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RESEARCH ARTICLE

A Qualitative Exploration of Survivorship Experiences of Breast Cancer Patients from Northern Kerala, India

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Abstract

Introduction: Early detection and advancements in treatment have led to an increasing number of women living with breast cancer globally. The issues and challenges faced by these women post-treatment was varied, and this study aims at looking into the survivorship experiences of women who have completed six years of treatment. **Materials and Methods:** Survivors diagnosed in 2016 were taken from the Hospital Based Cancer Registry of a Tertiary Cancer Centre (TCC). From those under follow-up and traceable in 2022, in-depth interviews were conducted among 15 long-term survivors, selected purposefully, to understand their survivorship experiences. The interviews followed the principle of saturation. The transcribed interviews were analyzed manually. The codes were clustered into themes as per the emerging patterns. The Consolidated Criteria for Reporting Qualitative Research was used for study reporting (COREQ). **Results:** The analysis followed a deductive coding approach. The themes that emerged from the interviews are the following 1) survivor identity 2) The survivor and stigma 3) The socioeconomic support 4) Social expectations 5) Service provision-related experiences 6) Survivor's role as ambassadors. **Conclusion:** Even after successful treatment completion, breast cancer survivors were experiencing challenges and issues both personally and from society even after 6 years. The needs and expectations of these survivors during their post-follow-up period also cannot be ignored. The survivors can be effectively utilized as ambassadors for promoting early detection and reducing apprehensions among newly detected patients. Implications for Cancer Survivors: A deeper understanding of the survivorship experiences will help formulate policies for improving the quality of survivorship, as such guidelines are non-existent in most low-middle-income countries.

Keywords: Survivorship experiences- Breast cancer- Survivor- Kerala

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Introduction

Globally, breast cancer is the leading cancer among women with more than two million new cases in 2022 [1]. In India, it accounts for 13.6% of all cancers [2]. Hospital-Based Cancer Registry (HBCR) data from South India (2007 to 2014), also show an increasing incidence of breast cancer [3]. Due to advancements in early diagnosis and treatment, the five-year survival rates of breast cancer have increased globally [4, 5]. Indian studies also show higher survival [6] and rising trends [7], accounting for a five-year prevalence of 5.26 lakh [2]. The word 'survivor' was used to describe individuals throughout their cancer trajectory [8, 9]. Breast cancer survivorship refers to the period between the initial cancer treatment and the end of life, in a woman's cancer journey [10], enveloping multifaceted issues (both medical and psychosocial) and challenges faced by the survivor, during diagnosis and treatment [9]. Regular follow-up every four to six months during the first five years after primary treatment, and annually thereafter, is recommended for breast cancer [11]. Global studies discuss the physical and sexual issues, threat of cancer recurrence, stigma from society, job-related issues, and financial burden, which may pose challenges to a survivor [12-14]. The need for survivorship research has now received acceptance globally, in understanding their challenges and bringing up solutions for improving the quality of

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life (QOL) [15]. Survivorship research was mainly from high-income countries, and the results may not be similar to low-income countries, owing to the influence of varied sociocultural setups [13]. Studies on breast cancer survivorship focused more on the psychological and treatment aspects of the disease [16]. Breast cancer, in India, is a largely understudied area, mostly quantitative studies focusing on QOL [17] or discussing immediate post-treatment survivorship issues[18], with limited data on long-term experiences and challenges faced by these women [17, 19]. Research outputs associated with breast cancer from Northern Kerala, especially on long-term survivors are still scarce. This study aims to explore the survivorship experiences of breast cancer survivors registered in a Tertiary Cancer Centre (TCC) in 2016 and disease-free in 2022.

Materials and Methods

The study was conducted in a TCC in northern Kerala, an autonomous institution under the government that provides comprehensive cancer care to the northern districts of Kerala. The study was approved by the Institutional Ethics Committee of Malabar Cancer Centre (PGIOSR) where the study was conducted (1617/IRB-IEC/13/MCC/26-05-2021/2) and, Sree Chitra Tirunal Institute for Medical Sciences and Technology (SCT/IEC/1711/AUGUST/2021).

The study population included long-term breast cancer survivors registered in the TCC in 2016, and under follow-up in 2022. The number of breast cancer patients registered in the TCC in 2016 was 534. After the deaths and loss to follow-up over the years, the number of participants contactable in 2022 was 209. Of these, 199 survivors were disease-free, while 10 participants had recurrence [20]. This study was conducted among the disease-free survivors. The sampling strategy was purposive to represent a multitude of survivors. A qualitative study design was used as data available on this topic from Indian settings was limited. Face-to-face interviews (45 minutes) were conducted, at the hospital during follow-up or at any place of convenience for the women, allowing the presence of bystander, if they wished. The interview schedule was prepared after review of literature, researcher experience and expert consultation, translated into a conceptually equivalent form in the local language, and piloted for face validity and comprehensiveness. After getting informed consent, women were asked about their experiences throughout their survivorship period such as their perception of being a “survivor”, return to routine work and the related challenges, the support received from the community, the related stigma experienced, perceptions about follow-up care, and the financial support received during their treatment. The responses were audio recorded and field notes were taken. The interviews were conducted from January 2022 to October 2022 by the first author using the interview schedule. The recruitment was stopped and saturation was declared when it was clear that any new data were not likely to impact the key themes that had already emerged from the fifteen interviews.

Opening up gave a sense of relief to some, and a few thanked us, saying that this was the first time somebody was listening to their problems. They were ready to share their ideas to a physician in the same institution. Many continued to keep in touch and called up for their health issues.

Data analysis was done manually due to the small number. Thematic analysis [21] was used for a rich and complex account of the data collected. The audio recordings were first transcribed, translated verbatim into English, followed by a series of readings to familiarise the data. Codes were generated systematically, and data relevant to each code were collated. Codes were then clustered into potential themes, and relevant coded data extracts were collated under identified themes. A thematic map was generated, checking the codes back and forth, relating them to the themes, and to the entire data set, based on emerging patterns and categorised using a deductive approach (Figure 1). The ongoing exercise of refining and redefining the themes several times and naming them led to the final results.

The rigor of the study was attained through credibility, dependability, transferability, and confirmability [21, 22]. Credibility: The first author was a female pursuing a PhD in public health at the time of the study and fluent in the local language. Both NAP and SK were well-trained in qualitative research methods. Though NAP was not involved in the outpatient care of these survivors, being a physician in the same hospital might have reflected in the analysis. SK, a non-medical person, helped interpret

Table 1. Sociodemographic Profile of Breast Cancer Survivors (n=15)

Age	n (%)
≤50 years	6 (40)
>50 years	9 (60)
Parity	
Yes	15 (100)
Marital status	
Married	14 (93.3)
widow	1 (6.67)
Present disease status	
Disease free	15 (100)
Stage at diagnosis	
Stage 2	10 (66.7)
Stage 3	5 (33.3)
Education	
Middle	5 (33.3)
Secondary	8 (53.3)
College level	2 (13.3)
Job	
Manual labourer	1 (6.7)
Clerk	1 (6.7)
Teacher	1 (6.7)
Homemaker	12 (80)

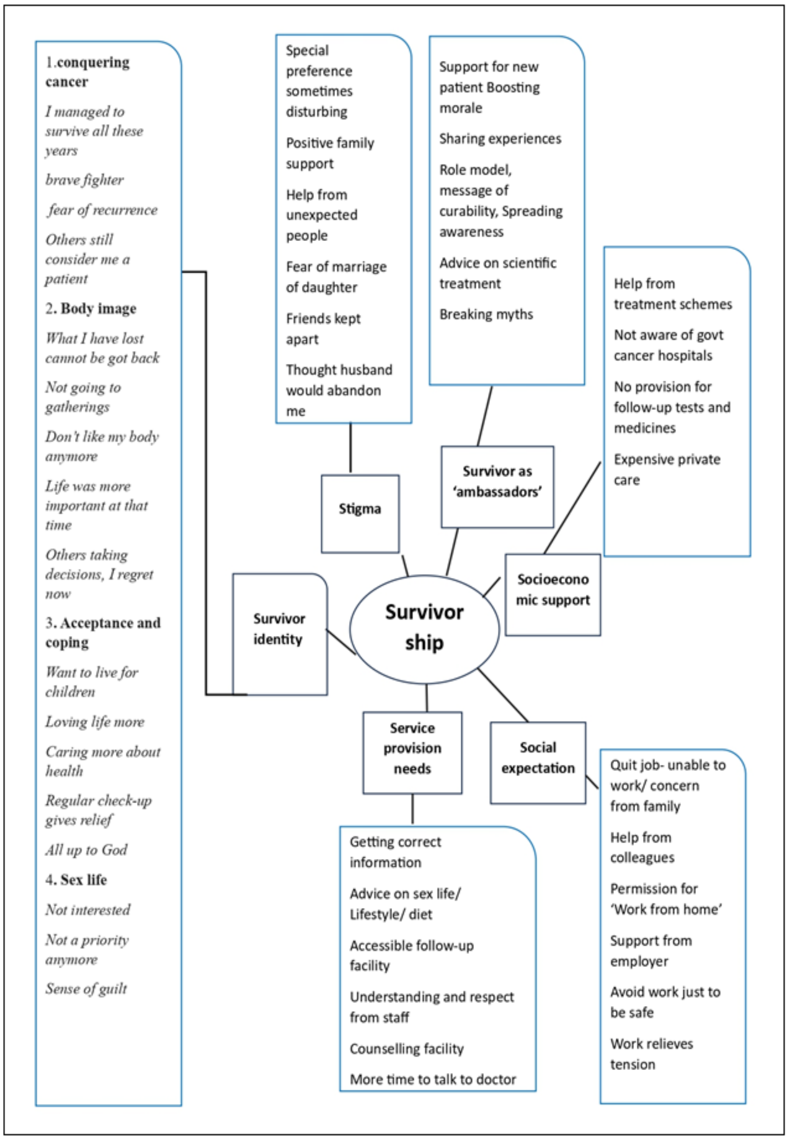

Figure 1. Thematic Mapping of Themes Related to Perceptions and Experiences of Breast Cancer Survivors

data from an outsider's perspective. Interview notes were shared with most participants at the end, for feedback and verification. However, the transcripts and study findings were not shared. Triangulation was done by discussing interview facts with other oncologists and comparing them with their medical records. NAP was involved in the code listing, cross-checking, and discussing with SK in creating code groups and analysing the findings. To ensure dependability, all the interviews were conducted by NAP using the same interview schedule, for consistency in data collection. The study methods, interview schedule, data collection, and characteristics of the sample were described fully in the manuscript, ensuring transferability. The Consolidated Criteria for Reporting Qualitative Research was used for study reporting (COREQ) [23].

Findings

In-depth interviews were conducted among 15 disease-free survivors (Age range from 44 to 67 years). The sociodemographic profile of survivors is given in Table 1. The themes that emerged from the analysis of the interviews were 1) Survivor identity, 2) The survivor and stigma, 3) Socioeconomic support, 4) Social expectations, 5) Service provision-related experiences, and 6) survivors as 'ambassadors.

Survivor identity

The perceptions of the survivor were discussed under five subthemes: 1. Conquering cancer, 2. Body image, 3. Sexual life, 4. Fear of recurrence, and 5. Coping with new life.

Conquering cancer

According to S1, the one who lives disease-free longer is a survivor. She stated, "Despite the difficulties experienced due to the disease and the treatments, I managed to survive all these years"

S2, 44 years mentioned: "When I first came to the cancer centre, I did not even know whether I would be cured and live again".

S3, 52 years old, said: "I fought the battle with courage. I think being a brave fighter is a survivor".

Failure of acceptance by society was discussed by 52-year-old S4 "While I want to be known as a survivor, people around me still consider me a patient."

Failure of acceptance by self, as a survivor in its full dimension as stated by S5, 53 years: "I would like to call myself a survivor, but I don't think I have fully conquered the disease. I always have the fear that the disease may come back."

Some could relate the word to being 'disease free', 'alive', 'fighter', and 'brave' as stated above. At the same time, some feel the fear of recurrence, and the ongoing presence of 'cancer' in their daily life, prevents them from accepting themselves as survivour.

Body image

Body image, 'an internal representation of one's external appearance', is an important aspect of survivorship in a patriarchal society. The changes in their body due to the complete removal of a body organ, a symbol of femininity, as part of cancer treatment, is a disturbing experience.

"I had to remove my whole breast. I cried a lot then. Even today I feel sad whenever I think about it. What I have lost from my body cannot be brought back, and no dress can mask the loss". 45-year-old S6 was trying to hold back her tears.

"I find it difficult to face people though I haven't had any bad experiences. I feel breasts are an important part of a lady and I don't like my body anymore," said S6 & S7. They were concerned about their bodily appearance as they firmly believed that they were continuously being watched and evaluated by others.

Though the younger women were concerned about their body image, the older women perceived it differently. "When the doctor talked about the chance of the disease coming back, I immediately consented to remove the entire breast, as my life was more important than anything else at that time" said S8, 67 years old.

Contrary views were also observed. "Doctors said removal of the lump alone would cure me. But my relatives said that I should not think of such things now, it is more important that disease does not come back. My feelings were not considered and I regret now," said S3.

"Though a breast-conserving surgery would have been enough for me, I decided to remove the entire breast," said 52-year-old S9. Being helpless due to fear of disease was the meaning of survivorship to these women.

Post-treatment sexual life

For the young survivor, body image was related to sexual life. S2 whose breast was removed as part of treatment said "I feel guilty, even though my husband is very understanding and supportive. I am not a complete woman anymore".

S7 44 years, said "I don't feel interested in sex. I am uncomfortable"

"I am afraid that my husband will get the disease, even though I know that it is not true," said 45-year-old S10. Despite being aware, the fear of their spouse also getting the disease haunt these women.

48-year-old S 11 stated "All these years have passed by and now I think more about my children and want to live for my family. All other things are not my priority anymore"

Despite their sexual life not being affected by the disease due to support and understanding from their spouses, they faced difficulties like pain and loss of interest due to guilt, fear or a change of priorities.

Fear of recurrence

The stories of others who had recurrence caused anxiety in most as stated by S3:

"The fear of recurrence is always there at the back of my mind. Coming to the cancer centre for follow-up is stressful".

Some had contrary views about getting a thorough check-up. "The very fact of coming for a checkup relieves me of my stress", stated S4.

S9 said "When admitted for surgery, I have seen one lady with disease recurrence, on treatment. But I feel, I was lucky enough. I cannot even think of going through the entire treatment again"

According to a 53-year-old S5, "After the disease, I could never be the same person as before. I am never happy from the inside. There was always this weird feeling that I cannot express. I keep on telling myself that it will not come back."

Coping with the new life

Women spoke about various ways of coping after treatment. S9: "It is all up to God. Anyway, there is no use worrying too much. Whatever has to happen will come". Coping up and embracing the new life, either for themselves or for their family, concealing their feelings from family members was their underlying perception of survivorship.

S13, 58 years "We built a house in our hometown. I also started to travel a lot, enjoy music, and interact with friends through WhatsApp groups. My son is my greatest motivator, support, and the reason for my new life."

S6 speaks of the changes in her post-disease life "I give more importance to my health now, do regular exercise, and eat lots of fruits and vegetables, do self-examination almost every day, and go for check-ups without fail."

"I recently received the best teacher award"

45-year-old mother, S12 said "Before getting cancer, I never thought about death. But now, I love my life more, and I want to live for my children."

Life situations and responsibilities were reasons for coping for some. "My husband could not accept my condition. He was silent after that. One day, when I was back from treatment he was found hanging. I was completely shattered, as I had to fight the disease as well as take the responsibility of my family".

2. The survivor and stigma

Positive support from family, friends, and society helped them resume their routine life and work, while experiences of sympathy, over-caring attitude, and stigma were also shared.

"Initially, when I was diagnosed, they regularly brought me my favourite food, gifted me new dresses, and so on. This special preference made me feel as though I was going to die soon. I always tried to smile and make them feel that I was ok". This was expressed by S6, who had early-stage breast cancer.

S3, mother of two, stated: "My family, including my in-laws, supported me very well. Sometimes I feel uncomfortable due to their over-caring attitude and sympathy"

On the other hand, those who were close to you often did not know how to deal with the condition of their near one. "My dearest friends kept apart, maybe they did not know how to face me or deal with my condition, but my colleagues frequently visited me, helped and supported me throughout", said S2.

Even though awareness about breast cancer has improved a lot, fear and misconceptions still exist in society.

The mother of two children S1, said: "I was already on treatment for heart disease, and now I am diagnosed with cancer too. I thought that my husband would abandon me, but he supported me the most"

"My prayers are that my disease does not come back at least until my daughter's marriage, I fear her marriage will be affected," said S3.

Most women reported that they received good support from their near and dear ones, but stated that they hate the sympathy shown by people towards them However, bitter experiences were shared by S13 "I was traveling by bus when I was on chemotherapy. I had hair loss. When I sat next to a lady, she immediately got up and shifted to another seat. I cried a lot on that day".

3. Socioeconomic support

Regarding treatment, S14 said "I had done surgery at a private setup as per the decision of my family. It was very expensive. Chemotherapy was from TCC, and all expenses were covered by the government treatment scheme"

Another survivor S15 who took the entire treatment from TCC said," I did not even spend a single rupee for treatment. I got the benefit of treatment schemes. But now, the expenses for the follow-up mammogram and hormonal medicine, have to be paid by me. We have to continue these medicines for 5-10 years. Only if these were covered too…."

S13 said: "My husband was a peon, so I was denied government treatment scheme as I am enlisted in the above poverty line category (APL). I could not take a costly medicine, which would help prevent recurrence". The criteria of treatment schemes may be detrimental to some [24].

"I went to a private hospital when my relative recommended a doctor, but the surgery was done by another doctor. That there are different modalities of treatment and for each one, there are different doctors, these were not known to us" said S1.

Being unaware of treatment facilities and schemes in the government setup, they go to private hospitals, leading to financial loss.

4. Social expectation

Cancer treatment results in long-term and late health effects as reported in the literature [25], which was also seen in our study. This may pose difficulties in their social normal duties.

"I cannot do much household work due to swelling of the arms. I am forced to decrease the speed of my work. I think I do only 70% of the work now."

"The work in the printing press involves lifting movements of the arm, which I cannot do now. I quit my job.", said S5 pointing to her right arm. The difficulties due to lymphedema were reported by other study participants who underwent surgery.

"I don't like to depend on others, but my family does not permit me to work, as my office is located far off".

"My husband and children don't allow me to do household work. It is difficult to sit idle. So, I take pain medication and do gardening work, which I like to do"

They also expressed their happiness in being able to support their family financially. The 44-year-old S7said. "After one year of treatment, I started to work. I am a manual labourer. My colleagues help me and I am happy that I can support my family"

S4 states, "Going to work decreases my tension. I feel happy as I forget about my disease"

"Now I am continuing my job, but switched to 'work from home', with permission of my employer," said S2.

Sometimes, the survivors themselves were concerned about their health and avoided work.

"I also don't want to do any strenuous work, just to be safe. My husband always helps with everything".

Thus, survivors have expressed their desire to return to work whether it is household chores or a paid job, as it gives them satisfaction, happiness, stress relief, and financial benefit.

5. Service provision-related experiences and expectations

Breast cancer patients have to undergo follow-up and mammograms for many years, though the interval increases with time. When asked about their needs during their follow-up, they said;

"We get a lot of information from others, but we are not sure whether it is true. If doctors had given us more information, it would be better." S6.

In a common busy outpatient department, doctors do not get more time to talk to them. This concern was also shared by S6 "Further, if the doctors also tell us about the symptoms of the disease recurring in other parts of the body, we could at least check. We know this is not possible in an overcrowded OPD where patients on treatment are also cared for."

"We would like to know the type of food we should eat, what exercises to do, etc. We would also like health workers to discuss other difficulties we experienced in addition to regular check-ups," said S8.

"I thought that sexual life was not possible after treatment. Nobody told us about such things", said S2.

"It would be good to have a counselling facility in our OPD"

Access to the facility was also a major concern.

58-year-old S15 "During the COVID period, I felt that, if some follow-up facility was available near my place, it would have been better".

"Even for minor illnesses, we have to come to the TCC, as doctors in our place don't attend to us", was raised by another survivor.

"I am a person whose both breasts were removed as part of my treatment. The comments from the health worker, about mastectomy, when I consulted a nearby hospital, hurt me a lot. Some facility with staff who respect and understand us…." said 52-year-old S4 with tears.

Health workers in noncancer hospitals may not be used to seeing patients who have undergone a mastectomy and may behave indifferently to the survivors.

Though they were happy with the follow-up at TCC, most have expressed the need for a special setup for survivors where they can get advice about diet, exercise, awareness about signs of recurrence, and even counselling facilities, in addition to their routine check-ups and mammograms. They believe they will get more support and respect in such a setting. Though our survivors have never heard of such a facility existing anywhere, they gave their views on their needs, which they would be glad to use if available.

6. Survivors as ambassadors

We asked the survivors' opinions about sharing their experiences with other patients.

S8, 67 years: "Newly diagnosed women from my place call me. I gave them support, told them about the treatment, and asked them to be brave. They felt relieved talking to me"

Even society wanted the survivor to help by giving moral support to their dear ones.

S12 said "Once during my follow-up, a man said his wife, who had been diagnosed with breast cancer, was crying and inconsolable. He requested that I talk to her. I told her to take me as an example and that she would also come out of this. I was happy that I could do something for her".

Another survivor said, "If I had a chance to speak with a survivor, my treatment would have been much easier. I feel that sharing experiences can make life easier for those under treatment"

Another survivour, S1, said, "One patient could not come to terms with her disease and committed suicide. I think a disease-free survivor can help in such situations, by speaking to such people, boosting their morale, and setting an example that the disease is curable"

58-year-old S15 "I purposefully did not regrow my hair after treatment. My hair will remind others of my disease, and I want to be a role model to tell them that this disease is curable"

The survivors were taking it as their responsibility to be a role model for others. They were also ready to share the mistakes they made so that others wouldn't do it.

"I was foolish enough to take some traditional medicine, for which I became allergic and suffered a lot". The 65-year-old mother, S14, told others to go for scientific treatment only and not to get trapped with unproven cancer treatment.

52-year-old S3, diagnosed in the third stage, said "I have shared my experiences in social media, and write articles about my cancer experience so that nobody suffers from a delayed diagnosis due to lack of awareness like me".

The fact that survivors can go a long way in creating awareness is clear from the above statements. Surprisingly, they can also help in early detection. 53-year-old homemaker, S5 said, "I am not a health worker, but I was surprised when one of my friends asked me to examine her breast lump. She told me that since I already had the disease, I would know the feel of a cancer lump".

Discussion

This is the first study from South India discussing the issues of long-time survivors and their views about survivorship.

Perceptions about survivorship: Various dimensions of survivorship were expressed by our survivors. As in other studies, our survivors also attributed positive and negative feelings when asked about the meaning of 'survivor', and expressed the feeling that the disease was not yet conquered [26]. They mentioned fighting the battle, being cured, and completion of treatment as the meaning of being a 'survivor', in confirmation with other studies [14].

Body image concerns due to mastectomy and not involving them in discussions regarding crucial decisions, such as removing an important organ, were in confirmation with another Indian study [27]. Though survivors in our study confess good physical relationships with their spouses, there were studies with contrary opinions as well [28]. Another study also mentioned that older women were less concerned about body image than young survivors, similar to ours [29].

Survivor and stigma: In general, society looks at 'cancer' as a terminal disease and a death sentence [30]. Stigma is a major source of distress and social isolation for those living with cancer, along with various demographic, disease-related, and psychosocial variables related to it [31]. The experiences shared in our study also relate to manifestations of cancer treatment, such as hair loss and mastectomy, as being stigmatising, when others perceive it as abnormal, or as the identity of a cancer patient [30]. The general discomfort of being with a cancer patient or fear was seen in another study from South India, which also explains the experience of our survivor with hair loss or the weird behaviour of friends [32]. People may feel uncomfortable speaking to cancer patients, due to this unfamiliar identity [30, 33], which may also be perceived as unsupportiveness, as expressed by our survivor. Though the initial social exclusion may be part of providing rest, it may be painful if it extends beyond treatment, as described in our study [30]. Support groups with others who are going through similar challenges may provide a safe place [33, 34]. Although family and societal support are important to a survivor [35], our study participants have stated that they felt uncomfortable at times, as in another study [27].

Fear of recurrence is a key concern for survivors, as expressed by women in our study, leading them to opt for the removal of entire breasts even when conservation was possible [16, 36]. Thinking about the stress it may induce in their dear ones, many patients avoid divulging their fears of recurrence, as expressed in another study [33].

The hope of being disease-free, and the urge to live long with their near and dear ones, helped them accept the changes, live life to its full, and move forward. Similar appreciation for life and relationships, improved self-care, and recognition of their inner strength were also discussed in other studies [14, 37].

Social expectations: A good workplace environment, and support from employers, colleagues, and family were the needs of these survivors to return to work. The fact that work reduces stress, and brings about financial security was also seen in our study [38] As in ours, other studies also state physical disability due to treatment [39] causing functional impairment [40], leading to adjustments and modifications in day-to-day activities [41, 42]. Changes in employment among long-term survivors were more due to personal factors such as self-concern or restriction from family, or work-related factors such as distance to the office, more demanding work beyond disability, as in our study [38]. The change from a caregiver's role to someone receiving care was experienced by most of these women [43], while facing challenges with household chores.

Socioeconomic support: Various treatment schemes of the government support cancer care [24], but accommodate only patients living below the poverty line (BPL), based on the state-level BPL census [44]. Most of the schemes available in India do not cover all medicines or have limited coverage [44], leading to high out-of-pocket expenses(OOP) [45] as expressed by our survivors. OOP expenditure is three times higher for private cancer care in India [46]. Lesser access to tests for secondary prevention of breast cancer in India further increases OOP [47].

The survivor as 'ambassadors of cure': The voices of people living with cancer are important in shaping the societal image of cancer and debunking myths [30]. From the statements of our survivors, it is clear that survivors were happy to become ambassadors and wanted to showcase themselves as role models of cure. They can facilitate early detection, provide moral support during treatment, and alleviate the existing fear about the disease and its treatment. Literature also supports the fact that these survivors can become breast cancer advocates and spread the message of curability [48]. It was also noted that patients found it more comfortable to approach the survivors for advice regarding their cancer journey. Unscientific treatment by local quacks can be harmful to the health of the patient or lead to disease advancement, as precious time is lost [49]. The experiences of survivors can help to create awareness about unscientific treatments as stated in our study.

Service provision-related experiences: Being diagnosed with cancer in itself is a stressful journey. Survivors often found themselves sandwiched between illness and health. While the health worker concentrates on cure, there are survivorship issues beyond cure that need to be addressed [19]. Our survivors have expressed various needs, like special clinics where their problems are heard with patience, counseling facilities, accessibility of follow-up care [18], and the presence of trained health staff who communicate with them, as seen in another Indian study [50]. A humanistic and empathetic approach from health workers and doing away with that 'casual approach' to symptoms during follow-up was also a concern raised by our women [28]. The health worker-patient relationship was found to be associated with the adoption of a healthy lifestyle in the survivor [51]. The knowledge about symptoms of recurrence would help in early medical consultation. The overburdened health worker may not be able to give proper guidance in the regular hospital clinic [52]. Survivorship-related services are not integrated with cancer care, in India at present [53]. Giving psychosocial support, and empowering survivors for self-support with productive activities would minimize the trauma caused by the cancer treatment. Only less than half of countries with a National Cancer Control Program addressed survivourship care, with 14.3% of low-middle-income countries, including India, lacking such a facility [53]. Such facilities exist in developed countries [54], and guidelines for survivorship care have been formulated by experts in cancer care, such as ASCO and NCCN [25,55].

In conclusion, this is the first study from North Kerala to provide insight into the experiences of long-term breast cancer survivors, which can guide survivorship plans. Specialised facilities with tailor-made approaches for addressing post-treatment issues, effective communication, providing employment opportunities, extending coverage of follow-up medicines by schemes, and breast cancer support groups, can alleviate most of the survivorship issues.

Strength and limitations

In this study, survivors from varied sectors were included for an enriched understanding of their survivorship. This is a single-centre study, and the experiences may be influenced by the geographic location. The limited sample size, though acceptable, may affect generalizability. Only survivors who were disease-free at the time of data collection were included, which excludes perspectives of those with recurrence or ongoing treatment. Future research on survivors with recurrence is suggested to provide a more comprehensive view.

Statements and declarations

Competing interests

The authors have no relevant financial or non-financial interests to disclose.

Author contributions

All authors contributed to the study's conception and design. Conceptualization: NAP, SK; Design: NAP, SK; Literature search: NAP; Data acquisition: NAP; Data analysis: NAP, SK; Manuscript preparation: NAP; Manuscript editing: NAP, SK; Manuscript review: SK. All authors read and approved the final manuscript.

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