

## The Psychological Impact of Breast Cancer on The Every Day's Life through The Eyes of Survivors

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### ABSTRACT

**Background:** The incidence of breast cancer in Eastern Country is unexpectedly increasing more than any other types of cancer in women. The purpose of this study was to explore and describe how breast cancer affects well-being of affected women, particularly their physical, emotional, personal and social aspects.

**Method:** For the present study thirty-nine women were interviewed at different stages of diseases. Thirteen patients were recently diagnosed with breast cancer, ten were undergoing chemotherapy, nine were on follow-up and rest consisted of socially rejected once by others for their disease. All participants reported their experience through structured interview. A constructive grounded theory approach was used where includes different areas of domains of problems having impact on daily life.

**Results:** Our study showed that, the reactions of the patients, when they were first informed about their disease is usually the thought of death. After first chemotherapy, behavioral changes were observed, in the form of lack of awareness about side effects. Social factors also play an important role in developing psychological stress.

**Conclusion:** Various stages of diagnostic treatment pathway give rise to a range of unique and diverse influences on physical, emotional social and psychological well-being.

**Keywords:** Breast cancer; Psychosocial issues; Quality of life

### INTRODUCTION

Breast cancer is common cancer found in females. It's incidence worldwide and in India. So that readers will know that we are talking more about breast cancer. Disease modifying treatment in breast cancer includes chemotherapy, radiotherapy and /or surgery which can adversely affect patients' physical functioning and occupational activities [1]. Occupational performance comprises of daily activities which is divided into eight occupational areas: basic activities of daily life, instrumental activities of daily life, sleeping and resting, formal education, work, play, leisure and social participation [2]. Functional capabilities often integrate with occupational performance.

Functional capability is associated with the ability to perform basic activities of daily life. It is characterized by the efficiency to execute daily life tasks and is linked to restoration of motor and cognitive skills being directly related to quality of life. Functional assessment seeks to verify the disease level and injuries that make patients incapable of performing daily activities autonomously and independently (i.e., performing daily activities without needing assistance). Therefore, functional assessment enables development of a plan for adequate care [3-5]. In addition to impact on physical functioning, inadequate stress management can lead to impairment in professional role and can affect directly on quality of life [2-7]. In comparison to different therapies, quality of life has become an important parameter that can also help physicians and patients to decide which therapy is more suitable. For this reason, the US Food

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and Drug Administration (FDA) recommended a quality of life assessment in clinical trials for approval of new antineoplastic agents because of involvement of physical, emotional, and social functions particularly during and after treatment [8-10].

In our country, most of the patients belong to poor socioeconomic status. So, it would be difficult for them to continue this type of treatment. Through this paper, we want to review that any health insurance or any schemes are available to cope up with financial constraints generally, women's experiences varied over time. The primary aim of this study is to understand how emotional experiences of breast cancer women changes at different stages of their disease and during the period of their treatment. The purpose of this study was to explore and describe how breast cancer affects well-being of affected women particularly their physical condition, emotional state, personal relationship status and social life.

## METHODS

### Design

A semi-structured face to face interview based on constructive grounded theory approach was used to collect data from study participants. Following this method researchers applied knowledge and experience from individual study participant by using constructing interview questionnaire. Acknowledging experience from this, constructive grounded the theory was computed. Hence, reality is grounded through interpretation of incidence from individual's point of view.

### Sample collection

This study was conducted at a tertiary cancer hospital in Kolkata, situated in eastern India, from April 2017 to August 2017. Thirty Nine non metastatic breast cancer female patients were enrolled in this study. An inclusion criterion was:

- Age between 30-60 years;
- Proven Clinical diagnosis of Non-metastatic Breast cancer;
- Patients undergoing Neo-adjuvant chemotherapy;
- Having at least primary level of formal education (upto standard VIII);
- Willing to participate in study.

Exclusion criteria were:

- Women with metastatic cancer;
- Previous history of major psychiatric illness;
- Inability to understand/ read Bengali language;
- Refusing to participate in study.

### Data collection

Data was collected from prospective observations of study participants. All patients answered questions regarding six different areas emerged as important to women with breast cancer. This type of questionnaire was developed by experienced researchers (Table 1). The demographic factors on which questionnaire were based were: age, level of education,

occupation, residence, family income and relationship status Interview section was applied on thirty nine patients.

**Table 1:** Semi structured interview guide: example questions.

1	Tell me about the events that led up to your diagnosis of breast cancer.
2	Tell me about the 1st situation when hard that you are a cancer patient
3	Tell me about the 1st situation after taking first chemotherapy
4	Did you face any embarrassing situation in society?
5	What had been the impact of treatment on you and your body?
6	What has been the impact of treatment on your family and relationships?
7	Impact of psychological well-being among participants

### Procedure

Written informed consent was obtained from all participants. The study was subject to approval by the Ethical Committee of our institute following guidelines given by the Indian Council of Medical Research (ICMR) (approval no: H15REA156). The study was conducted in a controlled room by minimizing extraneous variable including (sound, noise, and temperature.). The session of interview had taken at around 40-45 minutes. Demographic data were collected via interview using the semi structured proforma from only selected patients not from the family members.

### DATA ANALYSIS

The documents of interviews were carefully read and given codes line by line using a descriptive label to elicit highlight the data. The transcripts were initially read and re-read and coded line-by-line using a descriptive label to reflect the data segment. As coding and data collection progressed simultaneously, codes were organised into higher level categories which enabled greater explanatory potential. Theoretical saturation was reached when no new themes emerged from the analysis process that was significant to the emerging theory [11].

### FINDINGS

"We are not ourselves when nature, being oppressed, commands the mind to suffer with the body." –William Shakespeare.

When a patient comes to know that he/she is a cancer patient, stress begins from that point. In Eastern region of India, when woman has been suffering from cancer she usually experiences the deterioration in her relationship with her family members as well as her society which leads to the development of psychological distress and as a result it decrease quality of life. In the crucial stage they were subjected questionnaire based on six

specific areas related to their experience about pre diagnosis, post diagnosis and pre and post treatment. In the present study, we focused on the course of emotions whether cultural or sociodemographic factors. According to the data collected we found out there were some common elements of their experience which did not vary individual to individual. Their experience had varied in terms of variation of treatment type, their own mental state, family income and family support variation. For example, those who belong to poor economic background for whom expensive cancer treatment are not affordable that leads to the development of stress much more than the cancer term itself. People who are uneducated or literate people who are ignorant about cancer and its affect tend to depend on the doctor's advice.

## PRE- DIAGNOSIS STAGE

The process of being diagnosed with breast cancer varied from patient to patient as they presented to their doctor for different reasons.

I am age 46, coming from rural areas. First time I noticed a lump in under arms. I thought maybe got hit by something. There was no pain, so I did not go to doctors. After 6 months, one day I saw that its size has become increasing. Then go to a local doctor. Doctor preferred me to do some test. Then it was detected [Pt.2].

I am age 51 years, coming from urban areas. Last 1 year near nipple got swollen. I then went to homeopathy doctor. Doctor assured me that I have to take medicine for a long time, and then I would be ok after that. After taking medicine for 1 year nothing good happened. Then swollen part grew and suddenly one day it burst out from it. Then visited a doctor in town and got admitted in hospital [Pt.10].

I am 27 years. I was coming from urban areas. One day while taking a shower, I felt a lump in my chest. I was afraid what happened. I was too shy to go to the doctor. But, it was sure that can be ignored. After 3-4 months when I could not tolerate the pain and went to the doctor and went through different test [Pt. 13].

## FIRST REACTION AFTER DIAGNOSIS

Not surprisingly, the majority of respondents were shocked to receive diagnosis of breast cancer. For some women, the symptoms with which they had been living had previously been attributed to the normal ageing process.

I just found out yesterday I have breast cancer. I need to tell my children first before I can talk to anyone about this. I don't want them to see the fear in my eyes. I have to be strong. My girls are 20 and 23, but we are close as no other. Should I lie and tell them it's a cyst that they have to remove and hope they don't find out until everything is over? I had a lot of family members that died between ages 45 and 50 years, and they were all strong people. I lack both physical and mental strength [Pt.3].

I has had cervical cancer and three pre-cancer cysts removed. I just found out I now have breast cancer and has decided, after two months of thinking, that I do not want to treat it for various

reasons. I have been having really bad unexplained headaches that are not anything like me blood pressure headaches. I am now 39. I think I'm more scared of the results than my family member is [Pt.18].

I've been recently diagnosed with Stage 1, Triple Negative Breast Cancer and treatments are radiation and chemotherapy. My biggest fear is the first day of chemotherapy. How do you prepare your mind and body? I'm trying to be strong but fear I will breakdown that day! [Pt.20].

1st chemotherapy why it is crucial?

The crucially of the 1st chemotherapy lies in the changes behavior observed in the cancer patients, which mainly includes lack of awareness about side effects.

When I went to chemo for the first time, I was very afraid. I did not get enough sleep for three days. The day when I went to the hospital and entered the chemo room, I found some people like me who were talking chemo... seeing this I got some courage. It was very painful after talking chemo. I was feeling like vomiting for seven days. I was feeling uneasy all the time. Though after taking 2nd chemo did not feel that much like before. But, I broke down after first chemo [Pt.1].

I have heard from people that after taking chemo health deteriorates badly. But, I did not feel like that, maybe I was aware of it since the first day. I don't feel like this even when I was not well [Pt.5].

In capability to perform in family and social works, ultimately leads to depression.

Following the cancer diagnosis, participants sought to make sense of what had happened by reflecting on what they could have done differently and how health behaviours could be positively influenced as a result.

I can do all of my works. But, family members don't let me work extra. I get bored and feel very bad when I see my family members are doing so many things for me with hardship [Pt.15].

During the period of treatment each and every day like a year and in night I felt today I spend successfully with my disease whatever health condition was. Always lots of anxiety were running behind me [Pt.12].

When I thought tomorrow I will go to hospitals for taking 3rd chemo cycle then I was getting anxious more. Even on that day I had been suffering from insomnia and repetitive thought [Pt. 20].

## EXPERIENCE POST TREATMENT COMPLETION

Through my observations it can be seen that nothing world is more dangerous than sincere ignorance.

I was diagnosed with stage 3, triple negative breast cancer in 2011 and had 6 rounds chemotherapy with 21 days interval, and 33 radiation treatments with 1 week interval. I completed treatment in 2012 and I don't understand why I feel more tired now than I did a few months after completing treatment. I just

had my CT and bone scan and both were negative. I just do not understand this complete lack of energy [Pt.14].

Is it possible not having any symptoms of breast cancer? I went for my yearly mammogram a few weeks ago. They called me back for a closer look of my left breast after which they did an ultrasound. I am still waiting to hear what the ultrasound showed [Pt.9].

Improper treatment towards a cancer patient by the ignorant society!

Inspite of the people in the society knowing that a person is suffering from cancer does not stop them from criticizing the victims or their family members for their current situation. This makes the patients work herself to look normal to survive.

I was not afraid when I was diagnosed with breast cancer but what pained me is my surrounding, people and society. My family members did not let me participate in any ritual programs even when I wanted to join with them they started to avoiding my presence. I feel sad when I see these people giving long talk on development of society while at the same time comparing cancer with touch ability and untouchability [Pt.17].

I become upset whatever I think of my disease what hurts me most is my daughter's future what makes me anxious is if anyone knows that I have cancer they might reject my daughter. This kind of disease cannot be hidden for long time. People get it seeing my health condition [Pt.19].

## DISCUSSION

“The end of the cancer treatment is not the end of the cancer experience”

Appleton et al. had worked over the impact of prostate cancer on daily living. There, they elicited different experiences of patients during short-term and long-term journey of treatment [12]. They emphasized on how cancer affects their daily routine and turns into a psychological condition. The findings of our study emphasized the crucial aspect which affects wellbeing status of breast cancer patients during their journey through cancer (from pre-diagnosis to post treatment completion). In the present study, authors tried to reveal the emotional reactions of their disease across different stages of their treatment. Authors also found that socio-demographical factors or cultural factors play an important role in perception of experiences.

The crucial issue of a cancer patient is dealing with cancer diagnosis which may lead to the development of feeling of overwhelming. Worrying about their future differences in terms of the uncertainty about what to expect through treatment course between women's prior to and following chemotherapy and radiotherapy. Some women may find themselves in denial stage following begin treatment, which is often a lengthy process; they might find themselves facing various problems. After diagnosis, most of the patients think that these are results of 'bad karma' of their past life and they get worried regarding their symptoms, treatment plan, and duration of mortality. During those journey patients and their loved one always accept the situation and fight against it. But, sometimes, anger may be directed towards them when they try in their best level to give a

better quality of life but fail. In most of the cases, patients with breast cancer may be fearful of a possible recurrence or even of the possibility that breast cancer could take their life. Chemotherapy impacts their whole body and causes a variety of side effects including loss of hairs, nausea, fatigue, skin and nail changes, loss of appetite, changes in smell and taste, menopausal and sleep disturbances and that might be cause of their stress. They are worried about their role in the field of their personal as well as professional life. Because they think they are burden of their family members. For that reason, feel guilty during treatment and after recovery. So, the cause of their sadness is not only cancer but also its effect on their day to day physical deterioration. Even, those who were married there had been seen an unexpected strong wish to live not for herself, but for their family and they themselves want to share their experience which got throughout the treatment. That's why, they begin to feel hope and with good reason.

Cultural influence comprises of formation of the psychological contact, perceptions of violations of psychological contact and responses to perceived violation. Women with breast cancer often from different countries or professing different religious faiths have variety of experiences based on cultural variations. Environmental factor is one of them, and is also the most identified and predictable factor [13]. The incidence and prognosis of breast cancer can vary among different geographic regions of the same society. Despite, the developments in treatments available to treat cancer, the prognosis still have been found to vary greatly [14,15]. Ethnicity, environmental and socioeconomic factors, lifestyle, treatment compliance and differences in treatment response are implicated as reasons for these differences [16-18]. Socioeconomic-cultural factors may have either positive or negative effects on breast cancer. The incidence of breast cancer is low among women with low socioeconomic culture. However, their prognosis is worse [19]. Because of the lack of knowledge about detection of breast cancer, most women in India report to hospitals when cancer has moved to late stages. As the stage of the disease advances, more than one modality of treatment is needed to be applied because of which the cost increases. Among socioeconomic factors, health insurance is the very important factor to provide a better quality of life to the patients. This includes better treatment and care for the patients. The ratio of public-funded healthcare facilities in India is considerably low as compared to the population of the country suffering from cancer. Insurance schemes or government-funded schemes are few and sparse. Private hospital admissions are available mostly to those who belong to higher socio economic status. They also spend more money per member on both outpatient and inpatient visits compared to patients from low socio economic status. Households with higher socioeconomic status borrowed less for treatment. Adult labor force participation was less both in higher and lower socioeconomic households compared to controls [20]. In a study done in Punjab, more than half the patients were from rural areas. The households had many members (average size: 6); most of them being dependent. Most of the participants were literate and the head of the households were self-employed. The mean annual income of the household was Rs. 442,262.44. The food expenditure was 47% and



nonfood expenditure was 53% of the total income. The mean per capita income was Rs. 78,924.33 [21].

## CONCLUSION

In conclusion, the main findings of this research was focused to find if psychological processes such as emotions, and cultural beliefs helped shape the attitude of the cancer patients in dealing with their disease and prognosis. It was found that sociocultural factors and patients' health related behaviors did play an important role in the patients' psychological well-being, and may be a cause for making the patients psychologically depressed.

## LIMITATIONS OF THE STUDY

This study has its limitations. It was conducted on a relatively small sample size. Most patients belonged to lower socioeconomic strata and had lesser number of years in terms of formal education, hence it cannot be said to be representative of all Indian women. Finally, we did not look into the possible protective factors against depression, and more specifically, coping strategy in cancer patients. We hope to address these issues in future studies.

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## CONFLICT OF INTEREST STATEMENT

There is no known conflict of interest for any of the authors associated with this paper.

## CLINICAL IMPLICATION

Diagnosis with breast cancer and their family members should be more aware of the fact that the patient should be physically and psychologically supported, that patients should be provided with domiciliary care, and that they should be encouraged to participate in the social support groups.

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