

Psychological impact after mastectomy among Nepalese women: a qualitative study

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ABSTRACT

Breast cancer is one of the leading causes of death in women. Cancer epidemiologists have stated that breast cancer is the most common cancer in women in developed countries, Nepal is not an exception. Breast cancer is the second most common cancer in women of Nepal after cervical cancer. A Qualitative phenomenological study was done to explore the psychological impact of women with mastectomy after diagnosis of breast cancer. In-depth study was done with ten women age ranging from 36 to 50 years. Ten women were interviewed which was recorded, and verbatim were transcribed before taking next interview. The interviews were analyzed in three stages as stated by Miles and Hubermans. Findings revealed that respondents expressed 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. Breast cancer and mastectomy have impact on women psychosocial state. They develop stress due to loss of body part, loss of femininity, fear of recurrence of disease, fear of cost and prolong treatment protocol.

Keywords: Breast cancer, mastectomy, psychological impact, stress, experience, in-depth interviews.

INTRODUCTION

Breast cancer is one of the most frequent occurring cancers in women worldwide.^{1,2} There is a marked geographical variation in the incidence of breast carcinoma². The incidence of breast cancer in developed countries is more than 100 per million women where as it is less than 20 per million women in developing countries. However, cancer mortality is higher in developing countries than that of the developed countries. One of the most remarkable differences is higher incidence of younger breast cancer women (50 yrs) in our part of the world.^{3,4}

Breast cancer is the second most common cancer in women of Nepal. Nepalese women seek medical help very late because of lack of awareness and illiteracy.^{3,4} Breast is an identity of a woman; and fear of disfigurement is very critical. Therefore it is important to look at the possible impacts of mastectomy on the patient after the diagnosis of cancer because people think that cancer is a synonymous to "death" or the "big C" in the common language. The statistics published by National Cancer Registry Program, Ministry of Health and B.P Koirala Memorial Cancer Hospital states that there are 284 patients, 8.7% breast cancer patients in the nations. In Nepal, researchers have found that women hesitate to go to doctor due to the fear of diagnosis of cancer.^{4,5} The disease is already in advanced stage when women go to the health care services.³ Psychological aspects such as anxiety, uncertainty about the future, disfigurement, fear

of recurrent cancer and distress from surgery highlight the many factions of psychological adjustment reported in numerous literatures.⁶⁻⁸ Support from family and friends, normalization and spirituality has been found to help patients recover and relive normal lives.⁹ However, it has been noted that fears arising from a diagnosis of malignancy, with its implications of fear of death, fear of treatment procedure, and reoccurrence of disease are more important concerns than loss of femininity and physical disfigurement.¹⁰⁻¹²

Objectives: To investigate the psychological impact of mastectomy on women with breast cancer.

MATERIALS AND METHODS

Study design: A qualitative design based on the content analysis approach, was used for data collection and analysis of womens experiences after mastectomy. Phenomenological approach was used. The main focus of this study was to understand women's experience in regard to phenomenon and explore how they interpret their experiences.

Ethical Considerations: The study was approved by research committee, Nursing Campus Maharajjung, Kathmandu. Inform Verbal consent was obtained from all the respondents. Participants were informed about the objectives of the study; permission was taken to use the audiotape record to collect information. Code number was given to each respondent to maintain anonymity and

confidentiality. Privacy was maintained by interviewing the respondents in separate room from one another.

Selection of Study Population: The study population was women with mastectomy who had completed treatment. A total number of 10 women were taken by using the snowball sampling technique. The first subject was taken from the hospital record of T.U. Teaching Hospital. Other subjects were referred by the first, second and so on up to six subjects. The sixth respondent informed researcher about the interaction program on Breast Cancer support group of Nepal and four other subjects were taken from that group. Respondents included in the study met the eligibility criteria and were willing to participate in the study. In-depth interview was conducted at respondents home to observe their family relationship, and make them comfortable to express their experiences. Respondents residing in different parts of Kathmandu valley only were included.

Research Instrument: An in-depth interview guideline and field notes were used to collect respondent's response. Each respondent was interviewed 3-5 times for 45-60 minutes in one setting. For three respondents it was needed to have five interviews. Audio tape was used to record information. In order to maintain the validity of the research tool research guide and specialist surgeon were requested to review the interview guideline and some modifications were made after their feedback.

Data Collection Procedure: Data was collected by using open ended in-depth interview in which the researcher and the respondents were fully interactive. Probing was done to clarify and gain more details to understand the meaning of some statement provided by respondents. Interviews was conducted until it reached into data saturation. Interview was discontinued in between when respondent had emotional feeling while describing her experiences. Field notes were made during observations and used as supplementary data during report writing. All interviews were audio- recorded with the permission of the respondents. Unclear information was clarified with further questions to the respondents regarding impact on her day to day life and coping technique after mastectomy.

Data Analysis and Interpretation: Initial data analysis was done during the time of data collection. Recorded verbatim was transcribed before taking next interview. Field notes taken during interview were also analyzed after each interview. Data was analyzed in three stages as stated by Miles & Hubermans, these included data coding, sorting and summarizing then interpretation. All the process of data analysis and interpretation was done by first author adapting Hermeneutic interpretation

process. The interviews that constitute the text of this study were transformed into a structure that contributed to understanding and were analyzed by using the Gadamerian-inspired nursing research method by Fleming. After identification of the main themes in each case common issue was explored and put in two sets of findings; stress due to breast cancer and mastectomy and impact in women behavior.

Themes surrounding the psychological stress and impact on women behavior:

Theme: Stress due to operation, cost of treatment, social stigma, low self- esteem

Sub theme: Fear of death, fear of dislike from husband altered body image, disfigurements, fear of recurrent of disease and metastasis.

Validity/reliability: Data was collected by the researcher. The validity of the findings is related to the researchers' pre-understanding and interpretation of the statements made by the women. The researchers had substantial work experience as psychiatric nurses and were aware that their pre-understanding could influence the interpretation. The validity and reliability of a qualitative research process is based on four criteria of Lincoln & Guba, credibility, transferability, dependability, and conformability. In this study, credibility was achieved by ensuring that the participants' perspectives were represented. Transferability refers to generalizability, that is, whether or not the findings can be transferred to other settings or groups. The relatively small sample used in this research might limit its transferability. Dependability refers to the stability of the data over time and situations. The findings and interpretation were discussed on several occasions in the research peer group and validated by faculties of nursing and senior researchers during research seminars.

RESULTS

This research work revealed that mastectomy caused psychological impact on women with breast cancer, which included fear of death, disfigurement, Fear of recurrence of the disease, physical pain and discomfort, inconvenience in working and social communication, less sexual act and low spirit, which are described below:

Fear of death: All the participants have reported that this was traumatic news for them as well as to their family. They felt that they were going to die soon "*Ma chadai Marchhu.*" Out of 10 respondents, 2 women mentioned that they were not worried as they knew after surgery they would be fine.

Altered Body Image /Disfigurement: After mastectomy losing part of the body was a most traumatic experience. Almost every one said that they were conscious about their body disfigurement which lowered their self-esteem. Five respondents expressed that they also felt loss of femininity and they could not shared this feelings to anyone. Three women reported that they felt guilty and blamed themselves as a punishment from previous life. In Nepali, it is said as, “*PURBA JANMAKO PAAPLE HOLA YESTO BHAYO*” (punishment from previous birth).

Later, they were happy to know about the prosthesis. Eight respondents shared that they are using prosthesis. Two other women were not using any thing; they do not think it was necessary. Prosthesis was difficult to manage, but it was helpful.

Fear of recurrence of the disease: After surgery all the respondents said they were self-conscious, regarding their altered body image. They reported the problems like depression, anxiety, uncertainty about the future, appearance and fear of recurrent of disease and metastasis and distress from surgery.

Financial burden: All the participants have expressed that cancer treatment was very long and expensive which was a great challenge for them to start treatment and as they considered it as a financial burden.

Psychosexual impact: About the relationship with their husband, seven women did not feel comfortable to share their sexual relationship. Two respondents said they felt uncomfortable due to emptiness in chest. One woman expressed problem regarding sexual relationship and less desire to have sex.

Pain and discomfort: The respondent reported physical impact, painful scare, and numbness in the operated area discomfort on moving arm and painful shoulder, swelling, heaviness in the arm and felt incompleteness in living a feminine life.

Increased faith in religion: All the respondents expressed that their faith in God had become stronger because they thought their life is in God’s hand. As they described how dramatically their lives and meaning of life and thoughts had been altered due to cancer.

Change in intimacy or social isolation: Social and family stigma was another problem. After the Chemotherapy and Radiotherapy, eight women shared their problems such as: hair loss, nausea, vomiting and tiredness, etc. which lead them to face difficulty and humiliation. This made them to avoid social gathering for almost one year. They were afraid that if someone asks about their surgery, they will feel embarrassed, “*GAUNLE HARULE KURA KATCHHAN*”.

DISCUSSION

Breast cancer is shocking news when it is diagnosed, especially for women in third world countries such as Nepal where women hesitant to discuss intimate problems with a predominantly male doctor.⁴ This research work revealed that majority of the respondents in this study reported physical impact, after mastectomy such as; swelling arm, physical discomfort, fatigue, weakness, limitation in movement, stiffness, numbness, inability to do daily task.¹³ The psychological stress and pain in operated area. Disfigurements were the biggest problem 82% reported that affected arm became the problem that collaborates the concerns expressed by the majority of the women in the sample.^{14,15} Few years after remission from cancer the respondent said that they had fever and common cold and worried of recurrence of disease. Their main concerns were how to cope with their illness.¹⁰ Stephan have stated that breast cancer patients experience intrusive thoughts, avoidance, anxiety, depression, and impaired relationships. All these signs were expressed by the sample group of breast cancer sufferer. The literature is the evidence that the majority of women with mastectomy had problem with sexual relationship.^{15,16} Majority of the respondents hesitated to share about sexual relation but, only one respondent expressed that she had problem with sexual relation after mastectomy. Stewart¹⁵ has highlighted that absence of a breast have become a sexual problem because her husband was not cooperative so their sexual life was disturbed. Majority of women stayed isolated; hesitate to attend any social function until one or two years after mastectomy due to loss of hair from chemotherapy and change in skin color.¹⁸ The research have evidenced that when a human being have crisis in life, they became spiritual for better understanding of the problem and to cope with. Irvine^{17,9} has highlighted that spirituality gives the power to cope and thinking positive in crisis “She believed that her GOD would make sure nothing drastic happened to her”. The literature has stated that spiritual practiced helped them to cope with such problems.^{2,9,19}

Financial crisis is another main aspect that majority of respondent have felt during that time. In Nepal, majority of women are financially dependent on the male member of the family, mainly the husband. Shrestha *et al*² has highlighted that the majority of people are under low-socioeconomic so it impacts on the treatment of cancer because it is costly and time consuming.

This study indicates that women with breast cancer suffer more psychological impact, and the movement was stressful to the survivors as well as family. In conclusion, the phenomenological approach explores

the real experience of the respondent with breast cancer and mastectomy and various impacts on physical, psychological/psychosexual, social/spiritual and financial aspects. The problems they experienced were pain, swelling, limitation in activity and fatigue. Additionally, they experienced psychological distress soon after the diagnosis of breast cancer and faced difficult in coping. Eventually, their main concern was fear of death and recurrence of the disease. Majority of respondents also faced problem in their sexual life which they hesitated to express. After mastectomy the impact was not only physical and psychological but also social and spiritual. The respondents have expressed change in social interaction, as they felt guilty losing body part, being disfigure and losing their hair after chemotherapy, which made them have low self - image.

Another most important aspect of this study is on financial matter. Majority of respondents had strongly expressed that the disease has brought them and their family financial burden due to increase in expenses and limited income.

This study revealed that the women with breast cancer after mastectomy encouraged sharing their feelings and seeking help to reduce the impact by talking with other people. Especially they should be encouraged to talk about sexuality before this impact become social problem. The health personal should encourage and counsel the women who suffer from breast cancer and mastectomy and share with other similar woman who is surviving after this disease.

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