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Exploring Brief Illness Experiences Among Breast Cancer Survivors - A Qualitative Phenomenological Study

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Abstract

Background: Breast cancer is the most common cancer among women worldwide, with improved survival rates due to advancements in detection and treatment. Survivors, however, face ongoing physical, psychological, social, and financial challenges that significantly impact their quality of life. The role of nursing in supporting these survivors is crucial yet understudied in the Indian context.

Purpose: This study aimed to explore the illness experiences of breast cancer survivors to understand their challenges and coping mechanisms.

Materials and Methods: Qualitative phenomenological approach was employed, focusing on five breast cancer survivors from Rajiv Gandhi Government General Hospital, Chennai. Participants were purposively sampled and interviewed using unstructured interviews. Data were collected over four weeks and analysed using thematic content analysis in NVIVO, ensuring credibility through member checking, prolonged engagement, and triangulation.

Results: The study identified significant physical challenges, including pain, hair loss, and vomiting, alongside psychological impacts such as anxiety, fear, and hopelessness. Family and peer support were vital but varied in effectiveness. Participants emphasized the importance of holistic care addressing both physical and psychological needs.

Conclusion: Nurses play a pivotal role in addressing the complex challenges faced by breast cancer survivors. Specialised training, improved survivorship care plans, and multidisciplinary approaches are essential to enhance the quality of life for this vulnerable population.

Keywords: Breast Cancer Survivors, Nursing Care, Survivorship, Psychological Support, Qualitative Research

Introduction:

Breast cancer is the most common cancer in women around the world, and it is a significant public health problem. In 2022, 2.3 million women were diagnosed with cancer, which is 11.7% of all new cases of cancer in the world. Six hundred thousand women died from cancer in that year [1]. As of 2024, the National Breast Cancer Foundation reported that over 3.8 million women in the United States have survived invasive breast cancer. This is about 1 in 8 women who will be diagnosed with cancer in their lives. The five-year survival rate for breast cancer has now reached an average of 90% around the world due to better early detection, new treatment methods, and a better knowledge of how breast cancer works [2]. Survival rates vary depending on where you live and what stage of cancer have at detection [3]. These differences are especially noticeable in low- and middle-income countries.

The word "breast cancer survivor" refers to people who have been diagnosed with breast cancer and have finished their first treatment. This includes people still undergoing maintenance therapies [4]. This growing group of people faces a wide range of problems after treatment that significantly affect their quality of life. There are a lot of physical side effects, like chronic tiredness, pain, and lymphoedema. As many as 90% of survivors feel tired, and this can last for years after treatment. Another 30% to 40% of survivors experience chronic pain [5]. About 20% of survivors have lymphoedema after having underarm lymph nodes dissected, and 50–90% have peripheral neuropathy caused by chemotherapy [6,7]). As Das et al. (2020) indicated, cognitive dysfunction, also known as "chemo brain," affects about 15 to 25 per cent of patients and makes it hard for them to do daily tasks and do well at work [8]. These symptoms not only get in the way of daily life but also make it harder for survivors to get back into personal, social, and work roles.

The psychological burden of survivorship is equally significant. Depression and anxiety affect 20-30% of survivors, while the fear of cancer recurrence is a constant source of distress for many women [9]. Fifty to sixty per cent of women who have been through treatment say they have emotional problems because of body image issues and low self-esteem. Also, up to 10% of survivors have PTSD symptoms like flashbacks and increased anxiety [10]. Stressors in social life and finance often make the mental effects worse, saying that survivors often feel alone because their interactions have changed and their family and friends don't understand them well enough [11]. Reintegrating back into the workforce can be even harder for some people, who may face discrimination or not being able to get the help they need. Up to 75% of survivors are having trouble paying their bills because of the cost of treatment and losing their jobs [12]. Financial strain is also a big problem for about 30% of survivors.

Healthcare organisations often don't meet all of the needs of breast cancer survivors because they focus on short-term treatments and neglect long-term care. Khajoei et al. (2023) found that survivors need complete plans that include regular follow-ups, psychological support, rehabilitation, and managing their lifestyles to meet all of their complex needs [13]. Nurses are very important in closing this gap. As part of their job, they must speak up for survivors' needs, help healthcare teams communicate, and help survivors change from treatment to recovery.

Despite their central role, the potential of nurses in survivorship care remains underexplored and underutilised. Specialised training for nurses in survivorship care is critical to enhance their ability to address physical and psychological challenges. Also, there is a need to integrate multidisciplinary approaches into survivorship care to provide holistic support. Addressing these gaps requires changes in clinical practice and policy-level interventions to ensure better insurance coverage, workplace accommodations, and public health awareness campaigns about survivorship needs. This study aims to explore the illness experiences of breast cancer survivors, focusing on the physical, psychological and social challenges they face.

Materials and Methods:

This study used a qualitative approach, using a phenomenological design to explore the lived experiences of breast cancer survivors. It uncovers survivors' rich, in-depth narratives and provides a nuanced understanding of their physical, psychological, and social challenges. The principal researcher and other researchers were nursing professionals with expertise in oncology care and qualitative research methods.

The study was conducted at the Oncology Outpatient Department (OPD) of Rajiv Gandhi Government General Hospital, Chennai. The study lasted four weeks, ensuring adequate recruitment and data collection time. Non-probability purposive sampling was employed to recruit participants who met specific inclusion criteria. Breast cancer survivors were selected if they were over 18 years old, had undergone treatment for more than one year, and were fluent in Tamil or English. Participants with other major systemic diseases, those unwilling to participate, or those involved in different studies were excluded. Sampling continued until data saturation was reached, ensuring no new themes emerged from additional interviews.

Ethical approval was obtained from the Institutional Ethics Committee at Madras Medical College, Chennai (No. IEC-MMC/Approval/68042024). Written permissions were also secured from the Department of Oncology. Informed consent was obtained from all participants, ensuring they understood the study's purpose, procedures, and their rights, including the option to withdraw without consequences.

Data collection involved two components: sociodemographic questionnaires and unstructured interviews. The guide included five primary questions based on prior literature designed to elicit narratives about their diagnosis, treatment journey, perspective changes, relationships, and advice for newly diagnosed patients. Additional probing questions were used to clarify and deepen understanding. Based on participant preference, interviews were conducted in Tamil and lasted 40–45 minutes. Questions asked include “Can you describe your initial feelings and thoughts when you were first diagnosed with breast cancer?” “Can you walk me through your treatment journey, highlighting any particular experiences or moments that stand out to you?” “In what ways, if any, has your experience with breast cancer altered your perspective on health and wellness?” “Could you share how your relationship with the family, friends, and colleagues were affected during your illness and treatment?” “What message or advice would you give to someone who has recently been diagnosed with breast cancer?”. Audio recordings ensured accurate capture of responses, which were later transcribed verbatim.

Audio recordings were transcribed verbatim and anonymised to protect participant identities. Transcripts were managed using NVIVO software, facilitating data organisation, coding, and thematic analysis. Data integrity was ensured through member checking, where participants reviewed their transcripts for accuracy and peer debriefing, which validated the findings. Credibility was established through member checking and prolonged engagement with participants. Trustworthiness was reinforced through detailed documentation of methods and findings and triangulation, which integrated data from interviews, sociodemographic questionnaires, and expert consultations.

Results:

Participant’s Characteristics:

The study involves five participants aged between 32 and 52 years, living in both urban and rural areas. All are married and predominantly home makers, except one who holds a private job. Their educational backgrounds range from 5th standard to a Bachelor's degree. Most participants come from joint families, with two from nuclear families. All follow a non-vegetarian diet. They are either Hindu or Christian. The disease stages range from the 2nd to the 3rd stage, diagnosed between 1 and 5 years ago.

Themes and subthemes:

This qualitative study explored the lived experiences of breast cancer survivors, focusing on their physical, psychological, and social challenges, as well as the support systems that influenced their coping mechanisms. The findings were organised under three major themes and associated subthemes derived from thematic analysis of the interview data.

Theme 1: Initial Stage

The initial stage of breast cancer diagnosis and treatment was marked by significant physical and emotional turmoil. Participants highlighted the uncertainty surrounding diagnosis and the physical toll of treatments.

Subtheme 1.1: Body Pain

Body pain was a recurring challenge for participants, with leg, back, and chest pain being particularly distressing. Pain intensity varied between treatment cycles, adding unpredictability to their experience.

"Next, in the 5th chemo, there was no vomiting, but my legs were paining a lot, from my back to my leg. I couldn't sit or lie down in bed, I could not sleep for 2 days... this was in the 2nd cycle." – Participant 1

"When I was given the first medicine, I had leg pain and back pain. I suffered a lot, it was so painful to endure, I even thought about whether I should still fight this or give up. In the 2nd round of medicine, the pain was not as bad." – Participant 3

Subtheme 1.2: Hair Fall

Hair loss, a common side effect of chemotherapy, carried substantial emotional weight. Some participants chose to shave their heads to regain a sense of control.

"From the 2nd chemo, hair was starting to fall, so I shaved my head." – Participant 1

"Even now, I have hair fall problems. My hair is coming out like threads. Without much pulling, it came off, so I shaved my head twice. Now it is better." – Participant 2

Subtheme 1.3: Vomiting

Nausea and vomiting severely impacted participants' nutritional intake and quality of life. These symptoms often made treatment adherence more difficult.

"When we started chemo 2 weeks after the surgery, more vomiting, I couldn't eat and all. At that time, I was feeling 'what is this,' and there were 8 chemos to be done. It was difficult. For 1 week, I couldn't eat or drink water; whatever I took, I would vomit." – Participant 1

Theme 2: Mental State

Participants' psychological experiences during and after treatment revealed significant mental health challenges and transformative shifts in perspective.

Subtheme 2.1: Mental Change

The diagnosis led to profound changes in participants' outlook on life, often resulting in a renewed focus on the present.

"It turned my life upside down. I changed my mental state to 'this is life.' I don't know how long I'll live, and was wondering for how long the gods have given me the days to live. I live as long as I can; I came to that mentality." – Participant 2

Subtheme 2.2: Fear

Fear of treatment, prognosis, and the potential impact on their families was a pervasive concern.

"Yes, I would think like what kind of pain do I have to endure and go through tomorrow in the treatment? The fearful anticipation of what if something happens to me next month will get me, but until now nothing has happened like that." – Participant 2

"I was afraid and scared very much. I was worrying about my kids, fearing that I'd leave them behind, but fortunately, after the treatment, I'm currently fine." – Participant 3

Subtheme 2.3: This is the End

Feelings of hopelessness and even suicidal thoughts emerged, particularly in moments of severe pain or observing others with poor outcomes.

"I would say not to worry and check with the doctor, follow all the procedures, and you will be all right. There was this one guy who was working with me who had blood cancer. His parents sent him to Canada, spending lakhs of rupees. After 3 months there, he found out about this. Now, the boy is no more." – Participant 3

Subtheme 2.4: Others Like Me

Depending on their conditions, seeing other patients evoked mixed reactions, from comfort to distress.

"I checked up in Karur only, in a medical college. Then I came to Chennai and I consoled myself by seeing others." – Participant 2

Theme 3: Support

Support systems, including family and peers, played a vital role in participants' coping mechanisms.

Subtheme 3.1: Family Support

Family members, especially spouses and children, provided emotional and practical support, often motivating participants to endure treatments.

"My husband was giving me hope that there are many people like this; we can face this together. Even though I had fear, I didn't show it outside. My kids did not know about this until I was discharged and went home." – Participant 1

"My kids only. They asked me to be brave and assured me that they would take care of everything. My two sons gave me hope." – Participant 4

Subtheme 3.2: Peer Support

Colleagues and friends contributed to emotional and financial support. Some participants faced challenges in disclosing their diagnosis at work.

"I haven't been to work till now, and no one knows about my situation at work except 2 people from work; they are supportive of me." – Participant 2

"My ASE helped me financially. I don't have a husband or a dad. I've got 2 kids and my mom with me." – Participant 3

These findings reveal the multifaceted challenges faced by breast cancer survivors, emphasizing the need for holistic care that addresses physical, psychological, and social dimensions of survivorship.

Discussion:

This study explored the lived experiences of breast cancer survivors, highlighting the physical, psychological, and social challenges they face during and after treatment. The present study identified key themes in the experiences of breast cancer survivors: Initial stage (subthemes: Body pain, Hair fall, Vomiting) addressing physical challenges; Mental state (subthemes: Mental change, Fear, This is the end, Others like me) focusing on psychological impacts; and Support (subthemes: Family support, Peer support) highlighting essential emotional and practical assistance.

The study's findings align with and expand upon existing literature on breast cancer survivorship. The physical side effects of treatment, such as body pain, hair loss, and vomiting, were consistent with observations made by Sebri et al. (2022), who emphasised the importance of proactive symptom management in improving patient outcomes. Similarly, this study reinforces the need for integrated care plans that address the unpredictable and distressing physical side effects, such as fluctuating pain and persistent hair loss, and their emotional consequences [14].

The mental health impacts identified in this research, including shifts in life perspective, pervasive fear, and episodes of hopelessness, resonate with findings from Ashton et al. (2024), who highlighted the importance of psychological interventions in reducing anxiety and depression among cancer patients. This study adds to the conversation by emphasising the dual nature of interactions with other cancer patients, which can provide comfort or exacerbate distress depending on the context [15].

Support systems emerged as a cornerstone of survivorship, with family and peers playing pivotal roles in patients' emotional and practical well-being. These findings are supported by Bilodeau et al. (2023), who emphasise educating families and coworkers to foster a supportive environment. This study contributes to this field by providing nuanced insights into the selective disclosure practices at workplaces and the role of supervisors in providing financial and emotional support [16].

Implications

The findings have several implications for clinical practice, survivorship care programs, and nursing education. They underscore the necessity of holistic care plans that integrate physical symptom management with psychological and social support. Nurses and oncology professionals should adopt anticipatory management strategies to mitigate the physical side effects of cancer treatment, such as implementing preemptive pain relief, scalp cooling technologies, and effective antiemetic therapies.

Limitations

The small sample size of five participants limits the generalizability of findings, although data saturation was achieved. The study's single-site focus in an urban hospital in Chennai may not capture the full spectrum of survivorship experiences across different regions or healthcare settings.

Conclusion:

This study highlights the multifaceted challenges faced by breast cancer survivors, encompassing physical, psychological, and social dimensions. The study underscores the vital role of nurses in survivorship care and the need for targeted interventions and education. While limited by sample size and context, the findings offer valuable insights for enhancing the quality of life for breast cancer survivors.

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