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Lived experience of women diagnosed with breast cancer: A qualitative study

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Abstract

According to WHO, one in every eight women will be diagnosed with breast cancer in their life time [1]. India stands first among other countries in breast cancer mortality [3], not only the estimates of breast cancer are creating frustration among women; the disease itself creates the feeling of worry and dread. Knowing the subjective feelings, experiences and expectations will highlight the importance of quality health care and better coping to the disease. Adequate delivery of need based care to breast cancer patients can be achieved through knowing the feeling, experience and expectations of women diagnosed with breast cancer. A study on lived experiences of women diagnosed with breast cancer in a selected hospital at Mangalore was conducted to explore the experiences and feelings of the women diagnosed with breast cancer.

Materials and Methods: A qualitative approach & phenomenological research design was adopted in this study. Women who were diagnosed with breast cancer for minimum of one year irrespective of their treatment who met the inclusion criteria and attended oncology unit of Justice K S Hedge Charitable Hospital, Mangalore were selected as the samples through the purposive sampling method. Instead, women who were suffering from breast cancer with multiple organ metastasis and women who had undergone surgery two weeks prior to the data collection were excluded from the study. After receiving the ethical clearance from Nitte University and the consent from the study subjects, the researcher interviewed them by using preset semi-structured open ended questions and tape recorded the conversations. Each interview lasted for about 30 – 40minutes. The recordings were transcribed verbatim. Data got saturated with 6 samples.

Results: Colaizzi's data analysis framework was used to analyze⁹ the transcribed data and from the analysis, six themes emerged and they were:

1. Ignorance
2. Awareness on the deteriorating physical changes
3. Powerlessness and death anxiety
4. Dysfunctional family process
5. Readiness for enhanced coping
6. Willingness for self-recognition and identity

Conclusion: The findings emphasized the necessity of nurse's care and concern for subjective aspects in women with breast cancer. It also helped to expose the hidden aspects of the need for concern and time for sharing the feelings in case of such dreadful illness which in turn many times brings ideas for better coping and improves the quality of life and that was agreed upon by many other former researchers.

Keywords: Breast neoplasms, qualitative research, phenomenological research psychological adaptation

Introduction

Background for the Study

Diseases happen all the time to each and every one; but how each one deals with a disease is different, particularly with chronic diseases. Such experiences, reactions and responses are usually unique and are based on one's perception towards the disease. The word cancer, for those who have never battled it themselves, is creating a sense of pain, suffering and death. Having been diagnosed with cancer is a dreadful event and coping to that even more terrible. It is not only a word that causes much dread and leads to hushed tones but also the figures speaks volumes, 8.2 million deaths and 14.1 million incidence of cancer in the year 2012. (World Health Organization). It is also expected to rise to 22 million by 2032 [1].

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There are four types of cancer commonly diagnosed worldwide, they are lung, female breast, bowel and prostate and they all together account for 42% of all new cases [2]. In accordance with the World Health Organization; one in every eight women will be diagnosed with breast cancer in their life time [1]. The numbers of breast cancer is increasing in the Indian graph too due to rapid lifestyle changes such as diet, habits and so on. Currently the largest estimated number of breast cancer is from India [3]. The data from National Cancer Registry Program (NCRP) shows that in India breast cancer (25.8%) has now gone beyond to cervical cancer (22%) as the most commonly diagnosed cancer in women and also the average age for contracting breast cancer is somewhere between 30 – 50 years and cancer among young women tend to be more aggressive [4]. Based on Population Based Cancer Registry there are about 0.15 million cancer cases at any given time in Karnataka and about 35,000 new cancer cases are added to this group each year [5] whereas the population of Karnataka as per 2011 census is 61,095,297 of which females are only 30,128,640; breast cancer is the major site for cancer in females, accounting for 27.3% of the total cancers followed by cancer of the cervix (15.9%) and ovary (5.7%) [6].

The fact of being diagnosed with breast cancer and the therapies which starts immediately after diagnosis causes various stresses for the affected women and their families. These stresses might be of physical or emotional character, usually not so clear and they often go undetected therefore, it affects the quality of life and causes long-lasting psychological and physical distress [7]. According to Delores (2014) [7], a cancer survivor “There’s a fear that goes through you when you are told you have cancer. It’s so hard in the beginning to think about anything but your diagnosis. It’s the first thing you think about every morning”. Such problems can be identified earlier through trustworthy conversations with the patient and the family which in turn help the patient to seek appropriate treatment and support. Knowing the qualitative experiences and feelings of the breast cancer patient is as important as the treatment of cancer. Knowing the subjective feelings of the patients will help the nurses to care and support the patients more effectively. Exploring the problems that breast cancer women experience will be a corner stone for planning and implementing medical and nursing interventions to help them live with their optimum level of functioning.

Statement of the problem

“A study on lived experiences of women diagnosed with breast cancer in a selected hospital at Mangalore.”

Objective

To explore the lived experiences of women diagnosed with breast cancer.

Research question / problem

What are the lived experiences of women diagnosed with cancer?

Research Methodology

Research Design

As the researcher aims to acquire deep understanding on the experiences and feelings of women with breast cancer, qualitative research design was adopted for the study since qualitative research is a systematic and subjective approach

to describe life experiences, events and feeling of the individuals, and to give them intended meanings⁸.

Research approach

A phenomenological approach was used in this study to understand the experiences, feelings and expectations of women with breast cancer.

Study settings

Considering the availability and accessibility issues, the study was conducted at the female oncology ward, Justice K S Hegde Hospital Mangalore.

Sample and sampling techniques

The study samples were the women who were diagnosed with breast cancer for a minimum of one year irrespective of their treatment and who met the inclusion criteria and attended the oncology unit of Justice K S Hedge Charitable Hospital, Mangalore – selected through purposive sampling.

Sampling criteria

Women diagnosed with breast cancer for a period of minimum of one year irrespective of their treatments and women who can speak and understand Malayalam (vernacular language), or English at a level suitable for the full completion of the interview were included in the study where as women who were suffering from breast cancer with multiple organ metastasis and women who had undergone surgery two weeks prior to the data collection were excluded from the study.

Data Collection Process

In phenomenological research studies neither the length of the time for data collection or the number of participants is defined before the study starts. Rather data are collected until all information is redundant of previously collected data, that is when no new themes or essence have emerged from the participants and the data is repeating.

In this study for the in-depth data collection the researcher used an open ended interviewing technique. The instruments used for the data collection were:

Demographic and Clinical Proforma

Demographic and clinical proforma generated the demographic data and clinical background of the participants. It consisted of a total of nineteen questions including age, educational status, religion, type of family, occupation, monthly income, diet, and so on.

Semi-structured interview technique with open ended questions.

Interview schedule consisted of a few lead questions exploring the experiences of women with breast cancer, which are related to the response to the diagnosis, response to the treatments, emotional and physical difficulties related to the treatment, areas of life affected with disease, support from the family and spouse, changes in the role performance, concern about body image changes, spiritual relationship with god and future concerns.

The interviews were started after obtaining permission from the ethical clearance committee, hospital authorities and informed consents from the patients with open ended clarifying questions like “what made to take an appointment with doctor?, Describe the your feelings as a healthy women

before the occurrence of the cancer etc.” The construction and flow of the questions were modified according to their flow of answering and ability to express their experiences. In addition to tape recording the interview, the interviewer jotted down the important points and facial expressions of the patients while answering the questions. Interviews were usually ended by asking the participants to share anything else regarding the phenomenon of interest till the participants were exhausted of their descriptions. Each

of the tape recorded interviews lasted approximately 30 to 45minutes. Data saturation was achieved by the fifth participant and the sixth interview was conducted for validation and clarification of the findings.

Results

The researcher used Colaizzi’s Data Analysis Framework (Shosha GA 2012) [9] to analyze the transcripts.

Table 1: Example of Derivation of formulated meanings and subthemes from significant statements based on Colaizzi data analysis framework.

Lead question	Significant statements (verbatim)	Formulated meaning	Subthemes
Describe your feelings as a healthy women before the occurrence of the cancer.	<p>PARTICIPANT 1: Sister what should I tell.....(pause).....I never ever thought that I am going to get such drastic disease in my life time..... I have never done any harm to anybody and I did not even think of that... (Long pause). I was looking after my home. Myself only was doing all the my works,.... (going to the market, cooking,... beedy rolling, looking after my son and mother in law and so on) I did not even had any sickness from my childhood..... I was healthy and leading healthy and hygienic life. I never had any clue about such big illness(crying)</p>	Participant was healthy from childhood and was leading healthy & hygienic life, supporting her family. She never expected such kind of major illness shatter her life. Patient had lack of knowledge in noticing the early signs of breast cancer.	Apparently healthy Prior to diagnosis Lack of awareness about the illness
	<p>PARTICIPANT 5: We are from a lower class family and daily wagers, I met with an accident 2 years back during my work and had a fracture on right leg other than that I am not remembering any disease and staying in hospital for any illness. I have 2 children, both are girls and very young age. I was looking after them and doing all the household works. Children, work and husband that was my world, I never ever thought beyond that. (Long pause) Sister why God did this cruelty to me, I did not do any harm to anybody</p>	Participant was healthy prior to present illness. She never expected that she will come across with a major illness like cancer. And she was ignorant about the disease.	Expression of helplessness Frustration shock

The above table gives us an idea about the qualitative content analysis. From the each participants responses to the question, the researcher identifies the significant statements and formulated a meaning out of that (Formulated Meaning) from which again the researcher draws one sentence or word

theme which are called subthemes. Further all the subthemes which have similar meaning were clubbed together under clustered theme. (Note: as it is qualitative phenomenological study patients verbatim should be kept as original so the researchers not done the grammar correction)

Table 2: Example for clustering the subthemes

Subthemes	Cluster theme
1 Lack of knowledge on warning signs of breast cancer	Lack of awareness about illness
2 Lack of regular check up	
3 Non anticipation of adverse effect of illness	
4 Uncertainty about prognosis	
5 Reduced exposure to knowledge of treatment modalities, relaxation and coping	
1 Hesitant to expose the private body part to doctor	Delayed diagnosis
2 Negligence at the beginning	
3 Financial constraints	

All the subthemes which have similar meaning were clustered together under one cluster theme.

The derived subthemes were clustered accordingly and formed cluster themes, from these again six final themes or ideas were brought out which corresponded to the lived experiences of women diagnosed with breast cancer(validated by the participants and experts) and they are:

1. Ignorance
2. Awareness on the deteriorating physical changes
3. Powerlessness and death anxiety
4. Dysfunctional family process
5. Readiness for enhanced coping
6. Willingness for self-recognition and identity

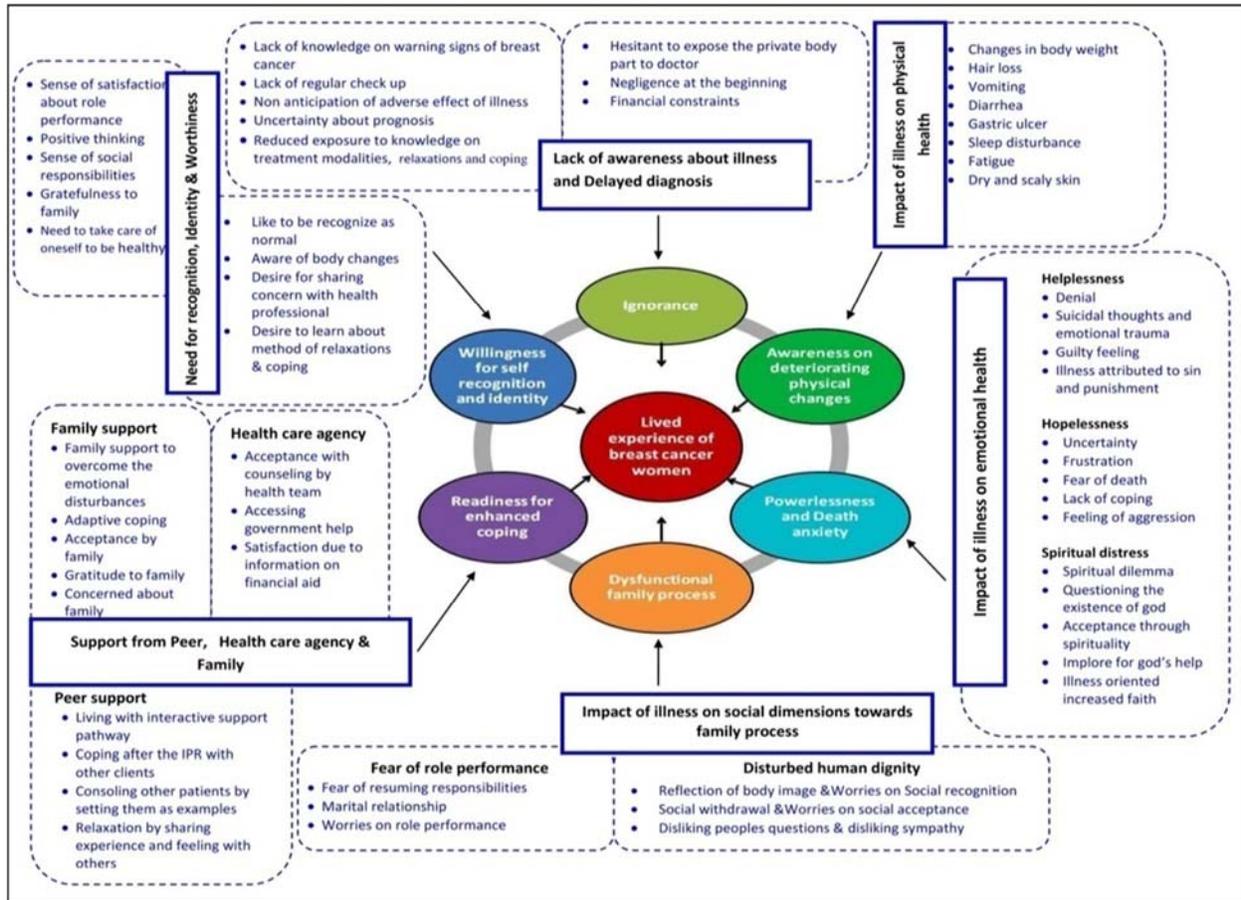


Fig 1: Derived themes from the verbatim

Discussion

Final themes were derived after sorting them out from the verbatim through repeated reading and re-reading and the derived themes were validated by the participants and the experts from the oncology and phenomenological research area.

Ignorance

All the participants expressed their lack of awareness regarding breast cancer prior to the diagnosis, they did not do any regular health or breast self-examinations also they had kept their early signs and symptoms of breast cancer hidden because of the non-anticipation of adverse effects, lack of knowledge regarding disease condition and some of them had hesitation to expose their private body part to doctors. Participant 6: “I started feeling some sort of pain, small mass like thing in my breast and some color change, but I did not tell to anybody for a month because I was not sure about how I will go and show this to everyone.....” All these responses are indicative of the ignorance of women with breast cancer. A descriptive study to assess the knowledge on breast cancer and utilization of mammogram among women in selected villages of Karnataka(2014)¹⁰ showed that, from the total number of the population (n = 320),the majority 46.6% had low knowledge on breast cancer and only 19.1% (61) were aware of mammogram. The expressions of present study participants and other literatures were emphasizing the necessity of education and information on breast cancer, its risk factors, and preventive measures.

Awareness on the Deteriorating Physical Changes

The participants had vivid and powerful memories of suffering. In fact, through questions about their treatment experiences the researcher felt, she had induced strong emotions in them. The quality of life of these patients was affected by these experiences of adjuvant therapies especially the chemotherapy. Participant 1: “During my chemotherapy I had undergone severe problems like vomiting..... I lost all my hair and color and also I become black now. Look at my hand and face..... I am looking very scary. During my treatment (chemo) I lost all my hope”. A number of studies have looked at the effects of adjuvant therapy on the quality of life and concluded that adjuvant therapies may explain lower scores on quality of life indicators (Casso *et al.*, 2004) ^[11]. All these physical differences impeded with the participants lives beyond the cancer.

Powerlessness and Death Anxiety

The participants had strong feeling of fear of death, and they considered the term cancer as synonymous as death. The participants were worried about themselves and their families. Most of the participants expressed the feeling of hopelessness and helplessness throughout the interview. Participant 5: “Future!!!! What future I got, sister?? Cancer means death know sister? (Looking away) Sometimes I may get cured, but I know it will come again know sister.... I know it will come or I may die with this”. Participant 6: “.... I have just crossed 30 years and..... my daughters what life I have any more.....”. As per the qualitative study done by the Harmurt and followers (Hartmut R, *et al* 2010)

^[12], the diagnosis of breast cancer causes, the fear of the spread of disease and death, the uncertainty about the future and fear of long suffering or adverse effects by possible treatment.

Dysfunctional Family Process

Participants of the study expressed the feeling of fear in resuming activities and responsibilities along with worries about the marital relationship during the interview. Participant also had strong feelings of discomfort on their body image and it reflected on their social interaction abilities. Participant 2: “look at my hair condition, I had long curly hair, now nothing, full bald it become. People might be laughing at me. I go never in front of mirror nowadays. (Tears rolls through cheek)” Participant 5: “..... I don't think that I can be a good mother taking care of my children well and giving whatever they want”. A qualitative study done by Melisa M K (2011) ^[13] on breast cancer women and interpersonal relationship states that many of the participants had good interpersonal relationship with family and husbands which is contradictory to the present study whereas the same study itself shows that some of the subjects mentioned that they had come across with problems in their marital and family life after breast cancer. So the researcher perceived that ultimately the worries on role performance and the inferiority complex due to the body image induced problems in the normal family process.

Readiness for Enhanced Coping

All the participants of the study expressed satisfaction over their family's efforts in making them happy and helping them to strive forward in life. During the interview participants expressed the wish to take up the greater course of consoling other patients by setting their lives as examples. Participant 6: “I feel happy even if I have this illness my husband and family take care me well. They look after me well; see my sister came with me to stay with me here. I feel so sorry to them for troubling them like this” “you know one thing now I am feeling some relaxation after talking with you” Participant 3: “I am lucky to have such husband who treats me like a queen.”

Manuel J *et al.* (2007) ^[14] pointed out that, quest for social support, reliance on God, positive suggestion and acquirement of information and education are the indicators of enhanced coping in women with breast cancer. Support from family, friends, and health care professionals was very important to the women and made a big difference on how the women felt and their ability to deal with the breast cancer.

Willingness for Self-Recognition and Identity

Throughout the interviews it was particularly noticeable that the women talked about a need of protecting their families, societies and to educate or make awareness about breast cancer at least in people who live around them. Participant 3: “I feel I should teach other women about breast cancer, also I wish to visit and console anybody suffering the same disease in our place”. Study by Bai Q P C *et al.* (2013) ^[15] described an evolution in breast cancer patients social roles, as they made modifications to activities and relationships; this was associated with a transformation of their overall perception, leading to a shift in their self-identity.

Conclusion

These findings emphasized the necessity of nurses care and concern on breast cancer women's subjective aspects of

problems, it highlights the hidden aspect of need of love, concern and time for sharing the feelings in case of such dreadful illness. Health professional education curriculum must emphasize not only the signs and symptoms and treatment but also the psychosocial effects of breast cancer, impact of illness on emotional health, need for self-recognition and identity among cancer patients and so on.

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