tayin to baitha hain. Han bas manu je bhagwan mare bimari kyun kari. Din m kitni baar subah sanan balkan ne diya vati karta, hum diya vati ni hue, snan huaye ni segery (surgery) pacha. Diya bati karta hain, jal wagera chadhta hun bhagwan jal chadhta hun. Abhi to nahi chadya mahino bhari hum tyaar ready raho karo bhagwan re puja. Bhagwan ke aage hath jodna diya bati bhagwan ko.

Aaine ke samne kharab lagta hai, chaati nahi hai, kharab ho lagta hai. Aisa hun ki chati nahi hai. Bura to kharab ho lagta hai, halat kharab ho gayi, baal bhi gaya.

**Interviewer: In samasyaon ke prabhandhan main aapki madat kon karta hai?**

**Interviewee:** Kaam oo meri ladki o kare kaam, khana bnana, kheti m kaatna, ghar ka kaam karna, padhai bhi karni. 14, 15 bich padhe hain ladki, sab kuch karti hai. Ek ladka hai, ladka bhi karta hai.

**Interviewer: Kya aap moka milne par stan punahnirmaan se guzarna chahtein hain?**

**Interviewee:** Han, ban sake hain? Kiye bna? Karwa sakta hun chaati lagwaun? Athu chaati or lagwate, lagwa sakta. Bimari to kumhich karna chahun. Hum kaye kar sakun, bimari to hata de doctor ne.

**Interviewer: Stan cancer ke bare main anya mahilaoon ke liye aapke kya sujhaav hain?**

**Interviewee:** Kya kahun....ahich hai jaldi se jaldi ilaaz kareyin.

**Interviewer: Kya aapko bhavishya ke bare main koi chinta ya bhavnayein hain?**

**Interviewee:** Sochtein to khani hain, soche jitrun hi hai. Sochta to kaya, bimari ki hui. Kaise aayi bahar. Aage bhai adi bimari mat aajaio. Han main theek ho jaungi. Theek hota hun, kaam aise karta hun, ladka ladki ki shadi karta hun.

**Interviewer: Kuch or jo aap kehna chahati hain?**

**Interviewee:** Ka btaun madam.

**Interviewer: Aap kitne samaye se stan cancer se pidit hain?**

**Interviewee:** Merko dard hone laga seene m, achanak pta laga, doctor sahab ne btaya ki gathan ander se ho gayi hai, merko mehsoos hi nahi hua tha, badhti gayi badhti gayi jaise hath lagti aise laga tight kis wajah se hai. Han tight tha, itani badi gathan ho gayi thi chamadi se judi hui thi doctor sir ne bola. Yeh karib 2-3 maheine ke baad pta chala merko yeh gathan ho gayi hai. Mujhe yahanpe 10 mahine ho gaye inko yahan pe dikhate hue. Kuch ilaaz chala tha dawaiyan wagera, janchein wagera. Phele to merko 6 chemo yahan pe hue the or 13 to abhi likh ke diye na. Mere mother ko sabse phele bataya cancer ka, wahi mere saath hospital aati thi.

**Interviewer: Stan cancer ke bare main pata chalne par aapki pahali pratikriya kya thi?**

**Interviewee:** Merko ye pta hi nahi tha ki merko breast cancer hai, merko yeh pata tha ki sirf gathan hai. Doctor sahab ne btaya tha. Matlab merko... Kisko hai ni cancer ki bimari, na mere nani ji ko kisi ko bhi nahi thi merko kaise ho gayi, yeh m soch rahi thi. Humare wahan parivar m kisi ko nahi thi.

**Interviewer: Aapne mastectomy se guzarne ka fainsla kyun kiya?**

**Interviewee:** Doctor ne kuch bataya ni, to bola operation hoga darne ki baat nahi hai bhari wajan or kaam nahi hai, kha sab kha sakte ho, wo bhi thandi cheez khana padega, garam garam cheezien nahi.

**Interviewer: Mastectomy ke baad se aap kin sabhi samasyaon ka samna kar rahein hain?**

**Interviewee:** Dard, ruk ruk ke dard tha, yahan pe ( showing axillary region ), jaise hichav ho raha tha or ruk ke dard ho raha tha phir or lockdown m hamara ilaaz band ho gaya tha september m doctor sahab ne kaha us samaye ilaaz chala tha, doctor sahab ne bola abhi nahi ho sakta aapka ilaaz (lockdown). Lockdown m band ho gya mera ilaaz, chemo bhi nahi laga, ek doctor sahab ne bola ki cancer ka hospital to band nahi rehti hai, chalu rehti hai, to humko to pata hi nahi tha is waiah se gathan or badh gayi phir. Operation ke baad chakkar aate the matlab sharir m khoon nahi tha, kamjori or chakkar bahot aate the or main Jaipur se aage thi 7 point tha blood. Mere sharir m blood tha na 7 point tha bilkul, safade thi bilkul. Kam tha doctor sahab ne bola kamjori is wajah se hui hai ki khoon chush gayi hai pura andar hi andar. Kamjori aa gayi sharir m operation ke phele.

Abhi bhi dard hai, tanke jaise aaye na andar, andar hi andar or bhi jayada dard ho raha abhi, jaise yeh operation Kiya hua hai tanke diye hue hain andar andar dard karta hai abhi bhi, khichav bahot jayada karta. Yahan se leke



yahan tak pura kiya hua hai, bada kiya hua hai operation. Abhi bhi soojan hai. Hath upper nahi hota tha ab thoda hone lga hai.

**Interviewer: In samasyaon ke prabhandhan main aapki madat kon karta hai?**

**Interviewee:** Mere bhabhi khana bnati hai. Subah uthke lagta hai, maine yeh ek kho diya matalb. Aaine m dekh ke lagta hai thoda change ho gayi m khud hi matlab thoda change lagti main khud hi, ek kho diya maine or chahre m badlav aa gya mere or baal gaye to is wajah se to jayada hi feel hota hai ki maine yeh kho diya. Jo hona tha wo ho gya ab kya karein, apan ke hath m to hai nahi. Abhi m bahar gayi ni, aisa lagta hai ki m bahar jaungi koi bolenge kya hua achanak ...yeh. kapde pahne m matlab ache se apan toper pehen lete hun na itna mehsoos nahi hota baki, kutra phenti hun to aise khicha hua rehta hai ki koi log dekhenge to merko bolenge, to feel to hota hi hai na phir. Ghar ka kaam mere ladkiyan karti hain, sara kaam. Abhi main apni mother ke sath rehtein hun mere sasural jate rehtein hain, abhi mother hai wahi karti hain kaam or bhabhi.

**Interviewer: Kya aap moka milne par stan punahnirmaan se guzarna chahtein hain?**

**Interviewee:** Banti hai waise ? .....wo pahan leti hun. Abhi doctor se puchenge phir. Pati waise hi mehsoos kartein hai jase phele. Sharirik sambhand bnati hun ache se. Chemo ka itna budjet hai hi nahi or doctor sahab ne bola ki itna chemo lagega 13 baar, 13 chemo lagega phele 6 baar laga, ab to jayada date badh gayi hai iski to hamara budjet hai nahi, tax cut jata hai or apan 15:57... Han bima kara rakha hai...jiska merko jayada pata nahi hai. Phele jaise karti thi wasie hi kartein hun m. Subah subah uthati hun bagwan ka naam leke phir, bagwan se dua karti hun ki aage bhi kuch na ho. To bagwan ki sewa puja karti hun to acha feel hota man ko thoda sukoon mila hai jaise.

**Interviewer: Stan cancer ke bare main anya mahilaoon ke liye aapke kya sujhaav hain?**

**Interviewee:** Main to yahi kahungi ki jaldi se jaldi doctor ke pass jaun or pucho unko.

**Interviewer: Kya aapko bhavishya ke bare main koi chinta ya bhavnayein hain?**

**Interviewee:** Kya soche hum, abhi wo itna feel karta nahi hai ladka, abhi jaipur m hai wo yahan nahi hai. Ab jaisa ho gya ho gya. Aisa lagta hai sahi to ho jayenge hum. Sahi ho jayein kuch dua kuch dawa se.

**Interviewer: Kuch or jo aap kehna chahati hain? Or to kuch nahi.**

**Interviewer: Aap kitne samaye se stan cancer se pidit hain?**

**Interviewee:** Woh 7 maheine phele hui thi, humko malum pada, 6-7 maheine ho gya to hum kissan adami the time mila nahi humko, time mila tab corona ka wo ho gya, phir baad m idhar aake check karwaya to doctor sahab yeh bola operation karna padega (phone ring).

**Interviewer: Stan cancer ke bare main pata chalne par aapki pahali pratikriya kya thi?**

**Interviewee:** Humko to dukh to hua, aisa tension aa gayi ki hum kya karenge humare pass paise nahi operation kaise karenge, bache chote chote humare ma'am. Late hua bacha isliye chota wala 12 saal ka hai.

**Interviewer: Aapne mastectomy se guzarne ka fainsla kyun kiya?**

**Interviewee:** Ganth wala hamare husband ko bola humare idhar dard ho raha hai kya hai , phir wo baad m keya btayenge btayenge..kissan aadmi us time mili nahi phir baad m mili to aisa corna ka shuru ho gaya phir baad m idhar aake check karwaya doctor sahab, doctor sahib to yahi bola ki aapko operation karwana hi padega. Surgery ka hi bola. Doctor sahab to yehi bola ki operation karwa do.

Humko operation ke pehle din hi aisa bola ki hamari puri chaat nikalne padegi to hum dard hua doctor sahab ko dar laga humko kya ho jayega humko maloom nahi, han dar laga madam, kya maloom kya hoga operation karenge hum zinda rahenge yeah nahi rahenge, hamare bache chhote chhote hain saas ko dikhta nahi hai woh bilkul aandha hai isliye to bahut tension main aa gaya madam hamare saath rehne wali koi nahi hamara husband ek hi ke baad m meri bhabhi aai operation ke baad.

**Interviewer: Mastectomy ke baad se aap kin sabhi samasyaon ka samna kar rahein hain?**

**Interviewee:** Baad mein to hum to rest main hi the, humko to nahi hamare ghar walo ko dikkat aai hai mam, wo to sahab kaam kaaj khana bhi Ma'am hamare husband banake bachchon ko khilate, gay bans hai ghar pe uska dudh bhi nikalna padta hai, gobar bhi dalna padta hai sab hamare husband aur bachon ne. Bhabhi operation karvaya to sath m hi thi phir baad mein hum idhar admit hone ke baad 10 bje wo aai or baad mein wapis chali gayi. Mere bhabhi operation karwake chuti leke ghar gaye tab mere saath m thi, phir uske ghar gaye wo.

**Interviewer: In samasyaon ke prabhandhan main aapki madat kon karta hai?**

**Interviewee:** Nahana dhona wo mere husband karate h, aaj bhi mera kapda mere husband dhotein hain. Mujhko maloom nahi ki hum kaam karte tu aur bhi jyada ho jata to kya karun to isliye humko bolta puri rest pe raho tum humara kapda bhi wo dhota hai humara. Kaya kartein Ma'am bahot takleef hai (sobbing) kisko bol de hain madat kar rahein hain.

Is hath m hota hai thoda dard, aisa thoda thoda idher se aata hai or wo wala to..humko aise lagta hai wo operation hone ke baad wo aisa hua , to thoda ajeeb lagta hai, aaisa aisa kartein to humko aise lagta hai ki kya hai idher hi aisa kyun rehta, dekho aap idher waisa rehta hai na operation karne ke aad thoda humko ajeeb lagta hai , ek to aisa wo ekdam sahi hai per idhar operation ke baad aisa hua hai saaf ho gya hai isliye humko thoda lagta hai kuch raha nahi hai.

Subah uth ke to kya lagta hai, humko chai bna ke deta or pete hain phir aise hi bachon ke saath ghumtein hain. Bache school nahi jate ,school to band hain. Abhi to ho jata upper hath, phele nahi hota , abhi to doctor sahab exercise karne ki bola ek to aise bola uper uthana ek wo wali side or ek aise ghumana. Soojan to nahi thi per dard hota , phele jada hota dard operation karane ke baad. Dard normal dard hota bahot jayada nahi idher hi hota. Tanke khole jab tak to koi bache ya aju baju m aake snan kra dete humko. Phir baad m humara wo hath dard kam hone laga to main dhere dhere karte.

Nahi hum ghar se bahar hi nahi jate, kidher jate aisa humko lagta kahin for jayenge kesa ho jayenge aisa bahar bhi nahi nikalte. Humare pass koi as jata hai baju m mahila, humare bache ghar pe hi rehte , time pass karte uske sath. Nahi chakkar nahi aata aise hi lagta hai ki jayada wapis dard ho jata hai isliye. Kuch nahi hota, nahi kar sakte hum.

Khetoon m mazdoor log dekhte hain tu abhi kya karte ek aadmi kya kare majdoor ke sath mai katttai buaai to karna padta ma'am boo to diya usko katna hi pade.

Theek honge aisa boltein hain log, rest karo theek ho jayenge. Aisa nahi hai wo boltein hain theek ho jayenge tension mat lo. Koi aisa acha aadmi ho to thoda bahot madat karta nahi to nahi karta. Koi aisa acha ho to kabhi jhadu nikalna aisa thoda bahot yeh bartan idher udher rakhna aisa. Humare mardwad junction ke pass ka adua ghawn hai. 200 km hai yahan se.

Kharcha byaaz pe paisa letein hai dusroon ke pass se. Hamare paas toh abhi toh koi income to char mahine phele aati nahi khati badi ki. Wo aata to mazdooron ko dena padta kya karein. Bima karaya hai, pura to humare husband ko maloom nahi. Han ek bima kara rakha hai.

Han kartein to the ghana abhi operation ke baad time fix nahi hota hai to nahi banta isliye aaise hi baghwan ka naam lete. Nahi baghwan ko nahi chod

sakte, takleef to humare nasiboon ki kya kare saktein, bhagwan to hath jodna hi jodna, acha lago chaye bura lago bhagwan ko to aise yaad kartein hi hain ki he bhagwan ....

Han abhi to admi rehta hi nahi ....isliye nahi bnaye. Ajeeb lagta hai, humko sir pe baal nahi hai aaisa lagta hai koi idher bhi aisa hai, body bhi humari loose ho gayi phele to acha tha hum ....patli hui hun operation se. Bimari hone ke baad sharir to thoda looze hota hi hai. Wahan to hum ma'am kabhi karate nahi, humara to chota gawn hai udhar kon wajan karta hai.

**Interviewer: Kya aap moka milne par stan punahnirmaan se guzarna chahtein hain?**

**Interviewee:** Nahi madam ab jo hai wahi sahi, ek to abhi ilaaz ka kharcha pura nahi hota aur...iske liye ek or operation krana padega to wo to nahi ho payega....kya karein madam..ab jo hai wo hi sahi.

**Interviewer: Stan cancer ke bare main anya mahilaoon ke liye aapke kya sujhaav hain?**

**Interviewee:** Ilaaz jaldi karwana chahiye aise hi boltein hain ...ilaaz karwana. Or kya baghwan acha kare kisi ke saath. Surgery karana , aise boltein hain ki karana.

**Interviewer: Kya aapko bhavishya ke bare main koi chinta ya bhavnayein hain?**

**Interviewee:** Kya sochtein hain humko kya maloon. Kya aata maloom nahi bhagwan theek kareinge to sab acha hi hoga. Hum to yahi sochte baghwan theek karein humko.

**Interviewer: Kuch or jo aap kehna chahati hain?**

**Interviewee:** Kuch nahi.

**Interviewer: Aap kitne samaye se stan cancer se pidit hain?**

**Interviewee:** Yeh madam mere breast main ek choti si ganth ho gayi thi, bilkul jara se thi wo dheere dheere to badi hone lagi, phir use doctor ko dikhaya to bole ki iska operation karna padega, maine galti se uski janch ni karaya, direct hi private hospital main uska operation karwa diya. Private main karwaya tha to ganth ganth to nikal de. Itani se thi, usko nikal ke uski janch kari thi, janch se pata chala ki yeh isme cancer hai. Yeh dubara operation hua hai mera do operation, janch main operation ki report aayi na, phir usse pata chala phir yahan dikhaya. Phir yahan pure breast main operation dubara hua. Phele January main dikhaya tha, Ajmer main dikhaya wahin 24 Ko dikhaya 25 ko chota sa operation karke uss uss ko nikal diya. Aisa hua.

**Interviewer: Stan cancer ke bare main pata chalne par aapki pahali pratikriya kya thi?**

**Interviewee:** Tension to hui thi madam dimag main ki bhai yeh bimari ho gayi to ab bahot mushkil ho gya, sab sath main hi rehtein hain. Wo to madam wo mere saab ko hi pata chala, wahi gaye the mere report lene ke liye. To unko hi pata chala ki yeh problem ho gayi hai. Phir unhone mujhe bhi nahi ki nahi yeh problem hai, bole ek baar aur dikhanyenge doctor Ko phir yahan lake dikhaya tab merko pata chal gaya ki konse doctor ko dikha rahene hain to phir bataya bhai kuch report hai isliye aapke ilaaz karwana hoga aisa.

**Interviewer: Aapne mastectomy se guzarne ka fainsla kyun kiya?**

**Interviewee:** Yehi bataya kya bola dobara operation karwa lo or is operation mein agar aapki matlab kuch report sahi aajeyegi to operation karwange se kuch hota to wo aage nahi badhega. To pura breast hi hatwa diya maine.

Niklwainge phir, bimari se to bachein kya karna. Wo to laga per kya karen madam zindagi se jayada or thodi na hai, bachein hain chote chote, unki dekhbaal ho. Dikhne ke chakkar m apni zindagi se chale jayein to unke piche wale ke kon rakshak.

**Interviewer: Mastectomy ke baad se aap kin sabhi samasyaon ka samna kar rahein hain?**

**Interviewee:** Operation ke baad, to kuch ni aayi madam, wo operation ki nalki nikali thi na usme koi aise hi thodi wo rasi payda ho gayi thi, jo phir wo antibiotics tablet wagera de to theek ho gayi. Sujan wagera to kuch nahi aisa wohi hui thi to uski wajah se bukhari hone lag gayi. Han infection ki wajah se hui, phir wo theek ho gayi. Aise to operation ka thoda bahot dard to hota hi hai. Dard wo dukhta hai thoda bahot, dukhta hai aise. Nahi yahi pe yeh twacha hi dukhti jahan operation hua ho. Han hath hilane m dikkat, hath ko

bola exercise bhi karo, hilate raho to main hilati hun hath. Us time m bta diya pura hilaoge hath. Han hath ko hila pa rahi hun. Phele to hoti thi dikkat, isko thoda kam hilati thi , ab to nahi oti nahati bhi khud hi. Mere bhabhi kart hai han wahi nehlati thi, abhi bhi wohi karti hai. Nahi abhi kapde to main khud badalti hun dhoo deti hai wo. Abhi to main khud naha leti hun, phele wo hi nehlati thi wohi dulati thi. Sab wohi banati main to kuch bhi nahi. Kaam to bahot hai hai lekin kya karen, main yahan bathi hun, wo kahwe ki bahi tu yahan aayegi kuch kaam karegi to tere jayada dikkat hojayega to tu rest Kar jaldi theek hoja isliye.

Subah lagta to hai hi madam jo nahi hai to sharir ka hisa, yahan waise hi lagta hai ki apne yahan se hta diya gaya hai. Vichar to yahi aatein hain ki apan bhi to bure lag rahein hain kya karen, kya hua hai apne sath sharir ka ang kat gaya. Maiyene to kya apne dikhne main thoda wo hogya, phele suroop lagte the ab wo to yahan se thoda bhada lagega or kya. Apan kare kya apne sath pareshani aise hai to phir zindagi bachani hai to, aage jaise doctor sahib ki salah ho wo karna.

Han ghumte phirti hun, thodi bahot ghumte hun jyada bahar ni jati. Nahi madam abhi to kuch nahi bolte log. Yahi puchtein hain ki apki tabihat kaise hai, aapne operation karwa liya to acha hi hai. Aapke aage bimari nahi badhegi. Madat to kya karein, mere ghar wale hi kartein hain log to kya kareinge, dusre to puch saktein hain bas or kya.

Wo to sahi dekhtein hain, boltein hain bahi to aaram se rest kar, tere tabiyat theek ho jaye jaldi se jaldi sahi rahe, phir apna kaam bache or ghar waise hai hi. Han silai ghar ghar ki kar leti hun. Han khud ke mere parivar ke ho gya, baki paion ke liye ni karti hun. Ab to wo bhi nahi ho pa raha.

**Interviewer: In samasyaon ke prabhandhan main aapki madat kon karta hai?**

**Interviewee:** Nahi madam sahi hai wo to dhyan rakh rahein hain barabar ilaaz karwa rahein jain mera, jaldi theek ho jayein to acha hai. Kuch ni wo to theek ho jaye bahi to acha hai phir or kya. Yahan par bar bar laana lejana, khane pine ka dhyan rahna, dawai wagera time pe dena. Khana to bhabhi g khilati hai. Juice wagera fal fruit aise, jab hua to unhone lake Rakha tha sab kuch khilane ka nahi Inka dekhrekh to acha karen jaldi those theek ho jayein bas. Nahi is operation ke baad nahi. Main to yahin hun madam jab se, wo bhi wahan hai merko dikha ke wapis ghawn chale jayein hain. Main idhar mere bhabhi ke pass hi hun. Wo apne ghawn m wahan bache bhi to hain na isliye. Chemo se ek din phele hi aajatein hain, khoon test karwake sare janchein wanchei karwake kal wo wapas wo chobis khante baad wo injection lagta hai ek kal wo. Teen din chaar din yahan ruk ke, mera ilaaz karwa ke , phir wapis chaye jatein hain aisa. Nahi bura to bilkul nahi lagta unko.

Wahi laga rahein hain. Ab wo kaise kar rahein hain merko to itana bhi nahi bataya operation main kitna kharcha hua, wo to bole tu theek hoja kahin se bhi laun, kaise bhi lagaun wo mera kaam hai. Paise se sambhandhit merko koi bhi problem nahi hai. Merko kuch problem matlab batate nahi ki tu tu bas tere to swasthye theek hona chahiye bas. Bima nahi karaya hoga. Karya hua to hoga mam shayad unke pass hi hoga puchna padega.

Galat hi hai lakin kya karein isme apne nasib main likha hoga wo to hoga bhagwan bhi kya Karen. Han bhagwan ko haath jod leti hun yahi hai bas. Vrat upwas hai wo to kar nahi rahi dawai chal rahi hai isliye. Subah sham agarwati kartein hain. Bhagwan ke upar hi wishwas hai ki jaise rakhega wase rehna hai or kya. Man ko thodi shanti or kya.

Aaine ke samne lagta hi hai apna sharir ka aang gaya, apni kya galti thi aise bhagwan ke samne jo yeh aisa hua apne sath. Or to kya batayein. Baal to utar gaye sare. Aise to kaam dhandha nahi kar paa rahi hun ghar ka.

**Interviewer: Kya aap moka milne par stan punahnirmaan se guzarna chahtein hain?**

**Interviewee:** Kaise bnayenge madam? Wo to madam apne ghar walon se salah leni padegi, moka mil jaye to lagwa lenge aisa.

**Interviewer: Stan cancer ke bare main anya mahilaoon ke liye aapke kya sujhaav hain?**

**Interviewee:** Yeh apne sath hua wo unko btayenge or kya bahi mere sath yeh yeh hua. Ilaaz dikhanyenge doctor Ko, ilaaz karwayen. Bhai doctor btayein surgery ka to karwayen or kya.

**Interviewer: Kya aapko bhavishya ke bare main koi chinta ya bhavnayein hain?**

**Interviewee:** Aane wala samaye main to kya hoga madam, kitna apna sharir sath dega utna hi kaam karega or kya. Ab wo to bhagwan rakhega waise rehna hai apne kya hai. Bhagwan rakhega waise hi revenge madam jaise kaam apne se hoga wo kare lenge nahi hoga to nahi karenge. Or kuch problem ho to fata fat dikhayenge doctor sahib ko or kya. Yahi lagta hai madam theek rahungi to acha hai agar kuch problem ho to fatafat doctor sahib ko dikhana, jaldi se jaldi ilaaz karen aisa.

**Interviewer: Kuch or jo aap kehna chahati hain?**

**Interviewee:** Aur to kya hi btayein. Sahi to kya kiya majbori hai to karwani padi, jaan bachane ke liye hi kiya hai. Acha dikhav rahte to apni jaan se chale jate, to wo.

**Interviewer: Aap kitne samaye se stan cancer se pidit hain?**

**Interviewee:** Cancer ka to mujhe operation ke dus din pehle he pata chala jab yeh sab check karwaya to sir ne 7 days ki tablet de di...o sukhne ki phir humko wapis doubt laga fnac..Ma'am phlele doubt lga phir second fnac karwai thi usme bhi doubt aaya tha phir true cut karwaaya tha to usme confirm hua ki mujhe breast cancer hai phir maine surgery karwai.

Dard nahi huwa tha jab main pregnant thi tab choti si ganth thi maine socha sab boltein hain meaid hain to normal hai kisi ne bola. Phir delivery bhi hogayi m sasural bhi chali gayi phir jaise jaise badhti gayi dard badhne laga ya kaam karti. Dada ki badi ladki ko tha, itani choti umar m mujhe hi hua hai.

**Interviewer: Stan cancer ke bare main pata chalne par aapki pahali pratikriya kya thi?**

**Interviewee:** Mujhe bahut bura laga mera bacha bahot chota hai. Dus mahine ka hai usko feeding choda ke aayi. Sabse zyada close papa ke hain per cancer ke bare m kisi ko nahi btaya ..mera bhai sath m tha unko baad m btaya humne report aane ke baad.

**Interviewer: Aapne mastectomy se guzarne ka fainsla kyun kiya?**

**Interviewee:** Doctor ne phele bola ....test confirm nahi the to unhone bola phele aapki surgery karenge surgery ko aadha ghanta rokenge ek piece nikal ke lab main bhejenge, agar usne confirm aajaye ki aapko tumor hai to usee hisab se surgery karenge. Agar nahi confirm to usee hisab se karenge. Phir humne doctor change kiya wo humara yeh hisa bachane ke liye aise surgery ka bola, phir maine Ganpat choudhary se contact kiya unhone pura hi remove kiya mera ki body m cells ptani kahan fail jata hai. Unhone phele surgery ki phir chemo kaha.

Thoda bura feel hua, thoda bura to mehsoos hua na. Vichar... kaise hoga, kaise operation hoga, kitna time lagega, wahi to. Bache to bhi chod ke aai, bachungi ki nahi bachungi. Kuch nahi pata tha.

**Interviewer: Mastectomy ke baad se aap kin sabhi samasyaon ka samna kar rahein hain?**

**Interviewee:** Uske baad is hath m bahot dikkat aai, uthne mein takleef aai yeh itna bhi nahi ho pata tha kyunki yahan ki sab nashein nikali thi niche ki, khichav hota tha, kamjori uthne bathne m dikkat, dard hota tha. Bhai bhabi wo uthate the baithate the 10 din tak to phir isko halka halka movement diya mere bhai ne. Ek time khanne m pareshani. Kha nahi pati thi jayada kyunki yahan pe nashoon m takleef ho jati thi. Yahan se thi na to khane khaana bhi



slowly , dhere dhere khaana padta tha. Takleef bhi hoti thi feel bhi hota tha tab tak yeh tha nahi phir biopsy report m aa gya ki nahi aapko yeh hai confirm tumor hai phir iske tension ho gai chemo hoga kaise hoga kya hoga socha nahin tha na life main ki kabhi aaisa hoga. Soojan hoti hai hath m iski liye mane kuch ni pehna. Ab mere to kapdoon m bhi pareshan ho jati hun aati nahi hai kuch kuch kapde. Swelling ho jati hai.

**Interviewer: In samasyaon ke prabandhan main aapki madat kon karta hai?**

**Interviewee:** Ab to kapde khud phen lete hain phele bhabhi karti thi. Phele sab bhabhi karti thi. Nahana dhona bhabhi hi karati thi 10 -15 din tak jab tak yeh hath cover nahi tha na. Ghar ka kaam bhabhi or mummy karti hai. Main thi nahi sasural m abhi bhai ke yahan aai hui hun 3 mahine ho gaye ghar jaye hue. Gaye nahi wapis bache bhi yahin hain nana nani ke saath.

Sasural m wahan karne wala nahi hai na itna koi. Jethani hai megar wahan ek to finance ki bhi dikkat hai sasural m , yahan acha hai maike m to dikkat nahi hai.

Subah uth ke acha ni lagta. Hota hai, aaine m jati hun to ekdum plain dikhta hai to acha ni lagta, feel bhi hota hai kya hua, kaisa hogya sharir, apne husband se bhi door hoti hun unse bhi baat nahi karti, wo boltein hain kuch ni hai yeh sab to bhi nahi karti ( sobbing). Maan ajeeb sa ho jata hai ki bhai nahi kisi se bhi koi baat karne ka koi maan nahi hai. Feel hota hai sabko dekhti hun bhabhi ki dekhti hun, main aise hun wo sab ache se ghume rahe phir rahenge hain (sobbing). Mera bacha bhi aata to usko door rakhti thi ki,kyunki m usko le nahi pati thi, ab usko leti hun, wo bar bar mere pass aata hai, dino bachoon ko. Hota hai takleef kabhi zindagi m , nikal jayega yeh bhi waqt.

Logo se milna acha hi hai waise to magar mere family wale bahot achhe hai wo mujhe poora support detein hain. Kabhi kamzor nahi karte hai himmat dete hai mujhko puri.

Pati se batein karna chod diya, abhi chemo ke baad mera man kisi se kyunki wo sab poochte the kaise hua kya hua phir wo neend aati nahi thi. Dimag me rehta tha kaise hua kya hua. Feeling to yahi hai ki bas himat rakho, sabhi boltein hain ki himmat rakho, karna hai sab kuch nikal jayega. Mere husband bhi pura support detein hain, bhai bhi detein hain. Bhai ka pura acha support hai, dono bhaiyon ka. Do bhai hain aatein hain sath m, treatment wahin karatein hain ek to yahin hain ek jo aata hai or do piche hai bhai bhabhi ka bahot acha support hai har bar himmat detein hain mujhko kuch nahi sab kuch hoga. Yahan lana, tujhko wapis theek karunga, theek karunga bas. Han bhai ka bahot support hai. Han pati aatein hain yahan bhi aatein hain, maike m bhi aatein hain. Jaise hi wo aatein hain bachoon se or humse milne.

Sharirik sambhand nahi, bas itna hi rehta, acha ni lagta abhi unko bolti hun ki ab mera ek hisa bhi chala gya tobbhi feel hota hai, unko kuch nahi feel hota magar mujhe feel hota hai, mujhko acha nahi lagta megar wo mujhse bahot pyaar kartein hain. Kuch nahi ignore kartein hain har cheez ko magar m kamjoor pad jate hun unke samne. Thoda bura lagta bura hota hai kaise zindagi thi kaise ho gayi. Kinta time ho gya inse door hue huye, ghar chod diya, bachon ko choda sabse door ho gaye ek pal ke liye. Acha nahi lagta mujhe abhi kuch bhi, bilkul nahi bas. Akele bhi rehti hun jayadatar apne sapne ke bare m bhi sochtein hun ki mujhe apna pura karna tha bich m hi yeh aa gya. Hai mera ek dream. Abhi to mere sirf ki achi post pe job karun ab bache bhi bade ho gaye to exam ki tayari karun, bahot achi post pe soch Rahi hun ab wo hoga ya nahi hoga dekhun... Baad m koshish karungi.

Logon se aram se gul multi hun. Bahar nahi nikalti ghar m hi rehti hun jayadatar. Nahi nikalti log puchtein hain kya hai kaise hua, uske sath aisa kyun hua , kyun kiya hazaron aise batein kartein hain Jo dil ko chubhtein hain isse acha kisi se baat ho na karen, wo or kamjor kar dete hain mujhko. Log puchtein hain yeh kya ho gya abhi yahan pe Kyun aree yeh karaya, kya ho gya aisa. Phone aatein hai tab bhi yahi puchtein hain inta bda ho gya bola nahi tujhe bura laga, mujhe kisi se bura nahi laga aap mujhe phone karo ya nahi karo. Mujhe time nikalna hai bas apna.

Nahi sab mere family or mieke wale uthatein hain sab. Mere bhai peher wale , mere husband ki salary itani nahi hai na. Yahan to kya business hai to phir thodi sale ho jati hai achi.kartein hain wo bhi help kartein dono.

Bhagwan ke prati bahot acha hai. Mera pura support hai mere bhagwan ke liye. Unhone hoke mujhe bachaya. Aaj m thoda sa bhi wait karti to m to mere bachne ka chance kam ho jata. Krishna ko bahot pujtein hain mere krishna. Bhagwan ki puja karke bahot acha mahsoos hota hai, relief milta hai Bhagwan mujhe bahot priya hai. Bahot himat rehte hai mujhe.

Yahi sochun ki future kaisa hoga, future m kaise sambhalungi sab kuch, bache ko, husband ko, ghar ko. Wo kaise hoga.

Future ke bare m sochti hun, yeh clear ho jaye treatment pura ho jaye apni study karungi acha future banugi, bachon ko bhi acha future dunga, or parents ki liye bhi kuch na kuch to baneige na or yeh bhi hai self dependent banugi, kisike samne hath na falun. Aisa to kuch karun, kabhi next aise problem ho to mujhe kisi ke pass Jana na pade na maike na sasural, khud pe depend hun. Isko bimari Ko bhulne ki koshish karungi, magar yeh pal aaya isliye aaya ki mujhe himaat de or apne paron pe khade karne ki.

Iske bare m sochati hun ki bhai kya hoga aage, wapis to nahi hojayegi magar bhulne ki bhi koshish karungi. Future ke bare m nahi sochungi past bnake

isko bhul jaun. Han aisa kuch pal aya tha zindagi m jo puri zindagi hil gayi mere, nikal hayega yeh bhi wakat.

Bura hota hai kab kitni achi tayar hoi abhi kuch ni tayar rehti simple rehti hun mera beta bhi mujhko bolta hai mummy aap kaise tayar honge kab tayar honge wapis aap aise kab banoge achi sadi pehen kar. Main pehenugi beta wo din jaldi hi hai. Aap ache tayar nahi hote ho aap kab theek honge m ka ho jaungi. Mera bada wala beta mujhko bahot support karta hai. Aap aajana hain operation kra Liya aapne ab aap aa jana Jodhpur se aungi.

**Interviewer: Kya aapko bhavishya ke bare main koi chinta ya bhavnayein hain?**

**Interviewee:** Kya batun sab kuch to bta diya

**Interviewer: Stan cancer ke bare main anya mahilaoon ke liye aapke kya sujhaav hain?**

**Interviewee:** Sabko yahi bolti hun himmat se karna, rona to sirf akeli mein subke samne nahi rona, rone se yeh thoda man bhi halka ho jata hai. Baat cheet kartein hain log hamari feeling btayein aisa hoga waisa hoga woh suggestion detein hai aise karna wasie karna wo bahut bura lagta hai aap humko suggestion mat do humko sub pata hai kaisa hoga. Unko yehi batana chahta hai ki ache se sochein sab kuch accha hoga bhagwan pe chhod de wo hamare saath bura nahi karega agar hum kisi ke sath bura nahi kiya ho.

**Interviewer: Kya aap moka milne par stan punahnirmaan se guzarna chahtein hain?**

**Interviewee:** Nahi mera bhai to bolta hai ki wapis surgery karwange ahemdabaad m lakin mujhe nahi karwani mera maan nahi hai bilkul. Koi log boltein hain ki achi ni rehti khuzali rehti hai pareshani Hoti hai. Aap mat karwao. Kuch boltein hain alag alag comments kartein hain. Abhi tak to kuch socha nahi iske bare m. Abhi to kuch 6 maheine iske hain phir dekhenge kya hoga. Dekho time btayega abhi to kuch nahi.

**Interviewer: Kuch or jo aap kehna chahati hain?**

**Interviewee:** Or to kuch nahi abhi to.

**Interviewer: Aap kitne samaye se stan cancer se pidit hain?**

**Interviewee:** Jaise abhi 8 -9 mahiene to ho gaye ilaaz karwate hue usse saal bhar phele pta chala to kisi ko nahi dikhaya koi takleef bhi nahi thi wo kya hai yahan pe mere bachi ka ilaaz chal raha tha na to main yahan pe aai thi wo bhi ek aap ki tarah the research kar rahe the unhone pucha ki aapke breast m cancer wo... ganth wagera to nahi hai tab manie bola hain mam mere ganth hai, merko check karwana hi hai. Phir pta chala, yahi per check kara pura ilaaz yahin pe karwaya. 2 saal ho gaye.

**Interviewer: Stan cancer ke bare main pata chalne par aapki pahali pratikriya kya thi?**

**Interviewee:** Ek dum se jhatka laga tha ki jaise yeh kya ho gya merko maine socha yeh ganth hai bikhar jayegi bache ko dudh ni pilaya, delivery ke time khatam ho gya tha paet main, to maine socha dudh ki koi ganth ban gayi hogi apne aap theek ho jayegi theek ho jayegi. Theek ni hui. kuch dhukh takleef kuch bi ni tha kuch bhi dukh bhi nahi tha mere to. Kabhi dard bhi nahi hua, phir yahan na choti choti ganth ho gayi thi or phir yahan pe check karwaya, biopsy hui yahan ki bhi, wo ki bhi hui, FNAC sab wegera sab ho gya tha. Apne pati ko hi btaya.

**Interviewer: Aapne mastectomy se guzarne ka fainsla kyun kiya?**

**Interviewee:** Surgery ko to jo ab 5 tarik aayegi jab 3 mahiene honge. Abhi October chal raha hai na November ki 5 tarik ko 3 mahiene brabar ho jayenge.

Chemo diye the Ma'am , ki phele aapko chemo karwane padenge or ek cycle pura karwa lo maine aath chemo ho chuke the, aath chemo hone ke baad hai na operation ka bola doctor sahib ne, phir operation ho gaya tha or ab wo radiation ke liye aaye the yahan.

Ab wo to ekdum jhatka laga ki ek breast pura haat jayega, phir inhone mereko himmat bana di ki merko hi koi problem nahi hai to tu kyun tension karti hai. Wohi bus ek dum jhatka lag gaya ki ab m phele jaise nahi rahungi bal chalein gaye or wegrea yeh sara...baal to ab wapis bhi aa gaye thoda thoda lakin sare itane lambe baal the chale gaye ekdum bahot roi thi main. Han lagta tha ki jaise m main oro ki tarah nahi dikhungi ab, unke to hain mere nahi hai to aisa lagta tha.

**Interviewer: Mastectomy ke baad se aap kin sabhi samasyaon ka samna kar rahein hain?**

**Interviewee:** Nahi maam, Allah ka shukar hai kuch bhi dikkat nahi aaye surgery ke baad.

Nahi sujan to nahi hai thoda sa sunapan rehta hai yahan pe, sun kartein hain na yahan pe operation karte wakat sun kartein hain, to wo abhi tak sun hai yahan pe, ab to ghar ka kaam bhi kar lete hun main.

**Interviewer: In samasyaon ke prabhandhan main aapki madat kon karta hai?**

**Interviewee:** Mere saas, mere bache, mere bache hai na badi 18 saal ki ladki hai, mere devrani sab sath m hain na ghar ka kaam karte the. Kapde phenana wo mera aadmi karta tha, badalwate the wo lagi hui thi na wo nalki usko bhi drain karate the roaz, bo sab ye mera aadmi hi karta tha.

Han subah uthe lagta tha kabhi 2, jaise kabhi kabhi to aisa lagta yah Allah merko utha lete isse acha to, mere saas sasur mere liye bahot rohe ki nahi beta tu kya kah rahi hai, nahi ki Allah sab acha karenge. Unhone merko himmat bhadai, mere pati ne, mere bachon ne.

Nahi surgery ke baad to abhi ek baar mere wo kya hai na jija ji the na unki death ho gayi thi to mere behen sadhe chaar maheine tak andar bathe tha na to wo bahar nikali jab main peher gayi thi, to do teen din mere peher reh ke aa gayi swanchi gate peer hai Jodhpur. Nahi maam, kahin ni nikalati, ghar ke alawa to bas yahan hospital aati hun. Aise hi nahi jati bas yun hi. Ab to m bhul hi gayi hun sab kuch, himmat badha de inhone, ab to bolti hun ki bas ab to aise hi rehna hai. Han wo mere saheliyan wegera sab merese milne aa jatin hain mere peher m aa jati hain or yahan sasural m bhi aate hain sab aatein hain sab mere liye dua bhi bahot kartein hain.

Bas theek hai acha hai. Han sharirik sambhand bnatein hain. Chemo ke baad thodi se jalan se ho jati hai to vivo plus istemal Karti hun m. Phele nahi hoti thi ab yeh chemo hone ke baad ho jati hai kabhi kabhi.

Nahi wo na janam hua na yeh aap se dawai lete the hum Modi ji ki dukan hai na wahan se lete the dawai. Han usse thoda kam lagta tha yahan se thoda wahan kam lagta tha.

Allah tala hi hai. Nahi m to Allah ka shukar karti hun ki Allah ke merko wapis ache se jaldi se theek kar diya. Shuru se aisa hi raha hai Allah pe wishwas or ab bhi hai. Jaise phele bhi main roze to kam hi rakhti hun kya hai BP wegera ho jati hai roze rekhti hun, to ab m roze nahi rekhti thi kabhi kabar nmaaz padhti hun kuraan sharikh padhti hun, matlab Allah ka sukar karti hun yah Allah tere lakh lakh sukar hai. Yeh bhi rote the mere sunke ki tu chali jayegi mera kya hoga. Bache bhi rote the. Ki tu tension mat karo main tere saath hun baaki to upar wale ki marzi hogi jo kaam aayegi.

Nahi jaise koi hath upar karti hun na thoda sa yahan khichav hota hai baki to sara kaam kar leti hun m or wajan uthane ka to waise bhi abhi mna kiya hua hai. Baki to sab kaam kar leti hun or aisa kuch jayada kaam nahi ghar pe bache kar letein hai. Kapde bhi machine m dhultein hain. Silai karti hun m lakin mere saas keh rahi hai ki do teen maheine abhi kar mat beta phele doctor se puch ki phir aake karna. Han abhi silai nahi karti hun. Khana bhi mere saas bnane nahi dete hai ki phele doctor se mil ke aao phir puch lo kya karna hai kya ni karna baki sara kaam mere saas kar leti hai. Mere ladkiyan devrani sab kar leti hain.

**Interviewer: Kya aap moka milne par stan punahnirmaan se guzarna chahtein hain?**

**Interviewee:** Nahi maam ab to ladkiyan badi ho rahi hain to unki shadi karni hai waghera isliye. Yeh bhi kah rahen hain ki jyada jaroori nahi hai ,hum wahan bhi jake aaye the Gupta ji ke number diye the brace ke liye wahan bhi jake aaye to ek bra milti hain na wo to wo panch hazar ki aati hai to inhone kaha dekhenge terko kharidani hai terko pehnana hai to m dila dunga. Waise doctor ne to keh diya chahe yeh bra pehn sakte ho, udher m rumal wegera dal leti hun bra pehen leti hun.

**Interviewer: Stan cancer ke bare main anya mahilaoon ke liye aapke kya sujhaav hain?**

**Interviewee:** Yahin pe mulakat hui thi ek Ajmer se aaye the ,to unko bhi maine himmat bdhai to aaj tak mera shukar gujaar kar rehe hain ki bhabhi ji aap bahot ache hain aapki itani badi problem ho gayi phir bhi aap khush ho matlab aap tension nahi karte ho maine kaha aap bhi mat kiya karo wo tension kartein the or unse baat hoti hai. Unko bhi janchn ho gayi operation bhi ho gya. Main to sabko yahi salah deti hun ki AIIMS hospital sabse better hai or yahan pe sab kuch check karwana sabko yahi kahti hun ki bas mere ladki ka yahan ilaaz baith gya. Ladki ko wo pf malaria ho gya tha to usko do teen bar dusre hospital legye wahan farak nahi hua uske bahot suj gayi thi, gurdoon m kharabi ho gayi thi. Manish Chaturvedi ji hain na yahan pe doctor unka ilaaz kiya tha ab theek hai isko do baar dialysis hui chori ladki ke yahan pe hi hui thi sab 10 din admit hui yahan pe. Lakin wo kya hai ki merko himmat dedeta hai Allah matlab m tension nahi karte hun Ma'am sab yahi kehtein hain (smiling). Madam sab yahi khetein hain ki tum tension nahi karti ho itna dukh aa jata hai phir bhi sehnaaz tum bahot achi ho matlab himmat hai aap ke andar. Ab tee. Bache bhi chale gaye hain do ladke ..ladka to hai hi nahi mere ek ladki chali gayi ab.

Han wo baal chale gaye the tab to bahot rona aaya tha or abhi ho raha hai ki kab aayenge to wapis kab honge baal wgera. Jayada to iski tension nahi thi usse jayada merko baloon ki tension ho gayi. Ab isko (Breast) ko dekh ke to

aisa hi lagta hai ek chala gya to feel hota hai. Andar aise hi vichar atta hai ab aisa hi rahega hamesha ke liye ab to wapis bna nahi jayega, dusra to aisa ka aisa bnege nahi. Ab jaisa hai waisa to ho gya waisa hi rehega to uske liye jayada tension nahi karti. Ab jo ho gya so ho gya uske liye to Allah ka shukar hai ki Allah ne mere jaan to baksh di.

**Interviewer: Kya aapko bhavishya ke bare main koi chinta ya bhavnayein hain?**

Yahi ki bas ab jo bache ke honge wo apne hi hain main ladkon ki bhi tension nahi karti hun bas ladkiyon ka shochti rehti hun shadi ke bare m wegra. Apne bare m to jaise yahi sochun ki apan ki aadhi to chali gayi adhi ab bachon m chali jayegi bas yahi waise bachon ki shadi hogi phir delivery unki wegera unko sambhalana padega ladkiyan hi hain teeno isliye ab hai na saal bhar toho gya mere ladkiyon ki sagai ho gayi dono ki. Ek pandra saal ki hain ek athara saal ki hai. Hain wo kya hai ki hmare rishte m hi hai to unhone keh diya ki hume pasand hai isliye. Dono bhai hain or yeh dono mere beteyaan dono behbe hain.

**Interviewer: Kuch or jo aap kehna chahati hain?**

**Interviewee:** Nahi bas m to sabse yahi kahungi ki bas kisi ko breast cancer hai to yahan pe check karwane or yahan pe ilaaz karwayen kyunki yahan per merko sab kuch suwidha wagera sab acha laga. Yahan pe sab jaise aap ke jaose koi bhi aatein hain na to yahan pe sab tasali se baat kartein hain jaise koi to hotein hain dhant dete hain yahan pe sab tasali se hi baat kartein hain dante nahi hain

**Interviewer: Aap kitne samaye se stan cancer se pidit hain?**

**Interviewee:** Nahin kisi Ko bhi nahi thi yeh to achanak hi ghanth hui yeh to merko malum pad gaya agle din hi. Abhi to kisi ko bhi nahi hai kuch bhi nahi achambha ho gya kaise ho gayi ganth.

Yeh mere to agle din hi malum pad gaya ganth ho gayi hai Feb March m, ye March m phir wo yahan dikhaya AIIMS main, phir unhone monography wagera kari to unhone kaha shuru hai abhi, shuruwaat hi hai to phir wo lockdown ho gaya, is chakkar main late ho gaya. Phir Vivek sir se baat kari iski. Phir unhone June main operation kara phir dobara biopsy karai yahan phir unhone. Phir CT scan karaya to phir, June main unhone operation kaha. 29 June Ko operation hua ek hafta bharti rakha bas, teen din baad chuti de di.

**Interviewer: Stan cancer ke bare main pata chalne par aapki pahali pratikriya kya thi?**

**Interviewee:** Mujhe to wishwas hi nahi hua, phir maine or do teen jagah dikhaya. Ye Ram Goyal hai yahan chopasini housing board m, Veena Goyal hai na jantein honge aap. Unhone shuru m ganth hi batai, unhone monography kari na to usme thoda sa doubt, us samaye kisi or ko bhi bheja tha koi reshtedaar hain unko bhi bheja tha, unhone kaha thoda sa doubt to hai monography main. Phir biopsy karai to usme aaya ki bhai hai, shuru hi hai abhi.

Nahi maine apne bete ko hi btaya. Wo to yeh chati bhari ho gayi thi na phir wo maine dekha nahate samaye to wo mujhe ganth lagi yahan. Han bhari ho gayi thi.

**Interviewer: Aapne mastectomy se guzarne ka fainsla kyun kiya?**

**Interviewee:** Nahi doctor ne to bas wo monography kari ultrasound kara or wo biopsy kari. Nahi unhone bas operation karna hai, phele isko dekhenge agar wo hua to jala dengein andar nahi to phir nikalna padega. Nahi mujhe kuch nahi hua maine kaha jo hua wo dekha jayega bhagwan sab hai hi.

Abhi to bahar nahi nikali ghar par hi hun, lakin abhi wo pad wagera aatein hain kahtein hain. Abhi to nahi lagati, ki kabhi jayein aayein to mere to itni saree padi hai, theek ho jaungi to phenugi. Phele to laga ki ab, achi bhali body hai, itani achi thi. Aap ache ho, shadi wadi pahente ho to ache lagte ho yeh lagte ho, nazar bhi to rehti hai, kisi ki lag gayi hogi. Kahin jati aati thi ache se shadi wadi to bas khete the aunti g ki aap ache lagte ho. Aapka seena wagera acha hai, firing achi rehti hai blouse ki, jimke kam hota hai unko lagta hai yeh hai. Han matlab achi thi. Abhi to kher pad wagera aane lagi gayein hain. Sab kahtein hain theek ho jao to pehen lena bas. Mere pass shadiyan hain, mujhe



shoak hai shadi wadi phenne ka bahot main hai nai nai shadi phenu. Abhi to nahi pehn pa rahi 6 maheine se, phele pehenti thi jati thi.

**Interviewer: Mastectomy ke baad se aap kin sabhi samasyaon ka samna kar rahein hain?**

**Interviewee:** Nahi mujhe dikkat kuch bhi nahi aai, nahi operation kara to mujhe maoom hi nahi pada. Han yahan pe na khichav sa hone laga pani bhar gaya. Ye hai na phool gaya. Yeh itna hoke phool gaya. Phir maine 3-4 theen chaar jano ko dikhaya, to kisine kaheya ki wapis aise ho jata hai. Phir maine kisi or se pucha to phir ek mere jethani ki ladki hai to usse pucha maine to boli nahi aise to nahi phoolta hai. Phir mere sir se Vivek sir se baat kari, unhone phir mujhe bulaya hume yahan, phir unhone dekha doctor sahab ne to jinhone operation kiya Vivek sir ke hi senior the. Unhone Vivek sir ne mujhe bulaya to unhone dekha to unhone pani nikala bole pani bhara hua hai, pani ki janch hui to janch normal aai. Uske baad m phir teen char din tak yeh aise chikav raha. Han dard hota that andar hi chtiyaan chityaan se chalti thin. Islie dheere dheere dheere theek ho gaya. Kabhi kabhi khichav hota hai. Do baar pani nikala to, han yahin nikala AIIMS main. Han sujan yeh aa rahi hai ab to kam ho gayi hai, issi hath m aai thi, yeh hai yahan pe. Han wo btai na exercise, ab to nahi karti phele btai thi karti thi. Han abhi phele hath m bhi dard tha ab to theek hai hath to. Phele tha ab to theek hi hai. Aise modti to dard hota that to, ab unhone bola hai exercise karo. To exercise karti hun to ab theek hai abhi bhi kar leti hun.

**Interviewer: In samasyaon ke prabhandhan main aapki madat kon karta hai?**

**Interviewee:** Nahi kuch nahi aati naha leti hun ab to lagawa apne aap kar leti hun. Han nahi merko dhyan hai nahati thi. Nahi koi pareshani nahi hai kapde badlne m. Niche ke kapde aapne aap dhoo leti hun. Thoda bahot kaam bhi kar letin hun halka fulka kaam. Halka fulka kaam jaise dhooth ubaal letin hun chaan ke rakh diya. Thoda sa or kaam khaana paros ke de diya kisi ko aise kaam. Nahi nahi wo rakhi hai roti wali rakh rakhi hain wo to hamare. Jadhu pooche wali rakhi hai. Han bahu bhi hai hmari yun to per rakhi hui hai nokrani.

Han shuru shuru main lagta tha, raat ko bhi lagta hai ki bhagwan ne kya diya sazaa de di aise hi. Mujhe to kabhi bukhar bhi nahi aaya abhi itane sare chakkar lag gaye. Kabhi kabhi lagta hai, rona bhi aata hai (sobbing) lekin phir sochati hun ki theek hai. Han aati to hai bra mere bahu bhi keh rahi thi, wo keh rahi mummy tension mat lo sab khetein hain theek ho jaoge. Ghar wale bhi, bahar wale bhi, sare rishtedaar bhi sab boltein hain. Baal sare ud gaye mere to (sobbing), baal mere bahot ache the. Han sab kahtein hain baal aajayenge. Han kar leti hun thoda bahot ghar ka kaam maan nahi lagta to.

Mere to achein hi hain sabse main to bahot kam bolti hun, jayada kisi se nahi wo nahi karti, kam bolti hun. Phele se kam bolti hun. Han wo to sab se mere wahwhar acha hai sabse se yahi rehti hun kudi housing board mein rehti hun. Wahan to sab ache log hain to. Nahi phele nikalti thi ab to tehlne jati thi jayada. Nahi abhi to nahi nikali, corona ki wajah se bhi sab mna kartein hain. Nahi Abhi to nahi hota sabke phone hi aatein hai ghar pe to koi milne ke liye mujhse. Nahi ghar wale to theek hain sab khetein hain nahi theek hojaoge theek hojaoge. Madat to kya apna kaam to khud hi kar leti hun, phir beta karta hai, khane pine ka dhyan hai bahu rakhti hai, ghar per hai abhi, lecturer hai college jati hai ab to chutiyaan chal rahin hain.

Nahi wo to humare pass hai jo apan bahr se kartein hain pension aati hai or waise bhi rakh rakha hai paisa bhi humare ghar main. Nahi makaan hai hamara ghar ka do manjeela gadi wadi sab hai padi bache ke pass main. Wo mujhe ptani kara rakhi hai unhone.

Bhagwan ki to manti hun lakin mere beti ki death hui uske baad phir main thoda sa wo hui lekin main manti hun bhagwan ko to abhi to bhagwan jo karta hai sahi karta hai. Iske to kabhi socha hi nahi tha ki aisa ho jayega. Han ni karti hun puja paath waise hi karti hun. Kuch ni lagta maan ko shanti milti hai, Bhagwan ne jo likha hai kismat main wo to hoga hi. Per rehta hai ki jab...hoga to acha hojayega nahi hoga to. Theek ho jaun main kisi pe bojh nahi banu bas. Waise main sab ghumm aai chali aai, matlab jaise mera maan tha ki ek baar aeroplane main bathungi. Jane ka maan thanks to main wahan bhi ghume aayi sab jagah. Phichale saal gayi thi Hyderabad Tirupati wagera ghume ke aayi thi August main. Phele saal gaye the Hyderabad walkani Tirupati Balaji sab ghum ke aaye the. Nahin yeh to abhi pta chala January main bhi theek thi February main theek, March main ek dum se.

Nahi main to karti nahi kaam ab to khaer hath main dard ho jata hai. Badlav yeh jaise koi kaam karti nahi sar sharir karti nahi, hilti hilti hai lagta hai, pani bhi piti hun to thoda lagta hai jaise andar jata hai na. Pani pitein hain to jaise lagta hai yahan pe idher. Koi bhi cheez pitein hain to aise yahan hoti hui jati hai niche niche maloom padta hai. Nahi dard to nahi hota lekin maloom padta hai ki yahan niche tak ja raha hai, mehsoos hota hai.

Shakal to ...hath wath kale ho gaye sab shakal to pata nahi kaisi thi kaise ho gayi. Baal mere bahot dukh hota hai ud gaye sare, yeh jali leti hun sara din. Yeh bandh ke rakhti hun sare din. Acha ni lagta mujhe khud Ko. Iski wajah se to lagta to hai to jab ek cheez nikal jati hai to kam to lagti hai lekin ab theek hai. Bhagwan ki marzi hai yeh to. Mere negative hi aayi thi report to, kam hi tha tissue wali jach hoti hai na, kam hi thi. To ptani kinte cycle karenge.

**Interviewer: Kya aap moka milne par stan punahnirmaan se guzarna chahtein hain?**

**Interviewee:** Ban jati hai? Nahi kya karna thodi se to umar hai, 70 saal ki to ho gayi hun main. Aage jo pad wagera aatein hain wo pehen lungi. Han karne wala bhi koi nahi hai abhi phir kya karna. Thodi se zindagi hai kya karna hai

**Interviewer:** **Stan cancer ke bare main anya mahilaoon ke liye aapke kya sujhaav hain?**

**Interviewee:** Wo to yahi hai na ki btatein hi hain na ki nahate samaye dhyan rakho dekh lo or to kya, aajkal to TV main to sab aata hi hai.

**Interviewer:** **Kya aapko bhavishya ke bare main koi chinta ya bhavnayein hain?**

**Interviewee:** Yahi sochtein hun ki theek hojaungi to theek hai nahi to theek hai jaisa bhi hoga bhagwan ki marzi hai. Khetein to yahi hain ki theek ho jaoge chemo band ho jayegi to theek ho jaoge. Ab dekho bhagwan ki marzi hai. Han yahi soch rahi hun theek ho jaungi to theek hai, nahi to bhagwan ki marzi hai jo bhagwan karega Wahi hai. Han kabhi to theek lagta hai kabhi lagta hai kamjori lagti hai or karne wala ladka akela hi hai yeh. Han iski bhi govt. nokariyan hai to isi khunav m duty thi ek tarik ko bulaya tha phir chunav m duty thi, nahi untees tarik ko bulaya tha.

**Interviewer:** **Kuch or jo aap kehna chahati hain?**

**Interviewee:** Na or to aisa kuch bhi nahi hai.

**Interviewer: Aap kitne samaye se stan cancer se pidit hain?**

**Interviewee:** Yeh to May main pata laga, yahan pe (left breast) dard hota tha, janch karwai sonography karwai thi, tab doctor ne bola ki aapko sui ki janch hogi sui ki janch aane se pta chalega. May to yahan pe to ilaaz karwaya tha or wahan Kuchaman, janchein karwai thi sonography, doctor ko dikhaya tha to wo doctor bole the ki sui ki janch hogi, sui ki janch aane se pata chalega. Sui ki janch aane ke baad main yahan par bheja. Han wo pta chala tab wo yahan pe bhej diya humko, yahan aake janche wagera karwai baad m doctor sahab ne bola tha ki aapke chemo lagega. 4 chemo lagwaye the. 4 chemo lagwaye ke baad doctor sahab ne operation ka bola. Phir operation hoga. Operation hone ke baad 1 September ko operation hua, 1 September ke baad main teen chemo lagai, yeh teesra chemo aaj lagega, do to lag chuke hain.

**Interviewer: Stan cancer ke bare main pata chalne par aapki pahali pratikriya kya thi?**

**Interviewee:** Wo to dard ho raha tha phele, dard hone se ilaaz karna to hai, ghar walon main pati ne or bachon Ko bataya.

**Interviewer: Aapne mastectomy se guzarne ka fainsla kyun kiya?**

**Interviewee:** Aise pata nahi that ki pura hi nikalega wo yeh aise bola tha doctor sahab ki, aisa bola tha yahan pe janch hui thi ki three fourth kai kaan merko samajh nahi aata hai nikalenge.

Wo to laga tha lakin upay kya hai, wo to laga tha bura lakin ilaaz to karwana hi tha na isliye.

**Interviewer: Mastectomy ke baad se aap kin sabhi samasyaon ka samna kar rahein hain?**

**Interviewee:** Operation ke baad to dikkat to kuch ni aayi, thoda dard aise to mehsoos hota hai, sujan yahan pe aayi thi or dard itne din to yahan darad hota tha, yahan do dedh mahene tak , aaj kal to thoda bahot kam hota hai dhere dhere. Wo dard to khoob tha, nahi bath to nahi raha tha lekin wo dard karta yahan pe, yahan bhari bhari lagta. Hath hilane main dikkat aati thi, dikkat to ab bhi aati hai, yahn tak aise or yahan se aise.

**Interviewer: In samasyaon ke prabhandhan main aapki madat kon karta hai?**

**Interviewee:** Kaam to bache katein hain. Wo to mere bhanji thi, han wo nehlati dhulati thi.

Yeh to aat pata sa lagta tha, aise to vichar karne se dikkat aati hai, vichar nahi Karti hun, thoda bahot mahsoos hota tha, bhai aise kya ho gya, kya dikkat ho gayi kya nahi hai.

Abhi haal nahi jate logon ke ghar, do teen maheine yeh dikkat hone se chuti hai. Aise to lagta hai ki kaisi dikhungi, loog kya bolenge, lakin Jana to padega na kaam hai. Sharirik sambhand nahi hai abhi to filhaal, bilkul nahi hain, yeh dikkat hone se. Dikkat to kuch nahi.

Bhagwan se prarthna kartein hain bhagwan humko sadha sukhi rakhein. Acha lagta hain puja karke. Bima nahi to, kharcha ko ghar ka hi uthata hai, kuch chaye mahina hogya Kahan hi karta hai majdoori bahar.

Mehsoos to....bura lagta hai. Logon se ghulna milna shuru karenge iske baad, wo dikkat to aayegi ki kaise dikhenge lakin kya karein majboori hai, bhagwan ki deen hai. Yeh to wahan bhaar ka kaise hoga, halkka halkka kaam hoga or to hoga nahi.

**Interviewer: Kya aap moka milne par stan punahnirmaan se guzarna chahtein hain?**

**Interviewee:** Nahi kya karna hai.

**Interviewer: Stan cancer ke bare main anya mahilaoon ke liye aapke kya sujhaav hain?**

**Interviewee:** Salah to yeh denge ki dikkat ho to ilaaz karwao, hospital jao, dikhao, janche wagera karwao. Wo to janch hi hogi, janch hone se pata chalega, phele to jaise hi pata chalega, wo to ilaaz to jaise dikkat hogi us dikkat ke hissab se ilaaz to karwana hi padega.

**Interviewer: Kya aapko bhavishya ke bare main koi chinta ya bhavnayein hain?**

**Interviewee:** Bhagwan theek hi rakhe sada ke liye. Wo to lagta hai, bura lagta hai lakin majboori hogayi kya karein karna hi padega, han dar lagta hai yeh dikkat ka hi or to madam kya hai. Yeh dikkat hone se lagta hai madam or to kya hai. Bhooj bhar ka. Yeh wajan bhaar ka or koi dikkat ho kaam karne main. Or to dar kis cheez na nahi lagta, yeh pareshani ka hi. Or to kya hai madam ab yeh phele jitna kaam bhi nahi hoga, har cheez ki dikkat aayegi or to kuch dikkat nahi.

**Interviewer: Kuch or jo aap kehna chahati hain?**

**Interviewee:** Or to madam kai bataun.

**Interviewer: Aap kitne samaye se stan cancer se pidit hain?**

**Interviewee:** Iska pata dus March ko laga ussi din maine dikha diya tha, ekdum hi ganth hui thi jab main ganth ko dikhane gayi thi, snan kar rahi thi jab mujhe aise hi apne aap pata laga tha ki upper ganth thi jab aise maine hath lagaya to aise ganth shayad dikhi thi, phir private hospital main dikhaya, usne saat din ki dawai de, phir rama samaj hospital to khula tha nahi, holi ke rama samye tha 10 March k, to phir saat din baad m yahan dikhaya, saat din baad m wo sir ne biopsy ki, phir baais 22 tarik Ko lockdown ho gaya that, 20 tarik Ko biopsy ki thi phir 29 untees ko janch aayi to phir baad main wo operation to kiye nahi chemo chalu kar diya tha. 4 cycles lage the. Sath m husband aaye unko pata tha baad main kisi ko nahi bataya.

**Interviewer: Stan cancer ke bare main pata chalne par aapki pahali pratikriya kya thi?**

**Interviewee:** Wahi bura laga tha....

**Interviewer: Aapne mastectomy se guzarne ka fainsla kyun kiya?**

**Interviewee:** Wo to maine to kaha thoda sa ganth nikal do wo bole wapis hone ke hotein hain chance, to ho gya wo to pura nikal diya. Wo hota hi na daar to lagta hi hai na. Operation ka lagta hi hai na maam ki kaise dikhungi. Operation ko do mahine ho gaye kal 2 tarik Ko.

**Interviewer: Mastectomy ke baad se aap kin sabhi samasyaon ka samna kar rahein hain?**

**Interviewee:** Operation ke baad chemo lagi jab paron m dikkat aayi. Bahot jayada payr dukh rahe the. Han yahan dard hai, sujan wo to hai hi hai abhi hath pura upper ho nahi raha hai. Aise aise taniz rehta hai. Aise tana hua hai. Uske ander jaise wo sar sar pani kaise chalta hai, waise waise chalta hai khoon, jaise paar pane ko koi khoon wagera hai. Ander se hi aise pani jaise tar raha hai na. Han pani petin hain jab bhi mahsoos hota hai, aise bhi sar sar chaltein hain chubtein hai, jalan se hoti hai matlab.

**Interviewer: In samasyaon ke prabhandhan main aapki madat kon karta hai?**

**Interviewee:** Ghar ka kaam mere mummy ne kiya. Naha to khyer apne aap leti thi. Sapta bhar to nahi nahai wo lati karte the wo pipe dala hua tha dus din phele jab to snaan hi nahi ki thi, jab to wo paper aatein hain na gila usse snaan karte the. Phir tanka kholne ke baad khud snaan karti dheere dheere hota kar leti thi. Kapde mummy pehena dete the snan ke baad. Subah uthke kadak ho gya, or to sahi hai thoda bahot to lagta hi hai.

Sharirik sambhand nahi, yeh chemo chal raha hai na to doctor se puchna tha phele to. Abhi to mere tabaiyat hi theek nahi hai , thakan bhi hai. Nahi doctor ne ni mana kiya, phucha hi nahi humne. Or nadein bhi kachi haina kahin lag na jaye. Aaine ke samne wo to yeh to cheez nikali hai to wo to theek hai. Wo baal utar gayein hain aise lagega to ajeeb sa to. Achein hain, madaat kartein hain mere padosi bahot achein hain, aatein hain baatein kartein thodi der time pass karatein hain. Bima to hai mere LIC karwai hui hai. Bhagwan ke prati to shradha hai hi humari. Bhagwan pe vishwas hai hi hai. Han bhagwan ki puja karke shanti mahsoos hogi, aur acha lagta hai. Wo to ghar ka kaam to chuta hua hi hai or puja path bhi itani nahi karte pati hun sirf muh se ram ram karo apne. Phele to aur bhi puja path karte the kabhi katha padhte the. Silai wagera wo toh kahan kar paungi abhi. Abhi to bahot thakan hai..

**Interviewer: Kya aap moka milne par stan punahnirmaan se guzarna chahtein hain?**

**Interviewee:** Operation se? Kaise bnatein hain matlab? Nahi wo to pta hi nahi hai humko bnatein hain, kya kartein hain. Dekho ab pta hi nahi hai ki bnatein hain kya ni wo to samaj main nahi, aap bole jab aaj pata chala humko. Pta nahi. Bra abhi to nahi pehenti, yahan se pehene hi nahi ja rahi yahan se tanke hain. Dard hota hai.

**Interviewer: Stan cancer ke bare main anya mahilaon ke liye aapke kya sujhaav hain?**

**Interviewee:** No response

**Interviewer: Kya aapko bhavishya ke bare main koi chinta ya bhavnayein hain?**

**Interviewee:** Yeh to hayi hai bhai bimari hai to nikal ayein to badiya ho jaye sab, nahi to aage falegi aur. Uska to kya hai. Kuch hai to sharir ke anusaar hai. Sharir sahi hai to sab sahi hai. Wo to lagta hi hai. Abhi to dard hai bahot jayada. Kab theek honyege, phir kaisa hoga aisa. Maine chemo rukane ka bola tha ki payr bahot jayada dard kar raha hai. Unhone likh diya tha parchi pe ki mera ilaaz nahi hoga aaga ka nahi karwana. Phir vo Ravikant sir ne kaha nahin main dose kam kar dunga per chemo to leni hai. Na khushi hai na dar hai, jo zindagi jaise bhagwan dikhayega waise dekhna hai bas aur kya hai.

**Interviewer: Kuch or jo aap kehna chahati hain?**

**Interviewee:** Wo to kuch nahi per wo mere jab se chemo chal rahi hai, jab se period nahi aa rahein hain. Phir baad m aajayega? Chemo final hone ke baad m. Jaise aap bol rahe the inke sath wo sharirik sambhand to wo ho sakta hai?. To phir inko koi takleef nahi mere chemo wagera chad rahi hai to.

**Interviewer: Aap kitne samaye se stan cancer se pidit hain?**

**Interviewee:** Mere actually ausgust m meko pta chala, phechale August m, to halka sa laga tha jaise koi simple se normal hai to laga tha kuch nahi hai phir baad m test karwaye to usme phele first m matlab bola tha ki isme kuch nahi hai report m. Nahi aise just normal hui thi aisa kuch ni laga kyunki pain to hota nahi hai. Itani ki matlab ho gayi thi ki dikh rahi thi, bahar dikh rahi thi to pain to hua nahi normal hi laga tha phir mane test karwaya to usme aisa kuch report m aaya nahi tha to wapis jaise jaise woh badi hoti gayi to phir maine wapis karwaya to usme aaya ki hai to phir chala treatment. August m bilkul hulki si thi aur pain tha nahi tu itna mind main liya nahi ki kuch hoga.

**Interviewer: Stan cancer ke bare main pata chalne par aapki pahali pratikriya kya thi?**

**Interviewee:** Ab wo to normal hi yeh hoga to reaction kaisa hota hai tension ho jati hai wahi. Ghar m husband ko pta tha, phir mere mother in law Ko maine btaya

**Interviewer: Aapne mastectomy se guzarne ka fainsla kyun kiya?**

**Interviewee:** Surgery phichle mahine ki 25 ko hua, phele chemo chali thi chemo 16 hui thi. Wahi phele matlab blood test ya jo bhi hai, kuch is tarah matlab jo bhi tha wo sab hua phir chemo ka bola phir chemo hui 4 plus 12 wo hui uske baad phir lockdown ki wajah se bahar hi the hum phir Bombay surgery hui thi. Chemo ka bhi process matlab ek chemo wahin se lga ke aayi thi Bombay se uske baad lockdown ke chakkar m Jodhpur m lagwai thi. Wo actually matlab main surgery ke liye or matlab family mein sabko tha ki ek baar dikhan de Bombay PT modal Jain hospital.

Bola tha, merse pucha tha ki aapka kya matlab hai sara remove karna hai, ki rakhna hai kya karna hai to maine doctor yeh bola ki jo aapko best lage. Han ab is cheez ka knowledge nahi hai or wapis kuch ho jaye to maine bola theek hai to.

Kya feel ho sakta hai pta to tha ki hona hai yeh to jo hota hai wo to hota hai ... tension. Bahar nikale ka tension wo to hai hi abhi bhi hai matlab thoda kuch...wo to ab jo cheez hai nahi uske liye to kya kare saktein hain. Per ab bahar nikalna to waise bhi nahi hai, matlab abhi to matlab bahar nahi nikalna hota nahi theeke.. ab yahan doctor ke jana hota hai. Uske alawa nahi ( sobbing)...I know mere jaise hain or bhi ..maine dekha tha sabke chemo chal rahi hain isliye.

**Interviewer: Mastectomy ke baad se aap kin sabhi samasyaon ka samna kar rahein hain?**



**Interviewee:** Matlab jaise yeh hands to yeh pura upar abhi bhi nahi uthta hai or yahan se matlab piche se yahan aake heavy heavy lagta hai ki kuch heavy hai to bola tha doctor ne ki ab wo to long time rahega. To wo ab jaise ab sone m problem hoti thi jaise matlab 20 days to wo bottle carry karne padti thi surgery ke baad wo 24 hours matlab bottles carry karni to woh or usme matlab sone m bahot problem hoti thi, matlab karwat badalne m , kya aap so nahi pate the. Abhi bhi hoti hai jaise uthne m sone m to wo uncomfortable to hai hi hai.

Thoda abhi kar leti hun waisa kuch nahi hai. Mere actually iske sath ovary ka bhi hua tha, to waise wo boltein hain ki bhai one month tak matlab jaise heavy cheez kuch uthne nahi hoti hai , ya niche baithana hai to ab hogya one month to main thoda bahot niche baithati hun, matlab wo bhi sirf snan karne ke liye just. Actually jab CT scan kra tha to unko kuch laga tha to unhone kaha ki ab matlab family to complete ho gayi hai aapki or actually bleeding jyada hoti to unhone kaha ki phir, apko to rakhne ka koi matlab nahi h aage jake kuch or future m problem ho to bola family complete ho gayi hai to phir kr deta hun, time bhi or age bhi ho gayi hai 41 ho gayi hai to 45 tak waise bhi nikal jati hai.

Subah nahi actually wo kitchen matlab wo time, housewife hain to time nikal jata hai, ab iska jaise first time thoda sa laga tha second time thoda habit m aati hai ki wo to hai hi jo hai, stitches jo hai wo hai hain wo to.

**Interviewer: In samasyaon ke prabhandhan main aapki madat kon karta hai?**

**Interviewee:** Mere helper aati hai jaise jhadu poche or khane ka kaam hai toh wo mere mummy karti hai, husband sath rehtein hain, phele se thoda sa supportive to hota hi hai is cheez se , jyada ho gaye hain.

Sexual relations nahi, surgery ke karan nahi, matlab abhi bhi to tension to thodi bahot rehti hai sabko, hain isliye tension hai to.

Aise baat karti hun aati hun to aisa kuch nahi hai ki matlab wo jaise phele bolti thi, baat karti thi waise normal hi hun. Bahar nahi nikalti matlab kabhi kabar kaam hota hai bachoon ka to bas. Abhi matlab aane ke baad Bombay se aane ke baad main nahi nikalti bahar, surgery hone ke baad to bilkul hi nahi, chemo ke doran to main nikalti thi or abhi jaise kuch lana ho. Nahi yeh cheez mind m nahi hai, actually kya wo bilkul bal bhi nahi hain chemo se sab chale gaye to thoda sa lagta hai yaar yeh laga ke jao. Aisa koi must kaam ho to nikalo, jaruri nahi hai to nahi nikalte hain. Waise bhi mere habbit nahi hai ki nikalana hi hai mere ko wo wali feeling nahi hai, phir kuch jaruri ho gaya to nikal jayenge , aisa kuch nahi hai. Health insurance merko idea nahi hai. Mere khayal se husband ko pta, unko pta hai is cheez ka.

Phele se ab jayada ho gya hai, phele thoda kam tha matlab itna nahi tha ab yeh cheez hone ke baad thoda sa jayada ho gya ki nahi yaar. Acha feel hota hai like subah subah jab, thoda time khud ko dena chahiye. Adha ghanta bhi do to dena chahiye. Wahi hai matlab thoda sa jaise yahan se yeh hua hai to bas wahi hai hath uthane m jo difficulty ho rahi hai thoda improvement ho raha hai jaise standup hoten hain to thoda sa abhi bhi bend rehta hai. Exercise btai thi wo chal rahi hai.

Per ab wo usko mind m bar bar main leti nahi jo cheez ho gayi jo ho gayi. Ab aage bhadna hai. Sochne se to kuch hoga nahi ab. Ab solution nahi hai is cheez ka to...

**Interviewer: Kya aap moka milne par stan punahnirmaan se guzarna chahtein hain?**

**Interviewee:** Nahi jaise wo to main Bombay se actually wo jo hota hai wo main wahan se leke aayi thi bra m dalne ka wo main wahan se purchase karke aayi thi. Bola tha doctor ne kafi dekhlo ki aise bahar nikalo ya matlab apki radiation ho jaye uske baad m agar continue pehno to wo habbit m ho jayega to ni lagega. Nahi abhi maine use nahi Kiya. Ab dekhtein hain bahar nikalna hota hai to karna hai, wo thoda sa ajeeb lagta hai. Ab to nahi wo actually kya doctor se bina puche to kuch nahi. Yeh ichha le nahi dimag m yeh pata hai ki hoti hai surgery jo bhi aap keh rahein hai pad dal ke to uske alawa mind m aaaya nahi na maine pucha bhi nahi iske bare main.

**Interviewer: Stan cancer ke bare main anya mahilaoon ke liye aapke kya sujhaav hain?**

**Interviewee:** Unko yeh bol sakti hun acha food khao bahar ki kam cheez, avoid karo hai to theek hai, ghar ka jo bna ho fresh food wo best hai na or yeh hai ki sprouts khao paneer khao ab yeh veg nonveg hai uske upar depend karta hai ki kya khate ho. Mere khisab se surgery karani chahiye, yeh wo to matlab iska pta hai step by step jo chalta hai uska process to karwani chahiye to isse aage future ke liye best rehta hai. Unko phir aage ke liye future m problem aati hai jaise acha hai theek hai agar aapko time pe karwalo jaise doctor botein hain waisa sabse to mera yeh suggest hai ki karwa leni chahiye.

**Interviewer: Kya aapko bhavishya ke bare main koi chinta ya bhavnayein hain?**

**Interviewee:** Waise kuch nahi sochtein hun matlab wo jo normal jaise tha phele continuous chal raha hai wohi Abhi bhi matlab chal raha hai jo bas. Iske bare m abhi kuch socha hi nahi hai.

**Interviewer: Kuch or jo aap kehna chahati hain?** Abhi jo CT scan jo hogi matlab isme marking karenge to matlab aapko lagta hai jaise tattoo wali marking jo kya hai wo to pain hota hai ya ...matlab injection jaisa kuch to.

**Interviewer: Aap kitne samaye se stan cancer se pidit hain?**

**Interviewee:** Mujhe pta chala operation ke kareeb 15 din pahle matlab 11 sep ko operation hua tha to matlab doctor ke pass milne tha sep se phele kon sa hota hai mahina August, 19 August ya samajh lo na August ke shuru m hi mujhe pata chala that is cheez ka. Wo mujhe pata bhi nahi tha wo m to yahun lati hui thi gharmi lag rahi thi maine yun hath pherna shuru hua to maine hath yahan chala liya. To mujhe thoda feel hua yeh kya nazar aa raha hai itna mota, thoda mota mota laga thoda maine itna dimag m nahi liya maine socha thoda bate wegera hui ho aisa. Phir ek din maine doctor se salah le bola ki main kya is tarah ki mmere chest m gathan type hai to unhone kaha sister ko bta do lady doctarni ko. Balotra main ladies doctor ko dikhaya to unhone dikha to kaha ki tumhare na tension wali ganth hai yeh operation karenge aap iski jaanch karwa dein. Phir humne janch karwai. Phele Palampur m karwai thi phir yahan se pata chala.

**Interviewer: Stan cancer ke bare main pata chalne par aapki pahali pratikriya kya thi?**

**Interviewee:** Yeh to humare relation m gaye the humare massi ke ladke gaye the sath m. Pariwar m matlab yun sabko phone lagaya tha ki bhai doctor ne mujhe yeh cheez btaai hai. Sabse phele maine btaya tha humari bhabhi ko btaya tha. Han wo matlab mummy papa to hain ni na to unhin se na contact rehta hai to sabse chote wali bhabhi ko btaya tha ki is tarah doctor ne btaya. To phir ek mo bta do to dheere dheere sab ko pta chal jati hai.

**Interviewer: Aapne mastectomy se guzarne ka fainsla kyun kiya?**

**Interviewee:** Bas unhone to janch hi kari sari yahan pe aake admit kar diya tha janchein kari sab. Janchein karne baad kaha tha ki aap hai na aap 10 din baad m aajana, aapki jo biopsy report hoti haina jo bahr jati hai, wo 10 din baad report bhi aajayegi aapki or jab report aajayegi jab aapka hai na 10 din baad report ane ke baad aapka operation kar denge. Us samaye to nahi bola sirf operation ka bola tha us samaye. Merko itna nahi pata khali bas hai na merko un logon ne itani baat karo ni thi mere husband Ko kaha tha sab tabhi operation hua. Phir operation m na unhone pura nikal diya. To Palampur wale doctor ne bhi kaha tha ki nahi pura nikalna, to us samaye na bura feel hua, roi bhi thi. Phir sab ne mana kar diya ki nahi Palampur m nahi karana matlab hamare relation m jitane bhi the unhone sabne mana kar diya nahi Palampur m nahi karana. Palampur m doctor sahi nahi, AIIMS m jaake karwao, AIIMS main behtar rahega. Sabki raai mashware ke baad hum AIIMS m aaye. Phir AIIMS m hi doctor se kya baat Hui inhone wo merko bhi bataya nahi ki main ghabrate to merko chupa ke rakha inhone. Phir Bbad m na maine apne aapko ko na rabke hawale kar diya tha ki nahi jo kare wo behtar hi hoga.

**Interviewer: Mastectomy ke baad se aap kin sabhi samasyaon ka samna kar rahein hain?**

**Interviewee:** Operation kara to mujhe koi na bas thodi kya hai na mujhe karzori bahot hoti thi. Jaise main na 5 -10 min khadi kya ho zati thi na to na jahir se baat hai ab mere bache to the hi nahi, ghar m akele rehti thi halanki khaana sister ke yahan se aata tha khanaa, kaam karne wali kaam karke chali jati thi. Bulate to kisi padose ki ladki wo jhadu kar ke chali jati thi or na kapde wagera sab dhoh diya karti thi. Phir bhi mera juice wgera ana hota hai rasoi m hai koi soup wagera bnana ho to to thoda m karti to mera saans bhul jata, dhadkan teez ho jati, kamjori hoti thi, mujhe wapis hai na bed m sona padta, soup bna to lete lakin mujhe kamjori bahot hoti thi, seena bhool jata, dhadkan teez ho jati. Paron m jaan hi nahi rehti itani kamjori rehti. Nahi abhi to is wakat nahi ho rahi lekin ghar pe to chalti phirti rehti hun na thodi to mujhe ahsaas hota hai kamjori ka bahot jyada. Nahi sujan aai to nahi lekin thoda bharipan rehta tha yahan pe thoda akdaa hua rehta tha pura bharipan yun bhari thoda kicha hua. Nahi dard to bahot kamm rehta tha, wo matlab kya that shuru m jab hi hua tha operation kiya tha na to operation ke jo ganda pani ki jo nalki lagatein hain na to wo na aath din baad unhoone humko bulaya tha to satvein din hi nalki nikal gayi thi achanak to phir immediately hum na hospital m aaye. Han wo apne aap hi nikal gayi ptqni kaise nikali. Phir wo doctor ne kaha thoda wo pani ka badav ho gya tha yahan pe to doctor ne kaha tha operation hai to wahan pe nalki to lagegi nahin to hai na phir pati di thi to usko hai na kas ke idher se dwab dekar pani apne aap sukh jayega.

**Interviewer: In samasyaon ke prabhandhan main aapki madat kon karta hai?**

**Interviewee:** Nahi nahne dhone m dikkat hoti thi to husband madat karte the. Han wo pati wati karne wo help karte the. Subah uthke nahi usko dekhte the ki ab aise hi yeh tai karta hai na, nasib m apne yahi likha hua hai to rub ki marzi hi thi jo karega bahtar karega, acha hi karega. Ghar ka kaam phele to main hi karti thi, abhi to maine kaha na, khanna to sister ke yahan se aa jate hai humare or mere liye ek ladki bachi wo kaam karti thi kapade thone ka. Nahi wase jate to nahi bahar theek hai koi bahar milta hai do ghadi humko btala leta hai ya koi apne yahan pe rehta hai padosi to btala leta humko. Jaise apan bahar to kate nahi or jaise bahar khade gate pe khade ho jata hai to koi bol leta hai to batla letein hain thodi der. Ya koi apne ghar ka ki rehta aram puchne ke liye to unse bol letein hain. Nahi apni to hai na aise hi humari aadat ghar par rehne ki hai. Hum bahar jate hi nahi hain. Main to mujhe soak bhi nahi hai bahar phirne ka shopping wagera karne ka main to ghar par hi mast rehti hun bas. Nahi nahi waisa kuch nahi hai ki aang nahi hai. Yeh to apne hath m thodi na hai. Yeh to chalo yahan ka aang tha, sharir ka or aang hota, nahi hota kisi ke to wo bhi to jeeta hai.

Ache hain, phele bhi ache the per abhi bhi achein hain. Bahot madat kartein hain. Nahi nahi sharirik sambhand ab nahi bnate. Nahi wo bnaye hui wase bhi mein bnati nahi thi or uske baad se na tabiyat theek bhi nahi rehti thi aisa hai. Bema wagera karatein hain to mujhe pata nahi lakin shayad hai ya nahi itana to mujhe pata nahi hai. Lekin dekho jo hospital se iski koi. Wo jo usne takleef deta wo shifa bhi Wahi beta hai. Takleef bhi wahi dega to shifa bhi wahi dega. Dua bhi usko sunayenge to uskne takleef di hai to usme shifa mojude hai. Hamare to na namaaj hoti hai na padhtein hain, jaise humare sajde m ni jate kurse m baith baith ke padh letein hain. Bahot sukoon milta hai. Aisa lagta hai bahot sukoon milta hai jaisa apne sath m apna Allah hai. Nahin main to bahot karta tha main yeh kar lun, lakin main kar nahi pati thi. Kamjori aa jati thi to. Jaise main khanna pakka lun or merko aisa lagta main kapde dhoo lun. Yahan per main jhadu pocha kar lun. Lakin main kar nahi pati thi. Mujhe apne aap ko bahot kamjori mahsoos hoti thi. Or thodi apne aap ko mera ab swasth bhi rehna chahti thi ki main ab thoda na apne aap pe control karun abhi kaam na karun to main aage ke liye sahi rahonge. Aaine ke samne aisa hai jaisa phele tha wasa ab bhi mahsoos hota hai. Nahi iska koi farak nahi bas yeh hai ki jo kara usne ache ke liye kara.

**Interviewer: Kya aap moka milne par stan punahnirmaan se guzarna chahtein hain?**

**Interviewee:** Chest ki jagah ab bnana to kya chahungi, jaisa hai na usme bhi kafi kya hua na usme bhi rehti hogi bnane m kya pta iske baren m itna knowledge nahi hai isme kya hai kya nahi hai filhaal jo bhi hai to filhaal theek hai. Han pahentein hain na. Phir na phene to ajeeb lagta hai. Abhi to sports wali phen rahin hun kabhi to sadhna wali phen letin hun. Kuch nahi bas humare liye aage ke liye dua karna. Acha yeh jo mahamari aati hai isme bhi wo band ho jayegi. Waise bhi mere to kam hi aati thi. Baal jayada chale jayeinge. Chalo aa to jayenge baal.

**Interviewer: Stan cancer ke bare main anya mahilaoon ke liye aapke kya sujhaav hain?**

**Interviewee:** Yeh salah dungi , salah main yehi kehna chahungi ki hai na sabse phele to usper nirbhar rehna wo apne aap asani karta jayega. Bas jo yeh hai na jo doctor or jo Allah ne jo hai na naseeb jo Allah ne likha hai or jo doctor ne kaha hai wo to apne Ko karna hai hai.

**Interviewer: Kya aapko bhavishya ke bare main koi chinta ya bhavnayein hain?**

Ane wala samaye na bahtar hi rahega acha hi rehega.

**Interviewer: Kuch or jo aap kehna chahati hain?**

Nahi

**Interviewer: Aap kitne samaye se stan cancer se pidit hain?**

**Interviewee:** Diwali ke baad main October ke last main or November...nahi November main hua, December yahan pe as gaye the hum. Ek mahine yahan pe chala phir ek January Ko unhone date de di thi.

**Interviewer: Stan cancer ke bare main pata chalne par aapki pehali pratikriya kya thi?**

**Interviewee:** Laga to beta bahot kharab, jhatka laga ki kya ho gya hai aisa to mujhe kabhi hua nahi hai. Close to maa se the, maa hai nahi ab. Humne to bimari ke bare main kisi Ko nahi bataya. Mujhe to btati mujhe aansu aa jate the. Main kisi Ko nahi bataya, mere husband ne mere bhai, papa sabko btaya. Unhone btaya maine kisiko nahi btaya. Han mere husband mere pass main hi the jab pta chala, bache or hum sab sath main hi the. Doctor Ko dikhanyenge tab mere husband aaye the, bachoon ko btaya bhai beta aise aise problem hai to unhone kaha ki mummy doctor Ko dikhanyenge

**Interviewer: Aapne mastectomy se guzarne ka fainsla kyun kiya?**

**Interviewee:** Doctor ko btaya, doctor ke pass aane ka matlab yahi tha unko maine hi ki yahi unke pass option bacha hai ki aapko operation kar lo. Sidha unhone yahi kaha, ki phele biopsy karni hai, phir wo karai , ek baar karai wo aai nahi sahi, dobara phir yahin karai to phir computer se to usse karane ke baad main aayi to unhone kaha...date de di unhone sidha or to kuch kaha hi nahi. Chemotherapy jaisi nahi that kyunki badh gayi hoti wo chemotherapy se kam kartein hain. Humari aise koi problem hi nahi thi. Dukh to yeh tha ki ek dedh mahina hi hua tha, jisme yeh chahte to mera sirf operation se ganth nikal dete.

To unhone yeh kaha ki dekho aajkal aisa chala hai ki yeh hum aapka aise Kar denge ki btanatein hain na. Han yeh nikala padega phele to btaya na to bhai dukh to hua lakin ab kya karna saktein hain. Uske alawa agar doctor hi yeh keh Raha hai ki koi wo nahin hai to phir matlab hun kya karna saktein hain. To maine kaha chalo koi baat nahi itani Umar beet gayi nahi bhi ho to koi baat nahi.

**Interviewer: Mastectomy ke baad se aap kin sabhi samasyaon ka samna kar rahein hain?**

**Interviewee:** Jeewan main beta bahot prabhav pada hai beta bahot dukhi hain pareshan bhi hain, dekhtein hain to main Ko dukh hota hai. Pareshani to hoti hi hai par ab wohi hai ki ab kuch ho nahi sakta. Operation ke ek mahine, wahi pe treatment pandra bees din chala yahin pe. Han dard to hota hi hai baki or koi jayada kuch nahi, nahane dohne main dikkat to thi.

Subah uthke aisa kuch nahi tha, jab ek baar yeh ho gaya na ki hogya phir usko kya socho, ghar main bhi kehte sochgi tab theek nahi hogi, yeh wo phir to. Pati ke saath sambhand to theek hi hai. Aise to har ghar main thodi thodi to bachoon ko lekar bhi, parivaar ko leke bhi Hoti hai. Isse related koi cheez nahi balki help ki hai hamari. Karcha yeh wahi pay karte husband karte. Han jeewan bima humne nahi karaya.

Uske baad yahi hai beta ki jo bhagwan karta hai uske aage kuch hota nahi. Doctor log to mainte nahin hai. Mainte ho tum log ? ...bhai bahot se doctor nahi mante. Kyunki bhagwan ki aab duniya main agar ek sutra hai to bhagwan hi hai wo jo tartein hain Wahi hota hai. Ab humne koi paap kiye honge phichle janam main to ho sakta hai uska bhog humko bhogna pada hai ki nahi..Abhi bhi maan hi rahein hai.

Parivartan to beta wahi, dincharya to beta wahi rahi subah uthna wahi khaana khana, Wahi nahana dhona. Yeh hai ki paaron ki wajah se main bhagwan ki puja nahi karte pati hun, jayada chaltein hain to ek to huphan ek to kamjori hai is samaye, chemo vemo lgatein hain, kuch khane pine dete nahi hain. Kacha na khao yeh na khao wo na khao ab roti khayein, roti se chaltein...challenge nahi to roti pache gi kaise to usme thodi kamiyaanaayi hain. Kya or dekhtein hain yeh khatam ho to pairon ka bhi karainye, shayad usse thoda sa aaram mile. Koi badlav mujhe dikhta nahi hai, bas yeh hai ki pareshani thodi rehti hai, dekhtein hain to thoda dimag pareshan hota hai baki aisa or kuch nahi hai jo ho gaya usko kya sochna, humara to manna yahi hai.

Aayine ke samne hi nahi jate, hum to sahi bta dete hain. Ek to baal nahi hain or ab jab baal nahi to kya sawarna kya sajana, koi cream laga li chere pe ek bimdi laga li bas isse jayada koi kaam nahi. Acha nahi lagta, wahi hai.

**Interviewer: In samasyaon ke prabhandhan main aapki madat kon karta hai?**

**Interviewee:** Ghar ke kaam to phir bachoon ne kiya, maine to nahi kiya, bachoon ne kiya. Ghar ka kaam us time to phele to bachoon ne sambhala khafi kuch, phir mere husband ne bhi sambhaala. Sab ne milke bhai is mood ko sahi leaaye.

**Interviewer: Kya aap moka milne par stan punahnirmaan se guzarna chahtein hain?**

**Interviewee:** Nahi abhi to bas bachon ki shadi karani hai....uska koi vichar nahi hai.

**Interviewer: Stan cancer ke bare main anya mahilaoon ke liye aapke kya sujhaav hain?**

**Interviewee:** Hum yeh hi kehtain hain jaise hi unko pta chale ki bhai humare idhaer udher main thodi badi ho chuki thi agar itni hi phele se jhukav rehta hai usme, jaise hi jhukav aaye na humne kaha bhi ghar pe sabne kaha nahi theek ho jayega aisa kuch nahi theek ho jayega, theek hone ki bjaye aur badh gaya. Agar usi time main aa jati to shayad mere yeh na hota, to sab ko yahi mere salah hai jiase hi agar kuch pariwartan aata hai, ya dikhai deta hai to ladies ko turant hospital jana chahiye, dikhana chahiye, check up karna chahiye aapna, or jeewan main mere tarah kisi ke na ho. Bas bhagwan se yehi pararthna hai. Wahi beta surgery jabhi hai jab agar hum agar hum phele se sajak rehenge to humko doctor ke pass jayein, gaye hum bhi sajak hum bhi rahe lakin humara wo ilaaz us samaye nahi karte paaye ladies doctorni jab keh dete mere bas nahi hai aap kahin or jao, to main yahan aati. Phele pata bhi nahi tha AIIMS main zindagi main phele baar aayi thi iske liye, kabhi aaj kinte saloon sr khula hai yeh, kabhi nahi aayi, sab kehtein hain AIIMS gaye AIIMS gaye, us time pata ni kaisa hai ab aaye to bhagwan ne isliye bheja mujhe.

Ab kya kare saktein hain. Royein bhi tadfein bhi (sobbing), ab kya kare saktein hain. Aap se phele bhi kayi logon ne pucha main jab bhi ki thi surgery tab bhi ek bhaiya the wo bhi Odisha ke the, ab jo bhi kuch puchte mujhe mere aansu ke alawa mujhe kuch nahi niklta, wo kehte jaise main roti to wo kehte the ....mere husband bhi khade rahe kehte ni isse kuch ni puchna. Ek baar beech main yeh corona ni ho gya, to do mahine inhone phir dwai de matlab medicine de or koi chemo vemo Kiya nahi, to baal mere aagye ab dubara chemo kara to baal wapis chale gaye. Ab maine kaha chalo ek baar khatam hoga tabhi aayenge tabhi sahi rahega.

**Interviewer: Kya aapko bhavishya ke bare main koi chinta ya bhavnayein hain?**

**Interviewee:** Ab beta bas yahi sochna hai mere bachoon ki shadi ho, ladkiyon ki abhi shadi nahi hui hai. To yeh sochtein hain acha ghar baar de unko, cheeze set ho jayein mere zindagi ka kya hai. Agar yeh sahi ghar pe chali gayin to mera bhi jeewan thoda tension main hai free ho jayega. Bimari ko to ab yahi kaha jata hai, ki agar yeh sahi ho jata hai phir to admi.. or zindagi kinti hai 20 saal 25 saal... Mera manna yahi hai ki agar yeh theek ho jata hai to 20 saal tak or jee jayein, bache apne set ho jayeinge. Beta usse jayada main kuch nahi sochte.

**Interviewer: Kuch or jo aap kehna chahati hain?**

**Interviewee:** Uske alawa kya btaun aapko. Tumhari dua hai ho jaye sab acha or tum ache se padho likho, aage badho yahi hai.



**Interviewer: Aap kitne samaye se stan cancer se pidit hain?**

**Interviewee:** Phele to merko malum nahi padeya, chati m or lare peeth par dard ho raha that, to dudh nikalti (gaye ka) to bahot zyada dard hone laga, to dard hone laga to hospital m dikhayenge. Bathu pepsi (FNAC) kari na, to janch karwayi to dhyan ni padya, Raj hospital private m, khoon nikala sui laga ke. Main samajhti nahi na to baad m pache wo janch karwai. Janch bahar gayi to isme btaya ki bahi normal cancer hai, to surgery wahi kara de.

**Interviewer: Stan cancer ke bare main pata chalne par aapki pehali pratikriya kya thi?**

**Interviewee:** Kese main janu, mar jaun aisa laga. Jiye ni nahi jiye, ab dheere-dheere laga jee rahi hun. Ghar m sabse jayada bache or pati ke nazdeek hun. Wo sath m hi tge, phele maine mere bhai ko or doctor wa ne btaya. Bhai ka hi hospital hai, massi ka ladka, wo khud hospital chalata hai (Raj hospital), Rakesh Raju.

**Interviewer: Aapne mastectomy se guzarne ka fainsla kyun kiya?**

**Interviewee:** Mastectomy ka doctor ne hi chuna, ki bhai ye nikal do. Chati puri nikal do. Maine kaha jab howe, jaise howe ni, jaise kar do. Nakal do bhai or kya, nahin bura nahi laga.

**Interviewer: Mastectomy ke baad se aap kin sabhi samasyaon ka samna kar rahein hain?**

**Interviewee:** Phele wo darad bahot karti or pache harda toot gayi yun matlab kamjori aane lagi, mere dard hai. Kaise hoyega kaise nahi hoyega aise. Soojan nahi hui, dukhati jada. Hath chalane par dukhati. Nahana dhona bahot kam kam. Pache wo to nikalti (gaye ka dudh), pache baad m gaye or wo sab bech diya, jayada dard hone laga. Operation ke baad kuch ni kiya. Aesa to nahi hua, main kya theek ho jaun , kya karna is ek hi ghani hai or kya karna didi. Log kaise hi nahi dekhtein hain, ki bhai bo bimari hai to nikal diya to acha reha.

Pati bahoot ....khayal raktein hain. Operation ke baad kuch ni koi sharirik sambhand nahi. Kharcha bus pati kamata hai. Pati petrol pump pe kaam kartein hain. Koi jeewan beema nahi kara Rakha.

Bhagwan ke bare m bahot, ki bhagwan sabo ni yahan aawe sabko theek karna, merko bhi karna. Bhagwan bus zindagi jo de ache de, bus khush rakhein. Bhagwan ko manti hun barobar.

Ye to humare karmo ki saza hai, bhagwan to kya karein. Operation ke baad baat cheet kam karun, sir m darad hota hai or sab acha hi hai. Kaam bhi hue to howe nahi, abhi to kuch ni karti.

**Interviewer: In samasyaon ke prabhandhan main aapki madat kon karta hai?**

**Interviewee:** Ghar ka kaam khana ladka or papa dono baap or beta mil ke bnata hai. Merko to acha ni lagta, phele jaise hi hai shareer to kam nahi hai. Acha hi lagta hai, wo to bimari to nikal gayi kya karna ab.

**Interviewer: Kya aap moka milne par stan punahnirmaan se guzarna chahtein hain?**

**Interviewee:** Koni janu. Nahi ek hi ghani hai.

**Interviewer: Stan cancer ke bare main anya mahilaoon ke liye aapke kya sujhaav hain?**

**Interviewee:** Bhai m to yahi kahun ki dard ho raha to us samaye to lage bahi nikal diya to acha hi hai, aise kehti hun. Koi dikkat aawye to jaldi dikhao, chati m dard hota hai to kehoon, bhai mere aisa hogya to aap phele hi dikhaon. Masik kapda bhi abhi aaya.

**Interviewer: Kya aapko bhavishya ke bare main koi chinta ya bhavnayein hain?**

**Interviewee:** Aane wale samaye ke bare m to acha hi sochti hun ki bhagwan achi rahke, ache samaye raah je. Kabhi khabi to dar lagta hai ki bhai ab ghar pura sambhati, ab m aise ho gayi to ab ghar nahi sambhala jayega.

**Interviewer: Kuch or jo aap kehna chahati hain?**

**Interviewee:** Aise koi baat ni, jo man m tha wo to bta de. Dard hai wo to sehan karna hi padega. Aage to bhagwan hai jo.....