

# Psycho-Social Impact of Breast Cancer on Patients, The Role of Family Behavior in Coping and Rehabilitation.

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## Abstract

*The research is based on the qualitative and quantitative study of women who are suffering/diagnosed with breast cancer. Sampling was done from one Private Hospital and one Government Hospital in Pune. It is a study that reveals the psychological and social impact on their health, behavior, treatment and rehabilitation. It describes and discusses the common emotional problems, treatment patterns and their coping mechanisms to combat the disease. Factors such as diagnosis, treatment, awareness of self and the role of family and support groups are outlined. Appendices include literature on the risk factors, awareness of early signs of breast cancer, factors in delay of treatment and the various patterns of rehabilitation.*

**Keywords:** *Psychosocial Impact, Coping, Health-seeking behavior, Breast cancer, Treatment, Awareness, Stigma, Support Groups.*

## Introduction

Breast cancer is one of the rising causes of mortality among women all over the world. In India there has been a marked increase in incidences of breast cancer in the last decade. Prevalence of breast cancer is highest in the metropolitan cities in India. Breast cancer is the second leading cause of cancer-related deaths (after lung cancer) and is the most common cancer among women, excluding non-melanoma skin cancers. According to the World Health Organization, more than 1.2 million people will be diagnosed with breast cancer this year, worldwide. Breast cancer is the second most prevalent cancer among Indian women, the first being cervical cancer. One in fifty eight women are affected by breast cancer in the age group of 30-70 years; predominantly in urban areas. Breast cancer accounts for 20% of the total cancer-related diseases, and 75,000 new cases occur in Indian women every year (Delhi Breast Unit, 2000). Breast cancer imposes considerable psychological

stress and trauma on the patients. The initial diagnosis and preparation for surgery can induce a period of emotional turmoil during which rapid mood swings cause immense disruption to the woman's lifestyle. By contrast, the patient may be euphoric during the immediate post-operative period, possibly due to relief from uncertainty and anticipation of a return to normal life. This initial reaction, however, is transient, and many women experience a period of shock and denial, followed by anxiety, about 2-3 months after surgery. Most women eventually develop coping skills, enabling them to live a normal lifestyle. Women's responses to the fact that they have a life threatening disease and that they must cope with unpleasant treatments, vary enormously. For some, the diagnosis in itself is a major emotional catastrophe; for others it is simply another problem to face, alongside the many other social difficulties in their lives. Volunteer groups, composed of women who have had breast cancer themselves, self-help groups, and

national cancer charities, can also offer valuable help and advice to breast cancer patients and their families. The role of family in the patient's coping mechanism will be studied. Included in the arena of study is the relation of awareness about the disease and the attitudes of family members of the patients, with the treatment and rehabilitation of the patient. Over half of the drop in mortality in women under the age of 65 years seems to be attributed to early detection of tumors, which has been observed since the mid-1980s. This could be a result of an increase in breast cancer awareness, predating the start of the breast screening programmes (Stockton D., 1997).

### Review of Related Literature

It was concluded that the awareness regarding breast cancer was very high in the general population (Camilleri-Brennan J., 1999). From this study, the conclusion was made that evaluating the potential for program adoption offers insight for tailoring preventive health interventions and their implementation strategies to improve diffusion in the field of practice (Halverson P.K., 2000). Awareness was not related to satisfaction, emotional distress, or quality of life (Iconomou G., 2002 )

Women from the low coping cluster also preferred more active involvement in treatment decision-making (Hack T.F., 1999). Coping through emotional processing was related to one index of greater distress over time. Analyses including dispositional hope suggested that expressive coping may serve as a successful vehicle for goal pursuit (Stanton AL, 2000). The findings support the view that changes of both benefit and harm are present in the experience of breast cancer (Arman M., 2001) Cognitive appraisal, coping strategies, and levels of emotional distress should be considered in designing programs for enhancing adherence to early detection procedures (Cohen M., 2002).

Study conclusions suggest that it is important

to intervene for traumatic stress symptoms soon after the diagnosis of breast cancer. Furthermore, women at greatest risk are those who are younger, those who receive post-surgical cancer treatment, those who are low in emotional self-efficacy, and whose lives are most affected by having cancer (Koopman C., 2002). The correlation of coping mechanisms at the beginning of radiotherapy with low quality of life and high psychosocial stress at 2 years could help to identify patients at risk for low psychosocial adaptation (Sehlen S., 2003).

Under the conditions of cancer diagnosis, patients do not tend to assign responsibility to themselves possibly due to a need to avoid guilt, low self-esteem, and social distance (Anagnostopoulos F., 2004).

Patients should be offered the opportunity to attend support groups, as they provide additional and necessary assistance; especially in the areas of new information on cancer and coping with its psychosocial sequel (B.S, 1993).

Breast cancer and its treatment may cause ongoing sadness, fear, anxiety, and anger. Primary care physicians, because of their close relationship with patients, are often in a position to notice when natural and reasonable emotional reactions go to an extreme. Sensitive support and education of patients who are trying to choose a treatment method may minimize anxiety (Williams T.R., 1995).

Social support may shield women with metastatic breast cancer from the effects of previous life stress on their emotional adjustment. Also, pain is greater among women with greater life stress, regardless of social support (Koopman C., 1998).

The main reasons listed for women participation in psychosocial support were mental distress, a desire to obtain help, and the wish to cope with the illness. The main reason for not participating was

insufficient support from family, friends or doctors (Plass A., 2001).

The findings of this prospective study suggest that participation in cancer support groups could have a long-term effect in reducing anxiety and depression in breast cancer survivors (Montazeri A, 2001).

Although strong evidence suggests that coping and psychosocial intervention can improve psychological outcomes for breast cancer patients, potential effects on physiological outcomes remain speculative (Luecken L.J., 2002).

Relationships between anxiety, social support, coping, and defence, in connection to mental health, were studied among patients with suspected breast cancer, awaiting diagnosis. The results showed that patients reported elevated levels of anxiety and required high levels of social support. Social provisions were somewhat related to 'instrumental coping', but sparsely related to 'emotion-focused coping'. Hence, social support and 'emotion-focused coping' did not in themselves repress anxiety. 'Instrumental coping' did; even in a situation where nothing could be done. Social support is suggested to be the product of an 'instrumental coping style', not necessarily contributing to it (Drageset S., 2003).

A review of literature was done on the relationship between stress and the development of breast cancer, which investigates the immune system as a possible mediator. Personality traits, response to stress, and stressful life events are considered.

Although the difficulty of measuring stress makes it difficult to demonstrate a tangible relationship between stress and breast cancer development, studies reveal that stress is related to breast cancer in various ways. Dealing positively with stress may improve the quality of life of patients with breast cancer (Bryla C.M., 1996).

A study was done to find out the relation between cancer and depression. Half of all cancer patients have a psychiatric disorder, usually an adjustment disorder, with depression. Anxiety about illness, such as cancer, often leads to delay in diagnosis, which has been estimated to reduce prospects of long-term cancer survival by 10-20%. Effective psychotherapeutic treatment for depression has been found to affect the course of cancer. Psychotherapy for medically ill patients results in reduced anxiety and depression, and often pain reduction. In three randomized studies, psychotherapy resulted in longer survival time for patients with breast cancer (18 months), lymphoma, and malignant melanoma. Thus, effective treatment of depression in cancer patients results in better patient adjustment, reduced symptoms, reduced cost of care, and may influence the course of the disease. The treatment of depression in these patients may be considered a part of medical as well as psychiatric treatment (Spiegel D., 1996). A pilot study was conducted on depression and anxiety symptoms in women at high risk for breast cancer. The objective was to study the effects of group intervention in high-risk relatives of breast cancer patients. Results showed that there was a significant reduction of depression symptoms as reported on the Center for Epidemiologic Studies Depression Scale. Similarly, there was a significant reduction of anxiety symptoms as reported on the State-Trait Anxiety Inventory state scale. They concluded that the group intervention model was effective at reducing symptoms of depression and reactive (not chronic) anxiety (Wellisch, D.K., 1999).

A qualitative met synthesis was done on the hidden suffering amongst breast cancer patients. The aim of this study was to review literature on how the lived experience of breast cancer and suffering was described, and to interpret and discuss the result from the perspective of suffering. When findings were interpreted from the perspective of suffering and an ontological health model; actions, values, and existential concerns were understood as both

expedients for alleviating suffering and a sign of the patient's inner struggle (Arman, M. 2003).

On the whole, cancer patients with children experience lower mortality than the childless, though without a special advantage associated with adult children. This suggests a social effect, perhaps operating through a link between parenthood, lifestyle and general health. Women who had never married did not have the same disadvantage (Kravdal, 2003 ), so they suggested that preventive care and medical services should therefore be directed to in public and financially disabled classes of patients. ( De Cuyper L et al, 2003,Nov-Dec). They concluded that , the lack of differences in certain psychosocial aspects may indicate a generally good adjustment in the TM(Total masectomy) patients after their surgery. Psychosocial disruption in the patients' families is reflected in the study where patients' husbands in the TM group were significantly more disturbed. (Yeo, W. 2004 Feb)

### Methodology

The study was conducted in two hospitals in Pune city.

- A Private Hospital (under the Apollo Group of Hospitals).
- A Public Hospital (Public General Hospital).

These hospitals were chosen due to the fact that they have a higher number of breast cancer patients. On an average, there are 5-6 patients per day in the Out Patient department and Day Care Units combined. Efforts were made to compare the difference between private and government hospital set ups.

**Sample Size-** The sample size for the study was 30.

Out of 30:

20 patients were interviewed from the Private Hospital.

10 patients were interviewed from the Public Hospital.

### Inclusion criteria:

All the women were diagnosed with breast cancer and undergoing treatment in both hospitals between 16th November 2014 and 30th December 2014. The sample also included recurrent cancer cases and follow-up cases. The main instrument used for data collection was informal patient interviews. These patients came to the hospital for their chemotherapy sessions. The interview was carried out on the basis of a pre-formulated questionnaire. The interview was a semi-structured one which comprised of both quantitative and qualitative questions. At first, an informal visit to the hospital was made. The persons concerned, e.g. the Head of the Oncology Department, the Medical Director of the hospital and the Head of the Mammography Clinic were met with and were informed about the research objective. They were asked about the official procedure of approaching the patients in order to carry out interviews with them.

Permission from all concerned authorities was taken to carry out the different procedures i.e. of interviewing the patients, and gathering technical information from the doctors, nurses and other administrative officials. This was done with the help of an official letter from the School of Health Sciences. In this way, a good rapport was created in the hospitals. Initial contact with the patients was made through the nurses in the OPD and Day Care Unit. They introduced the patients to the researcher. After getting introduced the patients and their accompanying relatives were told about the objective of the research. They were assured that the information received from them would only be used for academic purposes and for further research. While asking some personal questions, assurance regarding confidentiality was given to the patients. Language was not a problem, as all the patients understood Hindi and Marathi.



## Results

The following table shows the different reactions of patients after getting diagnosed with breast cancer.

Hospital	Fear of the death/cancer	Worried about children	Confused/ No Reaction	Accepted	Unaware of their cancer
Private	12 (60%)	2 (10%)	2 (10%)	2 (10%)	2 (10%)
Public	6 (30%)	0	3 (30%)	1 (10%)	

Reactions varied among the 40 women who were diagnosed with breast cancer. 60% were traumatized and shocked due to having a fear of death, 10% were more concerned about their children and their future (these were the young women who had small children), 10% were quite confused as they were not aware about cancer so they were in a passive stage, and 10% of the patients took the illness as an event which was destined for them, and thought that “thinking about the disease in a negative way won’t cure the illness”. They had a strong belief that they would be cured of the disease very soon and would be able to lead a normal life. 10% of the patients did not know that they were suffering from cancer.

## Uncertainties faced by the patients after being diagnosed with Breast Cancer

There were different types of uncertainties faced by the different patients. The following table gives an account of them:

Worried about children	Fear of reoccurrence	Fear of Operation	NO uncertainties	Other
2 (10%)	2 (10%)	2 (10%)	10 (50%)	4 (20%)
Nil	Nil	Nil	6 (60%)	4 (40%)

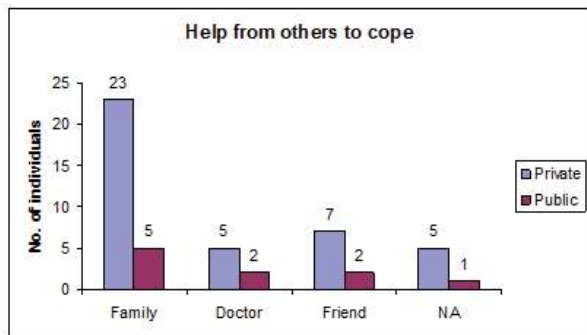
Among the 20 women interviewed in the Private Hospital, 50% of the women were very positive about life and did not have any future uncertainties, 20% did not know that they were suffering from cancer, and also some of them were cured, but they were the follow-up cases. 10% of the women were worried about their children, 10% were fearful of recurrence of the cancer in the same or the other breast, and 10% feared the operation (mastectomy).

Among the patients interviewed in the Public hospital, 60% of them were very positive about life and did not have any future uncertainties, and 40% were uncertain regarding the duration of treatment and wanted it to finish soon.

The following graph shows the help received by patients from different sources, enabling them to cope:





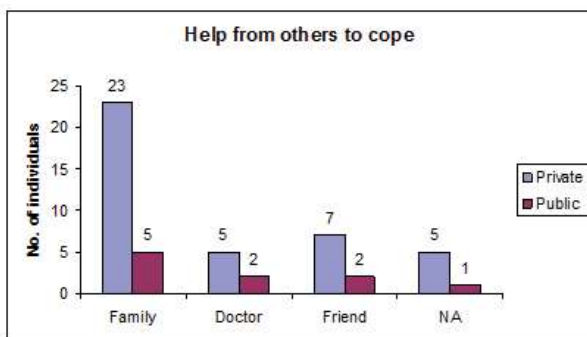


Among the 20 women interviewed in the Private hospital, 55% could cope with their illness due to the support of their family members, 10% could cope with their illness due to the support of their respective doctors, 25% were helped by their friends and 10% did not know that they were suffering from cancer.

Among the 10 patients interviewed in the Public Hospital, 50% could cope with their illness due to the support of their family members, 20% could cope with their illness due to the support of their respective doctors, 20% were helped by their friends and 10% did not know that they were suffering from cancer.

In both the samples, it was observed that family plays a major role in supporting the patients and helping them cope.

The following graph shows the influence of different sources of support on the patients:

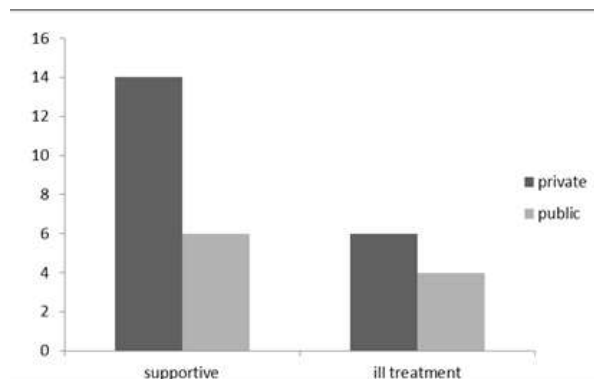


NB-These are the individuals who were unaware that they had cancer.

Among the 20 women interviewed in the Private hospital, 35% of the women were very confident that they would get cured very soon and would be able to lead a normal life. 25% held that their doctors were responsible for boosting their morale and helping them cope. 25% said that due to their family members' support, they could cope. 15% were still in doubt and were very uncertain about their futures.

Among the 10 women interviewed in the Public hospital, 20% of the women were very confident that they would get cured soon and be able to lead a normal life. 40% said that due to their family members support they could cope. 20% were still in doubt and uncertain about their future.

#### Impact of family behaviour on coping:



Out of the 20 patients in the private hospital, the graph depicts that 14 (70%) had a supportive family which helped in coping while 6 (30%) were not treated well by the family and in-laws, so the coping process had either not started or had been delayed.

In the Public hospital, out of 10 patients, only 6 (60%) had supportive families while 4 (40%) were not treated well and were neglected by their family members.

Workload given to the women by the family members after detection of the disease:

Hospital	Less Work	No Change
Private	13 (65%)	7 (35%)
Public	5 (50%)	4 (40%)

Most of the women received proper care and attention from their family members and were not allowed to do any work after they were diagnosed with cancer.

In one case, the woman was ill-treated by her parents-in-law after getting diagnosed with breast cancer. Some women were perceived as burdens by their family members; this made them more pessimistic and they wanted to die soon. A sense of guilt also gripped many women; they thought that they were wasting the hard-earned money of their children.

#### Impact of attitude of family members towards the disease on promptness of treatment:

From the above graph, it can be deduced that out of 20 patients in the private hospital, 12 (60%) received immediate treatment due to supportive family members who also took the course of treatment seriously. They also were aware that cancer can be cured completely if detected and treated promptly. 2 (10%) patients received late treatment due to either financial problems, or a lack of seriousness from the family members. 6 (30%) of the patients' families were absolutely ignorant about the disease and the course of treatment; hence they were delayed in receiving medical help. In the Public hospital, immediate treatment was received by 6 (60%) of the patients while there was a delay in the treatment of 2 (20%) patients, who were neglected for quite some time before they were brought to the hospital.

#### Changes in social interactions of the patient after getting diagnosed with breast cancer

The following table shows the differences in the social behavior of the patient after being diagnosed:

Among the 20 patients interviewed in the Private hospital, 45% had lesser interaction with friends and neighbors. 5% had increased interaction with their friends, as their friends came to meet them more regularly. For 42.5% of the women, there was no change in their social interaction patterns.

Among the 10 patients interviewed in the Public hospital, 50% of the women interacted less with their neighbours and friends, and for the other 50% there was increased interaction with friends.

This shows that the majority of the patients from the Private Hospital remained isolated and had less social interaction, as compared to the patients from the Public Hospital who received support from their friends; relating to their ability to cope as well.

#### Impact of breast cancer on the professional life of the women

The following table shows the changes faced by patients of the Private Hospital after getting

Hospital	Less Interaction	More Interaction with friends	No Change
Private	9 (45%)	2 (5%)	9 (45%)
Public	5 (50%)	5 (50%)	Nil

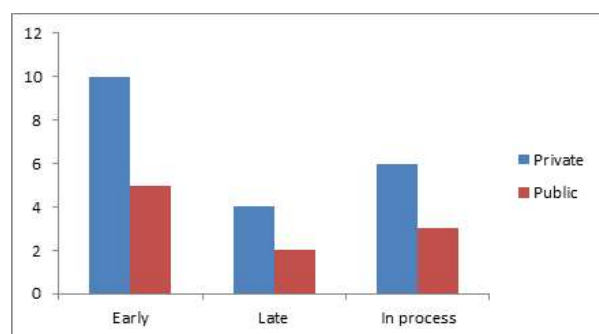
diagnosed with breast cancer:

Left Job	Take more leave	No change
1	2	4

NB - All the women interviewed in the Public Hospital were unemployed.

In the Private hospital, it can be seen from the above table that among the 20 women interviewed, 7 were working women and amongst them 1 had to leave her job as she was unable to attend, due to physical weakness. 2 had to take more leaves to attend their treatment sessions like chemotherapy and radiation. 4 of the women did not take their disease as obstacles, and continued to be regular at their workplaces.

#### Impact of acceptance of the disease on rehabilitation



Out of 20 patients in the Private hospital, 10 (50%) had early rehabilitation while 4 (20%) took some time to accept the fact that they were suffering from cancer and hence there was a delay in rehabilitation, though eventually they came to terms with the disease. 6 (30%) patients were under the process of getting rehabilitated.

#### Discussion

The objective was to do a qualitative study on the psycho-social impact of breast cancer on patients and to explore the health-seeking behaviour of breast cancer patients. The study explained the different types of psychosocial impact of breast cancer on the patients and their families. Aspects such as the coping mechanisms for mental trauma, social isolation, the role of family members and society in aiding coping, treatment, and rehabilitation are also explored. Focus was also given to the impact of the disease on the professional and social lives

of patients.

#### Psychosocial Impacts of Breast Cancer

Breast cancer has many sociological impacts on the patient. It brings a lot of changes in the patient's family life, her social life and her professional life. Different members of the family had differing attitudes towards the patient. In the Private hospital, most of the patients (70%) had a supportive family environment which helped them in coping, while others were not treated well by their family members. The latter seemed to be quite disturbed and said that their family members wanted them to die so that they would not have to spend heavily on their treatment. Some of them who were young were also told by their parents-in-law that they would like their son to be remarried, and therefore would not take any financial responsibility for their treatment.

#### Social life

There were different types of changes in the social life of the patients. Most of them (45%) had lesser interaction with the friends and neighbours. Among them, a few were so depressed and anxious about the disease, that they could not talk to anyone and wanted to stay alone and isolated. For few, the reason for less interaction with friends was because they were ashamed to appear before their friends, due to developing alopecia as a side effect of chemotherapy. They preferred staying at home, but liked to interact if any of their friends came to meet them. 45% of the patients felt that there was no change in their social life and the interaction level was the same as it used to be before the disease occurred. These were generally the working ladies who perceived the disease as a "part of life" and not as disease. Some of the ladies had a positive frame of mind and did not consider the disease as a hurdle in their life.

In the Public hospital sample, it was observed that for 50% of the patients, there was lesser interaction



with the society, and for the rest there had been an increase in their interactions, as more people came to meet them.

### Professional life

Among the working women, many faced some changes in their professional lives. Very few of the patients had to leave their jobs; being unable to take the strain of handling their job as well as home. Moreover, the treatment schedule was so long and it produced so many side-effects that it was difficult for them to continue with their jobs. For a few of the patients the significant change was that they had to take more leaves from their duties. They mentioned that their colleagues were considerate and were more co-operative after knowing about their illness. Most of the women said that they did not face any changes in their professional life, and would never allow the disease to interfere with their daily routine.

### Rehabilitation

It is evident from the results that most of the patients have been able to cope well and get rehabilitated, while few were under shock and it took some time for them to accept that they were suffering from a terminal illness. Amongst the ones who are in the process of rehabilitation, there are a few who are panicked about the whole situation, and some have gone into depression. They are anxious about the future of their children and families.

### Summary and Conclusion

In this study the different psychological and sociological impacts of breast cancer was studied. It was observed from the study that more than the pathological severity of the disease, it was the psychological setbacks which gripped the patients and reduced their quality of life. The access to health care was also studied in this context.

This study covered all aspects including the trauma or depression that patients went through

after their final diagnosis. It also explored the different mechanisms that patients adopted in order to cope, and how different people helped in coping with the ensuing trauma and anxiety. Cancer in one family member upsets all the members in a family and they also suffer from some form of depression and anxiety as an element of uncertainty grips the whole family. Along with family, there is a change in societal perspective towards the patient. One of the major changes in the lifestyles of the working women was that they had to leave their jobs due to long treatment schedules. This led to social isolation of some, which had a psychological setback on them.

Overall, the study revealed the attitudes, perceptions and the approaches of the patient towards the disease, the changing relationship with family due to the disease, and the communication between the patient and others, like health care professionals and family members.

The findings of the study can be summarized in the following points:

- No correlation was observed between the general education level, working status of women and awareness regarding cancer.
- Awareness and responses of family members, plays a role in early diagnosis and treatment.
- Counseling from the other patients (who are cured or whose treatment is ongoing) helped to build confidence in the newly diagnosed patients.
- Counseling of health care professionals like doctors and nurses played a major role in the coping process of patients.
- There is a direct correlation between the behaviour of family members in the coping and rehabilitation of patients.
- Apart from the above findings, some observations were made which aided in the early detection and diagnosis of the patients and also improved the coping strategies

- adopted by the patients; they are as follows:
- Different Support Groups were formed by the breast cancer patients themselves to help counsel the newly diagnosed patients. This plays a vital role in helping patients cope faster and think positively.
- The study of psycho-social impacts of breast cancer on the patient, their family and society has brought out some hidden lacunae. It has helped to highlight aspects related to the coping mechanisms of the patient, the support they get from different sources and their future uncertainties while they are suffering from the disease. It has also elucidated the impact of the behaviour of family members on treatment, coping and rehabilitation.

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