

A Qualitative Study to Assess the Lived Experiences among Post-Mastectomy Patients in the view of Developing a Grounded theory

Sadikshya Lamichhane¹, Dorothy Deena Theodore²
Mental Health Nursing, Narayana Hrudayalaya College of Nursing, India

Abstract: *The world is reeling under the impact of cancer. Among women, cancer of the cervix and breast are most prominent.^{1,2} Cancer of breast holds the second place in developing countries of which India is one.³ Patients diagnosed with breast cancer are usually treated with mastectomy which has its own re-percussion on their lived experiences.^{4,5} In order to help them cope it is important to understand the experiences therefore this study was undertaken to study the experiences and develop a grounded theory which would later act as a guidelines in planning the nursing care of these patients. The title of study was; A Descriptive Study to Assess the Lived Experiences among Post- Mastectomy Patients in the View of Developing a Grounded Theory. The objectives of the study were; To assess the Lived Experiences of post- mastectomy patients using unstructured interview technique and formulate a grounded theory. Qualitative Design, Grounded theory approach was adopted for the present study and conducted in a selected tertiary cancer center in Bangalore. The tool consisted of semi-structured interview schedule to assess the lived experiences of the post-mastectomy patients. Data were collected by interview schedule and self-report and recorded in the audio- recorder. Total samples were 30 post- mastectomy patients. The sampling technique was purposive. The data was analyzed using Glasser and Strauss grounded theory method.*

The recorded data was transcribed and then creation of analytic codes and categories were developed from the transcribed data obtained through the semi structured interview. The analysis process transformed the combined set of 30 narrative transcripts into 190 significant statements. Discovery of basic categories in the data was made. Inductive construction of abstract categories was done- 32 thematic clusters- 9 in immediate post-mastectomy, 12 in 6 weeks-2 years post-mastectomy and 11 in >2 years post -mastectomy group and validated with the follow-up telephone interview with the participants. These themes were arranged into 5 categories namely physical, psychological, social, economic and spiritual.

These findings led to a conclusion that rehabilitation of the post mastectomy patient is important for promoting well- being.

Date of Submission: 10-06-2020

Date of Acceptance: 27-06-2020

I. Introduction

Patients diagnosed with breast cancer are usually treated with mastectomy which has its own re-percussion on their lived experiences.^{4, 5, 6, 7} In order to help them cope it is important to understand the experiences therefore this study was undertaken to study the experiences and develop a grounded theory which would act as a guidelines in planning the nursing care of these patients.

II. Material and Methods Research Approach: Grounded theory approach

Research Design: Qualitative design

Setting: Tertiary care super specialty cancer hospital in Bangalore with 600 bedded having a oncology ward, 43 bedded (day care unit) with an average census of 8-10 breast cancer patients/ week, Radiation therapy unit and breast cancer out- patient unit.

Selection of participants:

Patients with breast cancer who had undergone mastectomy, and had come to hospital for chemotherapy and radiation therapy as well as those who came for follow up in outpatient department, during the study period of 6 weeks. Purposive sampling was used. No limit was set for the sampling; collected until the saturation of data (theoretical sampling). 30 patients with mastectomy participated.

Inclusion Criteria

Patient with breast cancer who

- were willing to participate.
- had undergone mastectomy.
- could understand and speak Kannada, Hindi or English.

Exclusion Criteria

Patient with breast cancer who:

- were psychologically compromised to the extent of being unable to communicate effectively.
- were not present at the time of data collection

Ethical Considerations: Ethical clearance was obtained from the Institution review board. Approval for this study was obtained from the hospital for data collection. Consent was sought from the patients before taking part in the study. Confidentiality, anonymity, voluntary participation was maintained.

Data collection technique: Using a semi structured interview technique; the patients with breast cancer who have undergone mastectomy were interviewed. The data was recorded with an audio recorder, transcribed, validated then analyzed. Self- Report technique was used and data was coded and transcribed. The transcribed data was later validated by the patients themselves.

Validation of the tool: Nine experts validated the tool-one psychiatrist, two consultant's oncologists, three Psychiatric Nursing professionals, three Medical Surgical Nursing specialty professionals. The content validity Index of the socio- demographic proforma was 0.81, semi structured questionnaire was 100%

Data collection instruments: For the data collection, two tools were prepared. Tool 1:- Tool to assess the baseline variables.

Tool 2: An open-ended semi structured interview schedule was used to assess the lived experiences of post mastectomy. These questions were modified after a pilot study of 3 patients and the formation of the questions were like "Please describe the problems you are experiencing due to the illness and its treatment." The pilot study revealed that the study was feasible but emotionally draining to the researcher.

Data collection procedure: According to the convenience of the participants, appointments were taken and permission to record was obtained. 1 interview schedule with the patients was completed in the ward, 7 in the outpatient department and 13 in the day care and 9 in Radiation unit. The audio recorder was used for 27 participants and 3 participants who had difficulty in speaking preferred to write.

The interview began with an open-ended question with few probing questions to explore in depth of their experiences. Clarifications were sought using questions such as 'How did you feel? Would you please tell me more about this aspect in detail? Please tell me more about it. What does it mean to you?' These questions were used to encourage the information to deepen their narratives

Follow- up for the validation of the themes obtained from the recorded data was carried out through phone calls.

Plan for data analysis: The data collected from this study was analyzed with Glaser and Strauss Grounded theory data analysis method.⁸ The collection and analysis of data was done simultaneously. The recorded data was transcribed and then creation of analytic codes and categories were developed from the transcribed data obtained through the unstructured interview. The study began with as few predetermined ideas – Existing literature and theory, and prior knowledge and experience of the researcher were the source of pre-determined ideas. However, this wasn't used for conceptualization of the grounded theory. Discovery of basic categories in the data was made. Inductive construction of abstract categories was done and validated with the follow-up interview with the participants.

Theoretical sampling was done to refine categories. Theoretical sampling is the process of data collection for generating theory whereby the analyst jointly collects, codes, and analyses his data and decides what data to collect next and where to find them, in order to develop theory as it emerges. Coding was done- open coding, axial coding, selective coding and concurrently memoing were also done. Open coding refers to the process of generating initial concepts from data. Axial coding refers to the development and linking of concepts into conceptual families- coding paradigm. And, Selective coding refers to the formalizing of these relationships into theoretical frameworks. Constant comparative analysis was made. Analytical memos writing during and after the data collection was done. As part of analytical memoing, Q- sort method was used to confirm the categories (axial and selective) with the help of 8 experts. Then, the integration of categories into a theoretical framework.

Results are discussed in three sections.

III. Results

Section A: Socio demographic variables of the participants Section B: Grounded theory related to post-mastectomy patients

Section A: socio - demographic variables of the participants Table 1: Frequency and percentage distribution of socio- demographic variable.

N=30

Socio-Demographic variables	Immediate Post Mastectomy n=7		6 weeks- 2 Years Post Mastectomy n=15		>2 years, post Mastectomy n=8	
	Frequency	Percentage	Frequency	Percentage	Frequency	Percentage
Age						
< 45 years	4	42.9%	8	53.3%	2	25%
>45 years	3	57.1%	7	46.7%	6	75%
Total	7	100%	15	100%	8	100%
Nationality						
Indian	7	100%	13	86.7%	7	87.5%
Bangladesh	0	0	0	0	1	12.5%
Sri-Lanka	0	0	1	6.7%	0	0
Nigeria	0	0	1	6.7%	0	0
Total	7	100%	15	100%	8	100%
Marital status						
Single	0	0	1	6.66%	0	0
Married	6	85.7%	12	80%	5	62.5%
Widow	1	14.3%	2	13.3%	3	37.5%
Divorced	0	0	0	0	0	0
Separated	0	0	0	0	0	0
Total	7	100.0%	15	100.0%	8	100.0
Source of physical and psychological support						
Husband	4	57.1%	4	26.7%	4	50%
Children	0	0	2	13.3%	2	25%
Other relatives	0	0	1	6.7%	0	0
Husband and children	3	42.9%	8	53.3%	2	25%
Total	7	100%	15	100%	8	100%
Affected breast						
Left	4	57.1%	12	80%	7	87.5%
Right	3	42.9%	3	20%	1	12.5%
Total	7	100%	15	100%	8	100%
Stage of cancer						
I	4	57.1%	3	20%	1	12.5%
II	2	28.6%	7	46.7%	2	25%
III	1	14.3%	5	33.35%	2	25%
IV	0	0	0	0	3	37.5%
Total	7	100%	15	100%	8	100
Number of hospitalization						
Once	6	85.7%	12	80%	1	12.5%
Twice	0	0	3	20%	3	37.5%
More than twice	1	14.3%	0	0	4	50%
Total	7	100%	15	100%	8	100%
Ongoing treatment						
Surgery	1	14.3%	0	0	0	0
Radiation therapy	1	14.3%	5	33.3%	3	37.5%
Chemotherapy	2	28.6%	8	53.3%	3	37.5%
Follow-up	3	42.9%	2	13.3%	2	25.0%
Total	7	100%	15	100%	8	100%

Grounded theory related to breast cancer patient after mastectomy

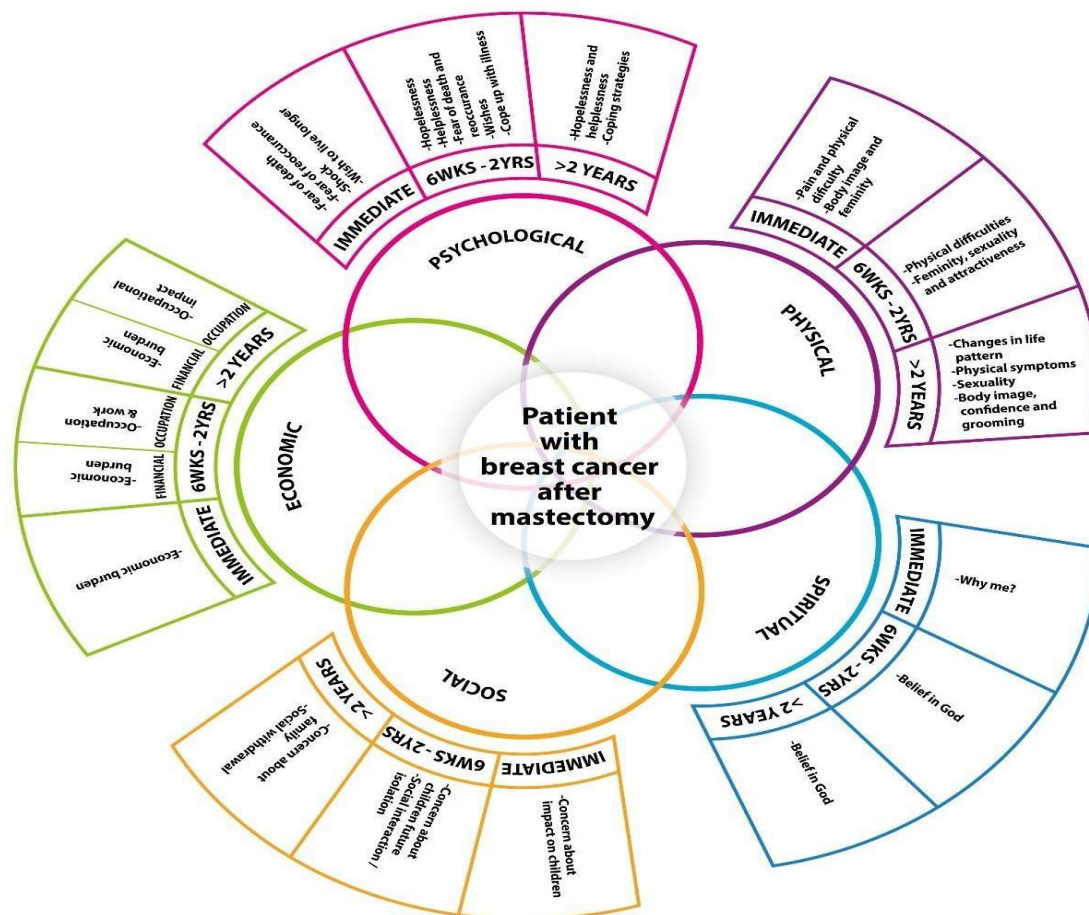


Fig 1: Grounded theory related to the psychosocial experience breast cancer patients after mastectomy.

From the result of the study, participants lived experiences were found to be all pervasive. From the interview with 30 participants, 192 significant statements were identified with 32 thematic clusters. It was identified that although patients presented similar themes the causative factors varied according to the duration post mastectomy. Therefore the patients were further classified into 3 groups based on the duration post mastectomy. There were 7 patients who fell in the group immediate post mastectomy (day 1 post mastectomy- 6 weeks), 15 fell into the intermediate group (> 6 weeks- 2 years) and 8 fell into the later group (>2 years). From the identified 32 thematic clusters it was further grouped into 5 categories namely; physical, psychological, social, economic, spiritual aspects.

Each of these aspects was interlinked to one another. This is depicted through the inter-linked circle. Details of each of the concepts depicted in the grounded theory are explained below:

- **Physical:** It indicates all the bodily functions relating to the human body or the operation of the natural forces generally. Here these physical experiences of the patients are expressed as Pain, Body image, Femininity, Sexuality, Changes in life pattern.

Here are the experiences under physical domain:

➤ **Immediate Post- mastectomy**

✓ **Pain and Physical difficulties:** Pain refers to the discomfort caused due to the surgical procedures namely mastectomy and refers to the difficulties in lying down on the operated site, loss of appetite, headache and decreased physical function in terms of self-care.

✓ **Body image and femininity:** Refers to the perception of one’s appearance in term of gender as expressed such as lost gracefulness, loss of feminine identity and refusal to look at oneself in the mirror.

➤ **Intermediate post mastectomy (6 weeks- 2 years’ Post- mastectomy)**

✓ **Physical difficulties:** Physical difficulties refers to difficulties in terms of biological functions such as nausea, vomiting, loss of appetite, tingling sensations, numbness, heaviness at the operated site and the adjacent arm. It also included fatigue and exhaustion.

✓ **Femininity, sexuality and attractiveness:** It refers to the emotions and perceptions related to

appearance, feeling of having lost the identity of women hood, decreased libido, grooming and acceptance of one's appearance having lost a vital body part representing one's femininity and sexuality.

➤ **Later post mastectomy (>2 years Post- mastectomy)**

✓ **Changes in life pattern:** Refers to the patient's perception of life and her role and responsibilities as expressed in terms of global alteration in life's activities, role reversal from that of a care giver to a care receiver, reduction in the number of activities being handled, changed from a cheerful individual to serious contemplative one.

✓ **Physical symptoms:** Refers to discomfort as a result of lymphedema, swollen extremities, restricted movement of affected limb, body pain and joint pain described as excruciating, loss of appetite, nausea and vomiting as a result of treatment modalities, numbness and itching at the operated site and breathing difficulties.

✓ **Sexuality:** Refers to the role performance as described as decreased and incapacitated as a result of loss of interest, fatigue and loss of the body part that represents sexuality.

✓ **Body image, confidence and grooming:** It is defined as the perception of oneself in terms of appearance acceptance and care. This was expressed in terms of feeling ashamed of one's appearance, non-acceptance of the current appearance due to the loss of the body part and hair loss including the eyebrows resulting in decreased interest in grooming, unsuccessful use of prosthesis such as wig and difficulty in looking at oneself at mirror.

• **Psychological:** It refers to the mental and emotional state of a person. The psychological experiences of the patients were expressed as fear of death and reoccurrence, hopelessness, helplessness, uncertainty about the future, wishes to live healthy and long life and coping with these feelings.

Here are the experiences under psychological domain:

➤ **Immediate post- mastectomy**

✓ **Fear of death:** is defined as the morbid, abnormal and persistent fear of one's own death which the patients expressed in terms of questions about their death and anxiety about their own death.

✓ **Fear of Reoccurrence:** refers to the recurrence of the disorder otherwise called as relapse. This was expressed in terms of anxiety related to recurrence of the cancer and questions related to the same.

✓ **Shock:** Refers to the sudden upsetting events or experiences. Here, it refers to the diagnosis of the breast cancer which precipitated a psychological upset as expressed in the form of tremors, giddiness and crying.

✓ **Wish to live more:** Refers to one's cognitive and affective expression of not wanting to give up on life as expressed in terms such as wanting to live longer in order to see that the family affairs are settled.

➤ **Intermediate post Mastectomy (6 weeks –2 years Post- mastectomy)**

✓ **Hopelessness:** Hopelessness refers to the feeling or state characterized by a lack of hope, optimism, and passion and has expectation of future as expressed in terms of uncertainty about the future, readiness to give up the fight against the disease and finding a total change in the life pattern.

✓ **Helplessness:** Refers to the feeling or state characterized by inability to help oneself, powerless or incompetent as expressed in terms of not having control over the disease process and being unable to do anything about disease with a death looming large on the horizon.

✓ **Fear of death and recurrence:** it is defined as the unpleasant emotion caused by the threat of losing one's life as expressed in terms such as death sentence, fear of normality of rest of the body parts.

✓ **Wishes:** Wishes refers to the strong desires or hope for something to happen. Here the patients desire to live a longer life, quality of life rather than quantity.

✓ **Cope up with the illness:** Cope refers to the method used to deal with the problems and difficulties. Here patients expressed their method of coping by using rationalization and self -help groups, discussion with medical personnel, and ventilation through crying.

➤ **Later post Mastectomy (>2 years Post- mastectomy)**

✓ **Hopelessness and Helplessness:** Hopelessness refers to the feeling or state characterized by a lack of hope, optimism, and passion and has expectation of future. Helplessness refers to the feeling or state characterized by inability to help oneself, powerless or incompetent as reflected in terms of inability to do anything about the life-threatening illness, metastasis of the cancer and as result of unbearable pain.

✓ **Coping strategies:** Cope refers to the method used to deal with the problems and difficulties. Here patients were found in different stages of coping. Some were in anger stage questioning the god, some at the bargaining stage saying that loss of breast was only means of saving of life, some were in depression stage pleading from freedom from suffering and some were in acceptance stage accepting their lot in life. Some found comfort by indulging in spiritual activities such as praying.

• **Social:** It refers to the interaction of the individual and the group for the mutual welfare, tending to

form cooperative and interdependent relationships with others. The experiences of the patients are expressed as social isolation, social withdrawal, and concern about the children and family.

Here are the experiences under social domain:

➤ **Immediate post mastectomy**

✓ **Concern about impact of illness on children:** Concern refers to the matter of interest. In this theory, it relates to the impact of the cancer on the children as expressed by the fear of leaving them alone in their young age and saddened by the fact that no one will be there to take care of their children after them.

➤ **Intermediate post mastectomy (6 weeks –2 years Post mastectomy)**

✓ **Concern about children future:** In this theory, it relates to the children future after their departure from this world as expressed by fear that their children will become orphan, wish to live longer with children.

✓ **Social interaction/ isolation:** Social interaction refers to a state of complete or near- complete lack of contact between an individual and society as reflected in terms of inability to attend the social function and interact with other people due to low self-esteem, unacceptable self- image and due to the fatigue caused by the treatment regimen.

➤ **Later post mastectomy (>2 years Post- mastectomy)**

✓ **Concern about family:** Refers to the concern regarding functioning family after their departure from this world as expressed as wanting to live until the family affairs are settled.

✓ **Social withdrawal:** Social withdrawal is the state of avoiding the people and social activities that one would usually enjoy. Here it is expressed in terms of inability to attend the social functions due to weakness and fatigue caused by treatment regimen, unacceptable self- image, changed appearance as a result of loss of body organ and hair.

• **Economic:** It refers to the availability of the money and resources. These experiences of the patients were expressed as financial burden and Occupational impact due to the illness.

Here are the experiences under economic domain:

➤ **Immediate, Intermediate (6 weeks-2 years) and Later (>2 years) post mastectomy**

✓ **Economic burden** refers to the cost required to deal with a specific situation (disease and its treatment expenses). Here it is expressed by patients as inability to afford the treatment expenses, feeling of guilt due to the heavy economic impact on family, fear of becoming burden to the children as a result of financially depending on them, compulsion to sell the property to support the treatment expenses, lack of sufficient earning member in the family, economic crisis and inability to attend the treatment due to lack of sufficient financial sources.

✓ **Occupational impact** refers to the state of preclusion from the engagement in occupations of necessity/or meaning due to factors that stands outside the immediate control of the individual which is expressed in terms of inability to continue their vocation due to need for long term treatment at hospital, weakness, fatigue etc.

• **Spiritual:** It refers to the aspects affecting the human spirit or soul. It mainly relates to the religion, religious beliefs, and one's own faith. These experiences were expressed as belief on god and anger towards and bargaining with god in different stage of illness.

Here are the experiences under physical domain:

➤ **Immediate Post- mastectomy**

✓ **Why me? :** Here it refers to the patients experience of anger which is a stage of grieving. It includes questioning the god about their illness, its causes and why they are the one who were suffering.

➤ **Intermediate (6 weeks- 2 years) and Later (> 2 years') post mastectomy**

✓ **Belief in god:** Refers to the trust, faith and confidence in the existence of god and supreme power. Here it is expressed in terms of surrendering themselves to god, carrying out the religious rituals for their well-being and health and also some expressed the decreased faith in god because of the suffering.

As product of this theory, the researcher has developed the nursing care plan based in the period of illness and post mastectomy.

IV. Discussion

Likewise, another qualitative study conducted to explore the emotional and psychosocial experiences of Ghanaian women living with advanced breast cancer revealed the similar findings as the present study. The participants were living with the advanced breast cancer and have passed 1 year to 3 years' duration after the diagnosis of the cancer. The experiences of the participants were similar to the findings of the present study as the major themes identified were emotional reactions, pain, lost hope, support, and coping where emotional reactions included sadness, fear, and anxiety, level of pain was severe and lost hopes included to loss of hope

regarding their marriage, parenting, and work. Support was received from their families, spouses, colleagues, health professionals, and spiritual leaders and coping strategies included accepting the disease and surrendering to God and having the will to live.⁹

The findings of the present study were similar to another qualitative phenomenological study to explore the psychological impact of women with mastectomy after diagnosis of breast cancer among Nepalese women. Findings revealed the similar themes as identified in the present study such as the fear of death, emotional impact of the loss of breast disfigurement, loss of femininity, fear of recurrence of disease, and concern about their family. The study concluded that breast cancer and mastectomy have impact on women psychosocial state and the survivors develop stress due to loss of body part, loss of femininity, fear of recurrence of disease, fear of cost and prolong treatment protocol.¹⁰

V. Conclusion

Nursing implication

- Nursing practice
 - ✓ Awareness of the experiences related to the illness and impact of the illness on the post mastectomy patients' can help the nurses understand their problems and provide a tailor made care.
 - ✓ Nurses who are working in oncology ward can use the theory to plan the day to day patient care activities.
- Nursing Education
 - ✓ Research studies about the lived experiences enable to make data based decisions rather than intuitive nursing decisions.
 - ✓ The Theory can serve as an educative tool for staff nurses and nursing students working in oncology units.
- Nursing Administration
 - ✓ In-service education in hospital set up to update the knowledge and skill in nursing practice about grounded theory for breast cancer patients can be conducted.
 - ✓ The administrators of nursing service can encourage their staff members to involve in inpatient counselling and enable them to explore their feeling.
 - ✓ The grounded theory derived from this study can be used to prepare and modify our existing nursing specialization in oncology care nursing.
- Nursing Research
 - ✓ It provides knowledge for evidence-based nursing practice for both staff nurses and nursing students and enhances the credibility to influence decision making policy and protocol regarding interventional strategies to update the knowledge and skill in nursing practice.
 - ✓ The findings of this study can form the basis of future research.

Limitation

This study had a number of limitations.

- The patients' knowledge of their conversations being recorded might also influence their response.
- The research was conducted in one setting only i.e. tertiary care hospital.
- The Data collection duration was limited to 6 weeks.

Recommendation

- The study can be done in a different setting.
- Similar study can be done for longer periods to note the lived experiences post mastectomy patients.
- The theory prepared by the researcher can be used and tested in further research studies.

References

- [1]. International agency for research on cancer. World Health Organization. Latest world cancer statistics Global cancer burden rises to 14.1 million new cases in 2012: Marked increase in breast cancers must be address.[online]; 2 December 2013. Available from: https://www.iarc.fr/en/media-centre/pr/2013/pdfs/pr223_E.pdf [Accessed on 19th November 2015].
- [2]. Breast cancer research foundation. Breast Cancer Statistics & Resources. [Online]; 2012. Available from: www.bcrf.org/breast-cancer-statistics-resources [Accessed on 16th November 2015].
- [3]. Rattue G. What Are the Leading Causes Of Cancer Deaths In India? [Online] ;29 March 2012. Available from: www.medicalnewstoday.com/article/243547.php [Accessed on 18th November, 2016]
- [4]. Lewis S L, Dirksen S R, Heitkemper M M, Bucher L et al. Lewis's Medical surgical Nursing. Volume II. 2nd edition. New Delhi: Reed Elsevier India Pvt. Ltd; 2015. Page1298-1299
- [5]. Montazeri A. Health-related quality of life in breast cancer patients: a bibliographic review of the literature from 1974 to 2007. Journal of Experimental & Clinical Cancer Research.2008; 27(1):27-32. Available from: <http://www.ncbi.nlm.nih.gov/pmc/articles/PMC2543010/> [Accessed on 1st December 2015].

- [6]. Heidari M, Shahbazi S, Ghodusi M. Evaluation of body esteem and mental health in patients with breast cancer after mastectomy. *Journal of Mid-life Health* [online].2015; 6:173-7. Available from: <http://www.jmidlifehealth.org/text.asp?2015/6/4/173/172345> [Accessed on 4th January, 2016]
- [7]. Shobhita R, Sathiyaseelan A. Experiences of Female Breast Cancer Survivors on their Appearance Related Issues Impacting their Identity. *International Journal of Scientific and Research Publications*. June 2013; 3(6): ISSN2250-3153. Available from: <http://www.ijsrp.org/research-paper-0613/ijsrp-p1871.pdf> [Accessed on 4th January, 2016]
- [8]. Polit DF., Beck CT. *Nursing Research: Principles and Methods*.7th edition. New Delhi: Wolter Kluber (India) Pvt. Ltd; 2008. Page 88,722
- [9]. Bonsu A B, Aziato L, Clegg-Lamptey J N A. Living with Advanced Breast Cancer among Ghanian women: Emotional and Psychosocial Experiences. *International Journal of Palliative care* Volume 2014 ID 403473
- [10]. Shrestha K. Psychological impact after mastectomy among Nepalese women: a qualitative study. *Nepal Med College J* 2012; 14(2): 153-156.

Sadikshya Lamichhane, et. al. "A Qualitative Study to Assess the Lived Experiences among Post- Mastectomy Patients in the view of Developing a Grounded theory." *IOSR Journal of Nursing and Health Science (IOSR-JNHS)*, 9(3), 2020, pp. 59-66.