Perspectives of Breast Cancer Survivors with Recurrence: A Qualitative Study from a Tertiary Cancer Center in Northern Kerala, India

Neethu Ambali Parambil[1] Srinivasan Kannan[2]

[1] Department of Preventive and Community Oncology, Malabar Cancer Center [Post Graduate Institute of Oncology Sciences and Research], Thalassery, Kerala, India
[2] Achutha Menon Centre for Health Science Studies, Sree Chitra Tirunal Institute for Medical Sciences and Technology, Trivandrum, Kerala, India

Address for correspondence Srinivasan Kannan, PhD, Achutha Menon Centre for Health Science Studies, Sree Chitra Tirunal Institute for Medical Sciences and Technology, Trivandrum 695 011, Kerala, India (e-mail: kannansrini@ymail.com).

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Abstract

Introduction Being diagnosed with breast cancer in itself is a trauma to a woman. Disease recurrence in a survivor is a separate entity with issues and challenges that differ from the initial diagnosis. Recurrence gives a message of incurability to the survivor.

Objective There is a dearth of qualitative studies from Kerala about the experiences of breast cancer survivors with recurrence. This study was undertaken to have a better understanding of the perspectives of these women.

Materials and Methods In-depth interviews were conducted among 10 survivors registered in the Hospital-Based Cancer Registry of 2016 in a Tertiary Cancer Center who had a recurrence in 2022, using an interview schedule. Interview transcripts were subjected to thematic analysis.

Results The Consolidated Criteria for Reporting Qualitative Research were used for the study reporting. The themes that emerged were: (1) diagnosis-related challenges, (2) work-related challenges, (3) financial challenges, and (4) treatment and cure-related perspectives.

Conclusion Survivors with disease recurrence had an array of multifaceted experiences that must be addressed.

Keywords
- breast neoplasm
- cancer survivors
- qualitative research
- cancer registry
- recurrence

Introduction

Presently, the most frequently diagnosed cancer among women globally is breast cancer. The state of Kerala in India has an age-adjusted rate of 35.6 per one lakh population.[1] Improved methods of diagnosis, better awareness, and advanced treatment have led to an increase in the number of breast cancer survivors.[2,3] Despite rising survival trends seen in India and the rest of the world,[2] one-fourth of the survivors are found to develop recurrence at later stages and die from disease dissemination.[4] Breast cancer has a wide window of recurrence spanning from months to decades from initial treatment,[5] and represents a separate entity, with challenges and issues different from the primary disease.[4,6] An individual is considered a cancer survivor from diagnosis to the rest of one's life.[7,8] Most studies focus on the quality of life of the survivor, and very few explore the specific issues and concerns from the perspective of those

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survivors with recurrence.[9,10] Research outputs on breast cancer itself are scarce in India. There are no studies on breast cancer survivors from Northern Kerala. This study aims to understand the issues and challenges faced by survivors with recurrence.

Materials and Methods

Study Design, Setting, and Participants

This qualitative study was conducted in a tertiary cancer center (TCC) in Northern Kerala, which provides comprehensive cancer care.

The number of patients with breast cancer registered in the TCC as per the Hospital-Based Cancer Registry (HBCR) in the year 2016 was 534. The detailed protocol is published elsewhere.[11] In this study, 10 female patients were found to have recurrence and progression to stage 4 as of 2022. A qualitative descriptive approach was used for this study.[12] Face-to-face in-depth interviews in the local language were conducted to understand their perspectives, using an interview schedule.

Objectives

The main objective of the current study was to have a deeper understanding of the perspectives of breast cancer survivors with recurrence after 6 years of treatment.

Inclusion criteria: Survivors diagnosed in 2016 as per the HBCR and undergoing treatment at the TCC for recurrence in 2022, were included in the study.

Exclusion criteria: Those who were unwilling or could not participate due to time constraints or health issues were excluded.

Participants were purposively selected. We asked them about their perceptions of disease recurrence, the financial burden of treatment for the second time, family support during the crisis, and the work-related challenges due to their ailments and treatments. Interviews were conducted during their treatment visits in the hospital, after obtaining consent and explaining the purpose and voluntary nature. Adequate privacy was ensured, allowing bystanders only if they wanted. Interviews were conducted by the first author, who was not their treating physician; hence, the participants could freely open up. Interviews were conducted only if the participants were comfortable; if not, it was postponed to the next visit. The interview lasted 45 to 50 minutes and the narratives were audio recorded and field notes taken down.

Primary outcome: The study will help to have a better understanding of the experiences of the survivors with recurrence and the challenges faced by them.

Secondary outcome: The findings can be used to improve patient care and policy-making based on the understanding.

Data Analysis

Data analysis was done manually due to the small numbers. Thematic analysis[13] was used for a rich and complex account of the data collected. All the interviews were transcribed and then translated verbatim into English, followed by reading and rereading to familiarize the data by authors. Codes were generated systematically, separately, by each author; constant comparison was made and similar ones were organized into categories. Discussion among authors helped reach a consensus. The ongoing exercise of refining the categories several times, organizing them into themes, and naming them led to the final results. For ensuring the trustworthiness of findings, the criteria of credibility, dependability, transferability, and confirmability were followed.[13] The first author, being a female trained in qualitative research, ensured credibility. The findings were checked with oncologists in the TCC to ensure the truth in the facts stated. All interviews were conducted by the first author, using an interview schedule for consistency in data collection. To ensure transferability, the characteristics of the sample, descriptions of study methods, data collection, and analysis are also detailed in the text.

Results

The 10 survivors interviewed were aged between 50 and 68 years (mean age of 59.25). The sociodemographic profile of these survivors is given in ►**Table 1**. The themes,

Table 1 Sociodemographic profile of study participants ($n = 10$)

Age	*n* (%)
≤ 50 y	3 (30)
> 50 y	7 (70)
Parity	
Yes	10 (100)
Marital status	
Married	9 (90)
Widow	1 (10)
Present stage	
Stage 4	10 (100)
Stage at diagnosis	
Stage 2	4 (40)
Stage 3	5 (50)
Stage 4	1 (10)
Education	
Middle	2 (20)
Secondary	7 (70)
College level	1 (10)
Year of diagnosis of recurrence/relapse	
2020	2 (20)
2021	6 (60)
2017	2 (20)
Job	
Manual laborer	2 (20)
Homemaker	8 (80)

Table 2 Major themes, subthemes, and codes

Major themes	Subthemes	Codes
Diagnosis-related challenges	Delay in initial diagnosis and delay in recognition of symptoms	Carelessness, ignored symptoms, fear, financial reasons, breastfeeding, not recognizing, feeling guilty, nature of the disease, not their fault, loss of trust in the treatment, decreased access to health facility
		Daughter's exam, daughter's delivery, family members taking it lightly, no one to accompany. Decreased awareness among spouses, spouse working abroad
	Health facility-related	Awareness regarding symptoms of recurrence, access
	Disease-related	Nature of disease
Work-related challenges	Symptom-related	Pain, breathlessness, inability to work, burden to family
	Financial-related	Repaying of loans, worry of depending on others
	Family support	Helping in work, doing all work, overprotective
Finance-related challenges	Government schemes	Treatment availed, out-of-pocket expenses, schemes exhausted, cancer pension, schemes not available, financial burden to family
Disease- and cure-related challenges	Facing treatment again	No courage, depression, crying, thinking of death, belief in a cure
	Hiding the reality	Not aware of the present condition
	coping	Optimistic, prayers, increased faith in God
	treatment-related worry	Worried about side effects of excessive medicine use
	Family-related expectations	Children have no time, children are employed, and loneliness

subthemes, and codes are given in ►**Table 2**. The following themes related to the perspectives of survivors emerged: (1) diagnosis-related, (2) work-related, (3) financial-related, and (4) treatment and cure-related challenges (►**Fig. 1**).

Theme 1: Diagnosis-Related Challenges

The survivors were asked for her perspective on why she got the disease a second time, though others who underwent treatment along with her were disease-free. The subthemes related to delayed initial diagnosis leading to recurrence were described under the following headings.

Delayed Initial Diagnosis

> *"I know that the disease recurred because of my carelessness. I ignored my symptoms initially."*

> *"It was my fault. I delayed the initial consultation due to fear and financial constraints."*

These were the words of two women: Survivor 1 (54-year-old) and survivor 2 (66-year-old widow), respectively. Looking back, they realized that the disease had recurred because they failed to get it diagnosed in the early stages, which now led to a feeling of guilt. They recalled that they either failed to recognize symptoms or to consult a health care worker on time.

Even in those who recognized that something was wrong, some reasons prevented them from undergoing a medical consultation immediately, such as family events, decreased awareness among family members, family situations, etc.

A 53-year-old, survivor 3, mother of three, recalls that "*I delayed initial consultation by almost three months as my daughter was having her degree examination.*"

> *"When I noticed the lump, it was my daughter's delivery time. I knew that something was wrong as I was always actively involved in organizing cancer detection camps in our place, but still delayed consultation. Only if I had consulted earlier……."* The words of survivor 4 (66-year-old mother), who was diagnosed with stage 3 breast cancer and developed recurrence in 2021.

> *"Even though I told my husband, he said that the lump would go away on its own. There was nobody else to take me to a doctor. There was a delay of 3 months"* said a 50-year-old, survivor 5.

> *"My husband was abroad at that time. Though I disclosed it to my sister-in-law, she said it was normal. At that time, I was breastfeeding my child, too. It was late by the time my disease was diagnosed,"* said survivor 6, a 50-year-old with two children.

Disease Characteristics Related

Two of the survivors, survivor 7 (63 years old) and survivor 4, stated that despite being diagnosed early, the disease came back. They believed that it was due to the nature of the disease called "cancer."

> *"I took all medications and did regular follow-up. I don't think that the disease came back because of my fault. The disease itself is so"*

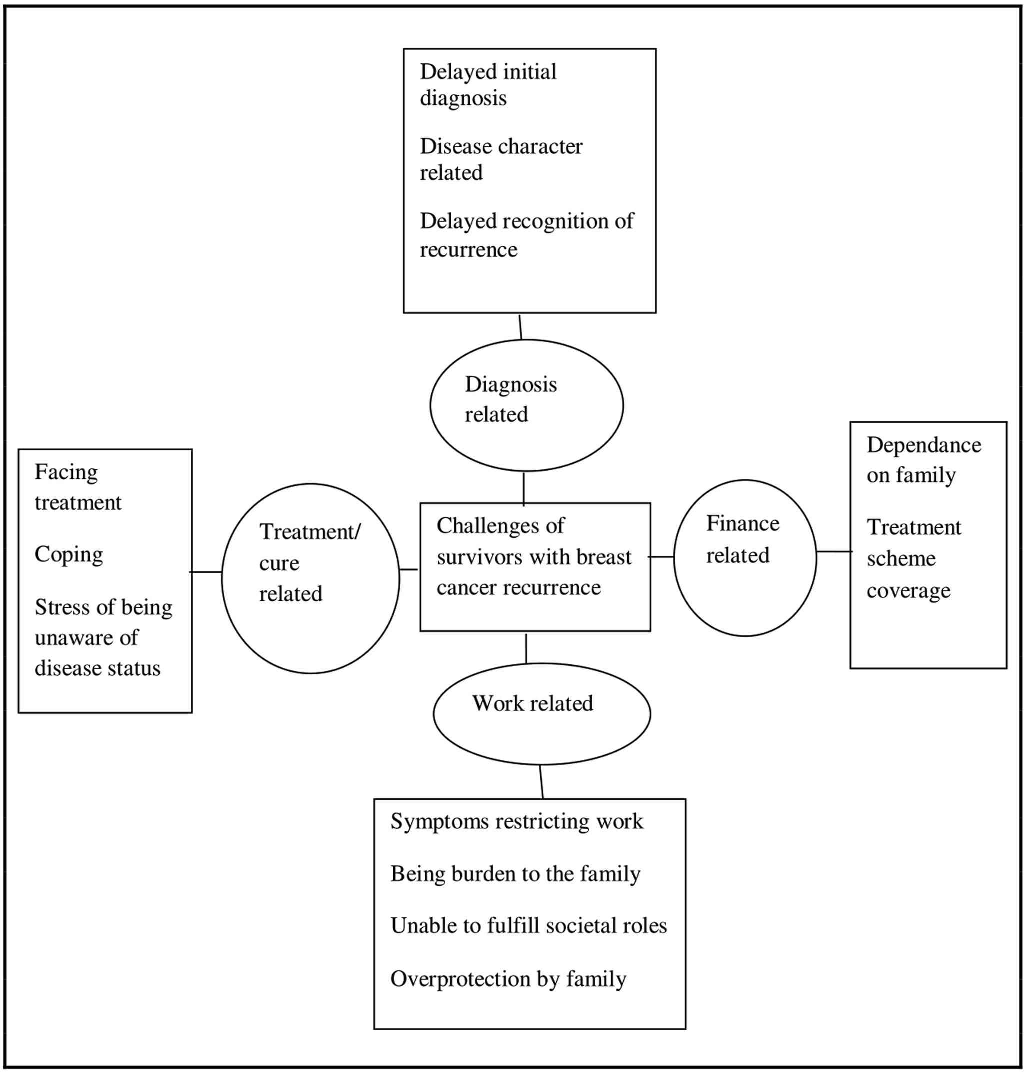

Fig. 1 Perspectives of survivors with recurrence of breast cancer.

> *"I took all treatments and followed all instructions of my doctor, but still the disease recurred. I don't know why"*

> *"I often feel that if my uterus was also removed during my initial treatment, it would not have recurred there," said* survivor 8 (68-year-old mother of two).

A feeling of helplessness and loss of trust in the cure after treatment were reflected in their words.

Recognition of Recurrence

For some, the accessibility to a health facility enabled them to get treatment immediately. They did not have to wait for the decision from the family.[4]

> *"For me, when the disease came back, I recognized it and informed my doctor immediately, even though my family said that it may be just my feeling. I could do this because I was going to the hospital for regular follow-up."*

> *"Though I felt something was wrong again, I could consult a doctor only after two months due to the COVID crisis. There should be some alternative,"* said survivor 5, diagnosed initially with stage 3 breast cancer.

Decreased self-awareness of the warning signs of recurrence and noncommunication from the health care providers were also described.

As stated by survivor 3, who developed recurrence in the lungs;

> *"I did not recognize. I thought the disease would come back only in the breast area. I had cough, but thought it was due to an allergy. There was painting work in the house in connection with my daughter's marriage. I consulted doctors only when the cough did not subside after 3 months…"*

> *"I regularly checked my breasts. I did not know about any other warning signs to look for. Nobody told us,"* said survivor 8.

At the same time, most of the survivors were vigilant and more careful during the second time, as stated by survivor 7, who developed disease recurrence.

> The words of survivor 7, a mother of four, also reflected the same sentiment. *"I regularly read health magazines. So, when I had severe back pain, I did not waste time consulting anywhere else, I came straight away to TCC."*

Theme 2: Work-Related Challenges

Women faced challenges related to their day-to-day activities as well as paid jobs due to the recurrence of the disease. These were related either to the symptoms of recurrence, or restrictions from family members.

Symptoms Restricting Work

> *"Now I cannot do any work due to cough and breathlessness. Cannot sleep at night"*- this was stated by survivor 3.

Being a Burden to Family

Survivor 2 said, *"I cannot do any work now due to pain. I was a manual laborer. I wish I could continue my job."*

Overprotection by Family

Support from their family members made them happy, but overconcern from the family posed restrictions.

Survivor 7, now undergoing treatment, said, *"I am able to do my work, but my husband and children don't allow me due to concern for my health. Without their knowledge, I take pain medication and engage in gardening. It makes me happy.*"

Unable to Fulfill Societal Roles

> *"My daughter-in-law has to do all the household chores when I feel tired after treatment,"* said survivor 4.

Theme 3: Financial Challenges

The financial burden was a major concern as they were all undergoing treatment for the second time. The words of survivor 2 and survivor 3 state that apart from the symptoms, the inability to support the family financially and dependence on them for treatment expenses, worried them.

Dependence on Family

> *"I am a widow. My daughter's husband also died recently. I am worried about family matters now more than my disease. My daughter has to work and look after me. I had taken a loan previously. I thought I would continue my job and repay it, but now that cancer has recurred, it is difficult."*

> *"My family has to spend money on my treatment. Nowadays, I cannot do any work due to breathlessness,"* said survivor 3, who is on chemotherapy now.

> *The medicines this time were expensive, my husband cannot work anymore, and the financial problem worries me,"* said survivor 5.

Coverage of Treatment Schemes

Though they were all beneficiaries of government treatment schemes, they had out-of-pocket expenses such as medicines, travel, etc. The words of survivor 5 and survivor 2 clearly state this.

> *"I am availing the benefit from the government scheme for my treatment. But still, the travel expenses and weekly blood tests all have to be borne by me,"* said survivor 2, who is on chemotherapy now.

> *"I got help from treatment schemes even for the second time, but all medicines were not covered".*

For some, the amount available was already utilized during their first treatment. This is evident from the words of survivor 7.

> *"I availed 'Karunya' treatment scheme for the first treatment. Now for medicines, transport, tests, etc. I have to bear the expense. I get the Government pension for cancer patients, but it is very irregular."*

Some could not claim the government schemes as they do not come under the criteria for beneficiaries.

> *"I am a taxpayer, hence did not get treatment schemes."* said survivor 8, who is under treatment now.

Theme 4: Treatment and Cure-Related Concerns

We asked the survivors' thoughts about undergoing treatment for breast cancer recurrence and their idea of a cure. Both positive and negative perspectives were seen.

Facing the Treatment Again

Most of them found it difficult to go through the whole treatment and tests again. These were evident from the words of the survivors.

> *"First time I had no tension. But now it is not the same. I have no courage or strength to bear the treatment,"* as quoted by survivor 7.

> *"Though I fought the disease with courage the first time, I was completely depressed this time. I thought I was cured and that the disease will not come back after all these years,"* said survivor 8 who was diagnosed with stage 2 disease and is now undergoing treatment for recurrence.

> Other concerns worried them equally.

> *"I have to take pain medicines now. I fear that my kidneys will be damaged due to this. The disease is already there,*

> *now if I lose my kidney too…"* said a visibly anxious survivor 4.

The family was trying to support the survivor well, but sometimes could not come up to their expectations or fulfill their needs.

> *"I am only sad that my daughters are busy and cannot come and stay with me. I feel very happy when they are with me. I know that they have jobs and cannot come over frequently,"* said survivor 8.

Coping Strategies

Some were optimistic and courageously faced the disease even for the second time. They gained strength by engaging in faith-based practices like spiritual beliefs, prayers, and reading holy books, irrespective of age.

> *"I believe in prayers. I read the holy Bible. I am alive at least in this way, because of the prayers of my loved ones,"* in the words of survivor 5.

> *"I believe that I can still overcome. I spend my time in prayer,* "said survivor 6.

> *"Don't know what will happen tomorrow. Whatever happens is for good,"* stated survivor 8.

Stress of Being Unaware of the Disease Status

This was expressed by two of the survivors:

> *"They did not tell me about my condition. I came to know about it only recently when my physician, who is treating me for diabetes, told me. I feel that family should not hide it from us,"* said survivor 9.

> Survivor 10 (50-year-old) said, *"I don't know about the extent of my disease and why I am taking treatment even now."*

> *"Only my daughter knows about my disease status. I asked her, but she did not tell me*," said survivor 4, whose elder daughter was accompanying her for treatment.

Discussion

Delay either in the initial diagnosis or in recognizing the signs of recurrence and disease characteristics were described by the survivors. One-third of women presented in late stages during the initial diagnosis,[14] as the decision to seek care is often initiated by the women's perception and awareness regarding the "main" symptom.[14] Failure to recognize symptoms or issues related to self or family was described as the reason for delayed consultation. Awareness about cancer was found to be low among Indian rural women.[15] The daughter's delivery, marriage in the family, and children's examination were causes of delay, as in our study.[16] Most women disclose their symptoms first to their husbands,[14] which means awareness among spouses regarding breast cancer is an important factor that determines the wife's attitudes and practices.[17] The involvement of family members in medical-related decisions was reported as the cause of delay in other studies, as in ours.[14] All these can result in late stages at initial diagnosis and high chances of recurrence.[4] All our participants agreed that early diagnosis would have prevented a recurrence.

Our survivors also stated that knowledge about the symptoms of recurrence would have helped in early medical consultation. The overburdened health worker may not be able to give proper guidance in the regular hospital outpatient department.[18] Hence, tailored screening programs for those at higher risk of recurrence based on their clinicopathological and treatment parameters were suggested.[4] Alternate arrangements for consultation during crises like the coronavirus disease (COVID) pandemic are also needed as visits to a health care setting itself could be a source of infection, and most of the follow-up visits were either deferred or done through telemedicine at that time.[18,19]

Women were finding it difficult to do household chores due to their symptoms, like breathlessness and pain. Symptoms negatively affecting the fulfillment of social roles, day-to-day work, and impact on family were also reported in a review similar to our survivors.[10] Though family support was there, there was a feeling of helplessness, as those who were working after initial treatment also could not do so now due to health issues.[20] The overprotective nature of the family was also mentioned in other studies.[20] The change from a caregiver's role to someone receiving care was experienced by most of these women.[21]

Various government treatment schemes[22] were availed by these survivors even during the second round of treatment. However, not all medicines prescribed were covered by the schemes, as reported by them. Only 40% of patients with metastatic breast cancer in Asian countries receive second-line treatment through treatment schemes.[23] The expenses of the laboratory tests, travel, etc., have to be borne by the patients. Moreover, cancer care costs in the private sector are three times higher in India.[18]

Facing the disease again is more distressing to the woman than the primary diagnosis, as this points to its uncertain nature.[9,10] Though many had negative thoughts about cure, positive coping strategies were exhibited by some. Religious beliefs and support structures were important coping strategies, as per literature, which was also found in our survivors.[24] The worry about complications following treatment, loneliness due to the lack of presence of near and dear ones, and stress due to the feeling of being a burden to the family were also expressed by the survivors. Adjusting to the new prognosis related to the disease, uncertainty about the future, and helplessness were looming in their words.[20] Though the family members thought that the patient would not be able to bear the reality of recurrence, and it was better to hide it from them, the patient's point of view was different. That information provision could lessen anxiety and improve understanding of the situation were also described in other qualitative studies.[20] As in our study, concerns of women regarding knowledge about their disease and receiving support from health workers and family was described in other studies too.[10,24] Though our study describes experiences and challenges of a limited number of survivors, we tried to include a heterogeneous group, and we believe that we could cover their perspectives in depth. This is a single-center study, which is a limitation. We tried to unravel a few perspectives of survivors with recurrence. More qualitative studies are needed for a deeper understanding of survivorship in India.

Conclusion

Recurrence, many a time, was the outcome of presenting late for the initial diagnosis, in addition to the clinicopathological characteristics of the disease. Improving awareness of cancer among spouses and family members in general is suggested. The findings also point to the need for health workers to provide awareness of signs of recurrence for early recognition and proper communication of disease status with the patient and help them cope with the reality. Financial assistance in treatment in the form of increasing the coverage of second-line drugs in government treatment schemes is needed. A system for regular disbursement of benefits to cancer patients, such as cancer-related pensions, should also be ensured. An overall health support system to deal with the challenges related to the fear of the unknown caused by the recurrence, and a strategy to deal with situations like COVID-19, is needed. More research is required to shed light in this direction.

Authors' Contributions

The manuscript has been read and approved by all the authors, and the requirements for authorship have been met and are provided in contributor's form. Each author believes that the manuscript represents honest work. Study conceptualization and Methodology, Data analysis, Review and editing, and Final approval of manuscript have been done by S.K. Study conceptualization and methodology, Data collection, Manuscript writing, Review and Editing and Final approval of manuscript have been done by N.A.P.

Ethical Approval

All procedures performed in this study followed the ethical standards of the institutional and/or national research committee and with the 1964 Helsinki Declaration and its later amendments or comparable ethical standards. The approval for the study was obtained from the institution where the author undertook her PhD study, and from the institution where the study was conducted (1617/IRB-IEC/13/MCC/26–05–2021/2 and SCT/IEC/1711/AUGUST/2021).

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Conflict of Interest

None declared.

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