Psychosocial impact at diagnosis and coping strategies among women with breast cancer-A qualitative study

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Keywords: Breast carcinoma, In-depth interview, Phenomenology, Social adaptation

ABSTRACT

Background: Breast cancer diagnosis can be devastating and challenging for most women. After the initial shock, they adhere towards adopting multiple strategies that enable them to cope with the situation which directly impacts their day-to-day life. This study seeks to understand the psychological and social impact of diagnosis as well as the coping strategies taken up by these women.

Methods: The study uses a phenomenological approach to examine the lives of newly diagnosed women. Semi-structured interviews were conducted with 12 diagnosed women. These interviews were recorded for clarity as well as future reference. Audio recordings were transcribed verbatim in the local languages and then translated into English. Data was analysed according to steps described in Interpretative Phenomenological Analysis. MAXQDA software was used for coding.

Results: Three prominent themes and eight subthemes emerged after data analysis. Stress and uncertainty, financial distress, family distress, and social withdrawal were the initial psychological effects at diagnosis. Family support and religious belief were the main coping strategies identified. Being unaware of signs and symptoms and misdiagnosis were the reasons behind delay in diagnosis.

Conclusion: Breast cancer diagnosis impacts the patient’s psychological, social, and financial well-being. This consequently burdens not only the patient, but their immediate family as well. This necessitates women to develop different strategies to cope with the situation. Understanding the intricacies of initial breast cancer diagnosis from the perspective of a patient may aid medical professionals in providing holistic cancer therapy.

1. Introduction

Globally, the leading cause of cancer mortality in women is breast cancer. At present, India is faced with a rise in breast cancer cases which pose a great risk to women’s health.

Each breast cancer diagnosis reveals an account of an existential or life crisis that necessitates a great amount of resilience and directly impacts the patient psychologically. The diagnosis causes psychological distress in almost every patient and involves emotions like doubt, disbelief, hopelessness, anger, fear, worry, and grief. Women must assume a new persona as cancer patients, in addition to dealing with psychological and financial challenges. This sudden transition has an impact on their families and their daily lives.

Social and sociocultural factors may have an impact on breast cancer patient’s experience. According to a recent qualitative study on breast cancer patients, Indian women experience emotional breakdowns because of social expectations of their responsibilities as spouses, mothers, and caregivers. Evidence shows that each patient responds differently to their diagnosis and that these emotions have an impact on how well they cope and their adherence to treatment.

It is important to comprehend the patient’s experiences at the time of diagnosis, including their thoughts, feelings, emotions, anxieties, and concerns. There is a dearth of qualitative research explicitly geared at capturing the perspectives and personal experiences of Indian women who have newly received a breast cancer diagnosis. Therefore, the study aims to explore the psychosocial impact of breast cancer diagnosis on women in North Karnataka and the coping strategies adopted by them.

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2. Methods

2.1. Study design

This study is a detailed investigation of the phenomenon experienced by women diagnosed with breast cancer. As the nature of the study is exploratory, a qualitative methodology using in-depth semi-structured interviews was considered ideal.  

2.2. Sampling

For a better understanding of phenomena being examined, purposeful sampling was employed in this study. Purposeful sampling helps the researcher to select sources of information that would help answer the research objectives. Participants were selected with wide range of demographic and clinical variables, including age, education level, residence location, and stage of breast cancer.  

2.3. Inclusion criteria

Women diagnosed with breast cancer and undergoing treatment, along with consent to participate, were included in the study.

2.4. Sample size

The sample size required for this study was not predefined. Data was collected until data saturation occurred. In the present study, data saturation was ascertained by the end of 10th interview. Data collection was concluded after 12 interviews.

2.5. Ethical considerations

An information sheet was given to each participant regarding the study and its purpose was briefly explained. The participation was voluntary and written consent was given by each participant on a consent form. This also included their consent for the publication of study findings. Privacy of participants and strict confidentiality of the information collected was assured. The ethical clearance was granted by Institutional Ethics Committee (IEC), (KAHER/EC/20–21/001/2).

2.6. Data collection procedure

Files containing details of women who had completed treatment from KLES Belgaum Cancer Hospital were retrieved from the medical records department and they were contacted by telephone call. Women who met the inclusion criteria and accepted to take part in the study were interviewed in a separate room without the presence of their family and friends. All interviews were performed by the researcher along with a note keeper. Participants preferred to talk in the local language, which made it easier for them to describe their experiences.

An interview guide based on the QoL Patient Survivor Version and the gaps identified in cancer literature was developed and used to explore and probe the issues related to study objectives. Pilot interviews were carried out to pre-test the interview guide to ensure it was useful in eliciting the required responses. The body language of the participants and nonverbal cues were noted by the note-keeper during the interviews. The researcher explained the questions as needed throughout the interview and probed further to attain in-depth knowledge of what they experienced. Each interview took approximately 30–60 min. To facilitate precise information collection and convenience, e-recorders were used.

After the interviews were conducted, all the tapes were transcribed verbatim in the local languages. They were then written in English and translated back into the original language for quality control.

2.6.1. Data analysis

Data was analysed according to steps described in Interpretative Phenomenological Approach. Both deductive and inductive approaches were applied for analysis. Interview transcripts were thoroughly read multiple times, in order to familiarise with the breast cancer experience of each patient. Data was coded according to predetermined concepts from theory and literature. Significant reactions, comments, phrases, or quotations from the transcripts were sorted into these codes using MAXQDA software.

To find themes, codes were segregated into groups showing similar patterns to form clusters. The main and supporting themes were distinguished and categorised. The transcripts were examined again to look for any new themes. Selected quotations that demonstrated themes indicative of certain findings were used to create summary tables. Thorough analysis was done by focusing on each theme, in order to examine its contribution towards understanding the study phenomenon.

3. Results

Twenty women agreed to participate in the study and a point of data saturation was reached after conducting 10 interviews. Two more interviews were conducted to further check for any new information and this brought the total interview number to 12. The sociodemographic information of participants is given in Table 1.

After data analysis, three main themes and eight subthemes emerged. The first main theme Delay in diagnosis, describes the self-reported reasons for delay under two subthemes along with verbatim quotes in Table 2. The second theme Psychosocial effects reveals the impact of breast cancer diagnosis on women and their families which is compiled under four subthemes in Table 3. The last theme Coping with cancer diagnosis, explores the different coping strategies embraced by women to overcome multiple personal and social challenges post-diagnosis. Verbatim quotes related to this theme and its subthemes are given in Table 4.

4. Theme 1: delay in diagnosis

4.1. Ignorant of warning signs and symptoms

The most common symptom reported by the participants was a lump in their breast. They either didn’t experience any pain or discomfort, or the lump was very small. A few of them even turned a blind eye assuming the lump for a blocked milk duct. Such underlying factors led to the lump being overlooked until it increased in size or began to cause discomfort.

Nipple retraction was observed by one participant and her prompt decision to get a doctor’s consultation led to the detection of breast cancer at an initial stage. This health-seeking behaviour ultimately saved her life.

On another account, social media was responsible for influencing a contestant on television disclose that it was her delay in receiving a diagnosis of her lump in the breast that ultimately led to breast cancer.

4.2. Misdiagnosis

Most of the participants approached their preferred physicians or their nearby clinic for consultation on the lump in their breast.

In one case, the participant had lipomas all over the body including...
being only a lipoma. Consulted her family doctor a few times and was assured about her lump - her left breast. Before receiving a breast cancer diagnosis, she had psychosocial effects of cancer diagnosis, Subthemes and Verbatim Quotes. Table 3
Sociodemographic profile of study participants. (N = 12).

<table>
<thead>
<tr>
<th>Participants</th>
<th>Age</th>
<th>Religion</th>
<th>Marital Status</th>
<th>Education</th>
<th>Occupation</th>
<th>Cancer stage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Participant 1.</td>
<td>43</td>
<td>Hindu</td>
<td>Separated</td>
<td>High school</td>
<td>Housewife</td>
<td>Stage III</td>
</tr>
<tr>
<td>Participant 2.</td>
<td>47</td>
<td>Hindu</td>
<td>Married</td>
<td>High school</td>
<td>Housewife</td>
<td>Stage II</td>
</tr>
<tr>
<td>Participant 3.</td>
<td>34</td>
<td>Hindu</td>
<td>Married</td>
<td>Graduate</td>
<td>Accountant</td>
<td>Stage II</td>
</tr>
<tr>
<td>Participant 4.</td>
<td>52</td>
<td>Muslim</td>
<td>Married</td>
<td>Primary</td>
<td>Housewife</td>
<td>Stage II</td>
</tr>
<tr>
<td>Participant 5.</td>
<td>46</td>
<td>Muslim</td>
<td>Separated</td>
<td>High school</td>
<td>Housewife</td>
<td>Stage III</td>
</tr>
<tr>
<td>Participant 6.</td>
<td>50</td>
<td>Hindu</td>
<td>Married</td>
<td>Graduate</td>
<td>Bank employee</td>
<td>Stage II</td>
</tr>
<tr>
<td>Participant 7.</td>
<td>45</td>
<td>Hindu</td>
<td>Married</td>
<td>High school</td>
<td>Housewife</td>
<td>Stage III</td>
</tr>
<tr>
<td>Participant 8.</td>
<td>50</td>
<td>Hindu</td>
<td>Married</td>
<td>Graduate</td>
<td>Housewife</td>
<td>Stage I</td>
</tr>
<tr>
<td>Participant 9.</td>
<td>49</td>
<td>Muslim</td>
<td>Married</td>
<td>High school</td>
<td>Housewife</td>
<td>Stage III</td>
</tr>
<tr>
<td>Participant 10.</td>
<td>45</td>
<td>Hindu</td>
<td>Married</td>
<td>Illiterate</td>
<td>Housewife</td>
<td>Stage III</td>
</tr>
<tr>
<td>Participant 11.</td>
<td>49</td>
<td>Muslim</td>
<td>Married</td>
<td>High school</td>
<td>Housewife</td>
<td>Stage II</td>
</tr>
<tr>
<td>Participant 12.</td>
<td>62</td>
<td>Muslim</td>
<td>Widow</td>
<td>Primary</td>
<td>Housewife</td>
<td>Stage III</td>
</tr>
</tbody>
</table>

Table 2
Delay in diagnosis, Subthemes, and Verbatim Quotes.

<table>
<thead>
<tr>
<th>Theme 1: Delay in diagnosis</th>
<th>Subthemes</th>
<th>Verbatim quotes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Unaware of warning signs and symptoms</td>
<td>I felt a lump when I touched my breast. There was no pain or discomfort. I thought I had this lump for 4 to 5 months... it was very small. Then after 4-5 months, it grew in size like a marble. (Participant 4)</td>
<td></td>
</tr>
<tr>
<td>Misdiagnosis</td>
<td>This lump was in my breast for 4 to 5 years... it was very small so I didn't bother about it. Everyone used to say see these lumps are normal... these are milk lumps so I did not bother much about it. (Participant 5)</td>
<td></td>
</tr>
</tbody>
</table>

Participant 12. 62 Muslim Widow Primary Housewife Stage III
Participant 9. 49 Muslim Married High school Housewife Stage III
Participant 8. 50 Hindu Married Graduate Housewife Stage I
Participant 7. 45 Hindu Married High school Housewife Stage II
Participant 6. 50 Hindu Married Graduate Bank employee Stage II
Participant 5. 46 Muslim Separated High school Housewife Stage III
Participant 4. 47 Hindu Married High school Housewife Stage II

Table 3
Psychosocial effects of cancer diagnosis, Subthemes and Verbatim Quotes.

<table>
<thead>
<tr>
<th>Theme 2: Psychosocial effects of cancer diagnosis</th>
<th>Subthemes</th>
<th>Verbatim Quotes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Stress and uncertainty</td>
<td>Actually, I was shocked. I could not express anything there in front of the doctor. I was very sad. I cried a lot... I could not accept it. (Participant 8)</td>
<td></td>
</tr>
<tr>
<td>Family distress</td>
<td>We all cried and cried... everyone at home. (Participant 1)</td>
<td></td>
</tr>
<tr>
<td>Financial distress</td>
<td>No... we did not have any money... not even a rupee... I was very much worried about it. At that time, I was not thinking about my cancer... I had no idea how I will arrange the money for tests. How will I be able to spend so much. From where will I get the money... I used to think (Participant 4)</td>
<td></td>
</tr>
</tbody>
</table>

Similarly, two patients were diagnosed with lump in their breast as fibroadenoma without undergoing a biopsy. The first patient did not approach her doctor for a period of 4 months after the initial diagnosis as she believed her diagnosis was not very serious. The lump in her breast slowly increased in size and eventually cancer had spread to her lymph nodes by the time she sought a follow-up. The second patient underwent herbal treatment for her fibroadenoma for a period of 6 months, before receiving a confirmation of breast cancer.

5. Theme 2: Psychosocial effects

5.1. Stress and uncertainty

Almost all the participants were terrified after receiving a preliminary cancer diagnosis. What started with anger and frustration ended with depression and denial. Some of the participants were unable to hold their tears as they were uncertain about their future. While older participants were anxious about their daughters getting married, younger participants worried about their children’s education and keeping their homes together.

A participant was furious to receive the diagnosis of breast cancer as she believed her diagnosis was not very serious. The lump in her breast slowly increased in size and eventually cancer had spread to her lymph nodes by the time she sought a follow-up. The second patient underwent herbal treatment for her fibroadenoma for a period of 6 months, before receiving a confirmation of breast cancer.
5.2. Financial distress

The majority of participants in the present study were from lower socioeconomic classes. The family experienced financial hardship as a result of expensive testing and investigations required for diagnosis. Most of them received assistance from family and friends in this predicament. Two participants were more concerned about the costs than the illness itself.

5.3. Family distress

The news of breast cancer diagnosis was distressing for the family as well. They too experienced the agony of first shock and the anxiety of possibly losing their loved one. Distraught was brought to a majority of the family members. Two participants reported their children bursting into tears whenever they saw their mother weep. Another two participants had to battle their emotions and put on a brave face for the well-being of their ageing mothers.

5.4. Social withdrawal following diagnosis

Some participants stated that it hurt their feelings when others looked at them sympathetically. Due to this, they were unable to communicate with or socialize with extended family and friends. One participant observed how people who previously weren’t on good terms with her, had now started to show concern after the diagnosis. A few participants chose not to disclose the diagnosis to their relatives, fearing the added expense and housework associated with their visit.

6. Theme 3: Coping with cancer diagnosis

6.1. Family support

Family support was crucial in assisting participants to accept their situation and maintain emotional stability, following the initial shock of the diagnosis. Most participants relied on their husbands, sisters, and mothers for support. In addition to providing emotional reassurance, they further assisted the participants with housework and medical appointments.

6.2. Religious belief

Some of the participants found it easier to cope with the diagnosis as they had faith in God and trusted him to take care of them. Their fears were reduced by the conviction that God was responsible for their illness and that it was his responsibility to heal them. One such devout participant initially felt betrayed to discover her breast cancer. Two participants reported developing a sense of resentment towards God after cancer diagnosis.

7. Discussion

The study was aimed at understanding the psychosocial effects of breast cancer diagnosis and coping strategies adopted by breast cancer patients to accept their situation and regain stability. Several key elements were identified from the analysis which may help to greater understanding of the plight of women facing a breast cancer diagnosis. Even with advancements in early breast cancer detection and treatment, women are generally distressed with the diagnosis of breast cancer as compared to any other medical diagnosis. Largely, the prevalent psychological markers observed in newly diagnosed women are depression and anxiety. Mixed emotional reactions were observed among the participants when they learned of their diagnosis. Post diagnosis, the initial reaction was shock, followed by fear, denial, and uncertainty. This caused the patients to experience hopelessness, suffering and guilt, as shown in a similar study.

There is strong evidence that supports that dealing with a breast cancer diagnosis of a close relative may act as a stressful experience for women, especially for those who have a history of cancer in their family. However, some other studies have concluded that the level of distress in women is not associated with a family history of breast cancer. The current study showed similar results, revealing that two participants responded differently depending on whether their family member had survived breast cancer or not.

Cancer diagnosis is increasingly responsible for catastrophic health expenditures in India. Expensive diagnostic tests and investigations that were essential to confirm the breast cancer diagnosis of the participants, placed financial hardship on their families. This had an impact on the participant’s mental health, leading to feelings of guilt and worry and thus increasing their chance of developing depression. These findings complement the results of previous studies that assessed how cancer patients dealt with the psychological strain of financial burden.

When a woman is diagnosed with breast cancer, it impacts her entire family. These women battle to maintain a positive attitude while going through a very difficult time and try to protect their family’s well-being, especially that of their children. Participating in our study reported a state of panic in the family due to the breast cancer diagnosis.

A cancer diagnosis may impose stigma on patients and their family members due to misconceptions about cancer in society. This may also have a consequence on how people seek out medical care. Participants in the study gave a variety of reasons for their social seclusion, such as being unable to react to questions from others, not comfortable with other’s pity, and wanting to share only with close family. Other studies have come to a similar conclusion that cancer patients are unable to convey their emotions to individuals other than their immediate family because of the stigma associated with the disease.

Coping is beneficial while dealing with distress from stressful emotions. Cancer diagnosis causes patients to experience despair and mental upheaval, which compels them to come up with new coping mechanisms. Family support and religious beliefs were the main coping mechanisms among the participants.

In Indian communities, the immediate family members form a close-knit family network and every difficult situation is addressed as a
personal matter, in accordance with previous studies on coping mecha-
nisms of breast cancer patients in India.9–12 Strong family support was
reported by almost all the respondents and their husbands were their
biggest support.

Faith and religion helped most of the participants to cope. Offering
prayer along with a staunch belief that God will heal them, helped
women to calm themselves and develop a positive outlook. Previous
studies in India reported the use of religious beliefs and practices as
coping mechanisms.9–10

Newly diagnosed breast cancer patients in India experience extensive
psychological as well as social impacts. The coping mechanisms used by
the patients to restore one’s stability and accept their new condition
were highlighted in this study. This study was successful in terms of
capturing some of the problems associated with breast cancer, including
lack of knowledge, fear, stigma from family and society, myths and
misconceptions, and negligence. Being able to comprehend breast can-
cer patient experiences, circumstances, and emotional responses from
the patient’s perspective may help health practitioners provide holistic
cancer treatment.

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Declaration of competing interest

None.

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