

Lived Experience of Breast Cancer Survivors: A Phenomenological Study

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ABSTRACT

Introduction

Breast cancer (BrCa) is the most common cancer in women worldwide. The population who survive breast cancer is increasing; even so, they usually have to go through many problems in their life. Except for the diseased part, numerous socio-cultural factors may pose challenges for the survivors. Hence, the aim of this study was to explore the experiences of cancer survivors.

Methods

A phenomenological qualitative design research was performed with eight BrCa survivors in Kaski district of Nepal. Data were collected through semi-structured in-depth interviews and analyzed using Colaizzi's descriptive phenomenological method.

Results

Two major themes were extracted from the in-depth interviews. One was the reaction to the diagnosis and another was fear of disease. Most participants lacked awareness of their cancer diagnosis, and nearly all of them experienced fear that persisted until death. They faced a multitude of physical issues throughout the treatment phase and subsequent years, including headaches, loss of appetite, anemia, gastritis, body pain, and swollen extremities. Additionally, they grappled with psychological challenges such as anxiety and depression, rendering them more susceptible. Financially, due to the exorbitant costs of treatment, they had to resort to borrowing money from others, with the burden primarily falling upon their families.

Conclusion

Most of the participants had fear regarding illness, treatments, recurrence, and death. Patients were worried about the cost of care. Therefore, it is imperative for family members and healthcare professionals to recognize the experiences of breast cancer survivors in order to optimize patient health during critical stages.

Keywords

Breast cancer; fear; phenomenology

INTRODUCTION

Since 1990, more people have survived breast cancer (BrCa) thanks to improvements in biomedical technology that allowed for earlier diagnosis, detection, and management.¹ In 2020, worldwide 2.3 million women were diagnosed with breast cancer and 685 000 people died. The most common cancer in the globe as of the end of 2020 was breast cancer. More women worldwide, than any other disease, lose years of life due to breast cancer.² In the United States, breast cancer affects more women than any other type of cancer, regardless of ethnicity.^{3,4}

In the United Kingdom, 49,936 women were diagnosed with breast cancer in 2011, compared to 39,500 in 1999. Improved treatments for identification and treatment have raised five-year survival rates in England from 52% to 85% during the past 30 years.⁵ The second most frequent cancer among Nepalese women is breast cancer. While breast cancer is a significant burden on the Nepalese healthcare system, little is known about the number of women who have the disease.³

Understanding the experiences of breast cancer survivors from the time of their diagnosis through treatment and life after cancer survival is a subject of very little research.¹ Phenomenological approach will help to gain an in-depth understanding of the lived experiences of those who had gone through this state. It will significantly help to develop effective strategies to overcome the psychological effects of breast cancer to some extent. This phenomenological study's aim was to explore breast cancer survivors' actual lived experiences.

METHODS

Study design, study setting, and study sample

The research tries to learn more about the experiences of married women living in the Kaski District who had undergone at least one form of treatment for cancer. The sample size was determined by the data saturation. The subjects were chosen using a purposive snowball technique, and the research methodology was descriptive phenomenological.

Data collection

Eight BrCa survivors were interviewed in-depth utilizing semi-structured interviewing techniques. Which were created based on breast cancer literature. The participants were identified with the help of contacts. Then, phone calls and in-person interactions with participants were made. Interviews were scheduled at the participants' residences at a time that suited them after getting their consent. After briefing about the study, in-depth interviews (IDI) were conducted after getting informed consent. All participants underwent follow-

up interviews to learn more about their experiences and to get clarification on their diagnoses, treatments, and post-cancer lives. The study was conducted from September 2017 to January 2020 due to the inaccessibility of the sample in only one setting and inclusion criteria.

Ethical Consideration

Ethical clearance was obtained from the Institutional Review Committee of the Institute of Medicine (IOM), Tribhuvan University (IRC 41(6-11-E) 2/073/074), and informed consent was also obtained from participants after explaining the study's goals and plan and receiving assurances of confidentiality.

Data Analysis

The data were analyzed using Colaizzi's descriptive phenomenological methodology.⁶ (1) After the interview, investigators listened to an audio tape several times to understand the sense of the participant's response. (2) Researchers identified important statements from transcripts. (3) Researchers articulated meaningful statements. (4) Major two themes were developed by researchers through the organization and formulation of meanings, and the researchers matched them with the original interview and refined them to reveal real sentiments.

RESULTS

Up until data saturation, in-depth interviews with eight breast cancer survivors were conducted. The information gathered was transformed into two major themes based on their experiences. One is reaction to the diagnosis and next fear of disease with sub-themes.

1. The reaction to the diagnosis

Breast cancer survivors' degree of awareness significantly impacts how they will respond when told about their illnesses. Most of them are terrified. Participant 2 stated: *"When my doctor first told me I had breast cancer, I thought I was going to die soon and my kids would be left alone as my husband had passed away a few years earlier"*. Participant 8: *"When I saw the biopsy report, I felt like I had fallen from a tree."* Participant 7: *"I went to the doctor and suggested me to test Fine needle aspiration cytology. After 15 days, I received the report, looked at it, and discovered that I had breast cancer, though I had no significant symptoms. I had planned to seek treatment."*

Eventhough most of the participants went for a checkup as soon as they discovered a lump on their breast, they were unaware of the early signs of breast cancer, however, Participant 7 reported: *"I had noticed a lump on my breast for a long time and just did not go to check it but one day I suddenly*

felt that I should go for a check-up.” (She is a nurse).

2. Fear of disease

Regarding fear of disease, there is a generalized fear of illness, its treatment, and its recurrence. Fear of the side effects leads people to refuse therapy. Participant 1: When the doctor told me I needed surgery and my son objected, he claimed that is a woman's identity, and later surgery was arranged despite his argument. *“I felt I will die.”* However, Participant 7 expressed her confidence: *“I did not feel big, I feel I will be good after treatment.”*

Physical burden

Although breast cancer is a serious physical problem in and of itself, the various side effects of treatment include body pain, nausea, vomiting, hair loss, and unexplained symptoms.

Participant 1: *“I had lots of pain, unable to walk due to weakness, alopecia nausea, and anorexia.”* Participant 2: *“I had pain in my wound, body pain, unable to walk, headache, abdominal distention swelling on my feet.”* Participant 5: *“Hair fall, pain and swelling in hands and legs hospitalized due to pneumonia for a week during the treatment time, and now I am having gastric, body pain and feeling tingling on my leg.”*

Psychological burden

Most patients who get a breast cancer diagnosis struggle to accept it, but they eventually begin to understand the gravity of the situation. Some patients feel less trauma than others due to the varied histories of the individuals.

Participant 1: *“I used to experience anxiety, difficulty sleeping, increased heartbeat, most of the time feeling down, unable to express myself, restlessness, a sense of helplessness, and a want to be alone myself. I also take medication for depression.”* Participant 2: *“I feel an increased heartbeat unable to express my feeling”* Participant 7: *“I feel restlessness, no desire to do anything, wanted to stay alone”* Whereas, Participant 3 expressed *“I did not feel fear because I have strong self-esteem”* and Participant 5: *“I did not feel fear because I knew it would be cured after treatment.”*

Economic burden

It is a significant and popular domain. Lack of health insurance led to higher out of pocket expenses because of high treatment costs. Patients were obliged to borrow money to take loans from others due to the pricey nature of the procedure which caused them to refuse the treatment. However, most of the participants in this study had families who took care of the financial part.

Whereas, Participant 1: *“I spent 700/800 k NRS for my treatment which I had earned by myself. Nobody paid for my treatment”* Participant 3: *“Religious*

groups helped financially for my treatment.”

Family support

The presence of family is crucial in the lives of individuals with breast cancer as they assist in handling financial matters, making important choices, offering emotional backing, and staying engaged throughout the duration of the illness.¹⁷

Participants 1, 2, and 5 expressed similar support: *“I got support from my family in taking to hospital, home-based care, nutrition, and psychological support.”* Participant 6 appreciated her husband and children for their support and care and said her health is good now because of them.

DISCUSSION

This study was carried out to share the experience of IDI sessions with BrCa survivors. The result showed seven themes: awareness of BrCa, the first reaction to the diagnosis, fear of disease, physical burden, psychological burden, economic burden, and family support.

According to the findings of the study, most of the participants were aware of the initial symptoms of breast cancer even though when they noticed a lump on their breast they went for a check-up. The study conducted in the United States mentioned that prior awareness and understanding of breast health assisted them to seek early treatment and mentioned the annual mammogram.¹ It might be due to the participants being from a developed country. In the current study, one of them was health personnel and she had noticed a lump breast but she did not go for a check-up immediately. Mehrabi et al. stated a similar experience from the participant and felt uncertain due to the idea that breast cancer is a terminal condition with little chance of recovery for full care as this study finding on the first reaction to the diagnosis of the participants has expressed that most of them felt shocked and thought about their children.⁵

Regarding fear of disease, almost all of the survivors expressed the feeling of shock and fear which is supported in the study conducted by Lundberg et al. stating that she was shocked when health personnel told her that she has to remove her breast and she was reminded of her grandmother who died from breast cancer.⁷ But in another study, most of BrCa survivors expressed that they were worried about the side effects of chemotherapy.⁸

Breast cancer itself has a huge physical issue however the treatment of it produces different physical side effects such as body pain, nausea, vomiting, hair loss, and unexplainable symptoms one of them had pneumonia. Similar health problems were shown in a study done in Jordan which are severe pain (15.9%), severe tiredness (26.6%), and severe nausea (6.4%).⁹ In another

study, fatigue was 46.3%.¹⁰ Similarly, the study reported weakness due to anemia and vomiting so that they could not perform simple activities like eating, drinking, and walking after chemotherapy.¹¹ Some Irani also experienced anorexia, loss of libido, infection susceptibility, alterations in the emotional dynamics of interactions with family members, constrained relationships, and social isolation.¹² Headache, hair loss, fever, breathing difficulty, dizziness, coughing, etc. are some physical difficulties experienced during their treatment.⁹

After the diagnosis of BrCa, most of the patients did not accept the diagnosis and suffered from anxiety with different symptoms so some of them were taking medication for the problem. A similar study in Ghana responded that they felt shocked, sad, and cried because of not getting enough information to understand and cope with the diagnosis.⁸ Whereas, another study has shown anxiety and depression among breast cancer patients. About 55 percent of patients experience anxiety and depression and the peak time for anxiety is before treatment (38%).¹³ whereas another study showed that depression (46.4%) and anxiety (63.1%).⁹

Most participants were supported by family not only for treatment but also in caring in every aspect of life, which aligns with the literature.^{1,5,7} But this statement does not support a study conducted by Hajian et al. stating that her husband did not support her either financially or emotionally therefore she had to arrange money by herself by taking loan treatment.¹⁴

CONCLUSION

There were two major themes identified as a means of addressing areas that have yet to be adequately addressed. The majority of the participants had negative experiences with breast cancer, so identifying the experience of breast cancer survivors and health personnel is critical to optimizing health and well-being during critical phases.

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CONFLICT OF INTEREST

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