

Perceived Need Experience Of Breast Cancer Survivors Seeking Health Care – A Qualitative Approach

Shankar Shanmugam Rajendran¹, Dr Pradeep kumar Naik², Rajeswari Subramaniam³

Nirmala Asaithambi⁴, Shakila Shankar⁵

¹Associate Professor/Reader, College of Nursing, Madras Medical College, Chennai-3.

²Professor & HOD, Dept. of Biotechnology & Bioinformatics, Sambalpur University, Odhisha.

³Nursing Tutor, College of Nursing Madurai Medical College, Madurai, TN

⁴Nurse Educator/Independent Researcher, Chennai

⁵Staff Nurse, NIRT/ICMR, Chennai-17.

Corresponding Author:

Dr Shankar Shanmugam Rajendran, Associate Professor/Reader, College of Nursing, Madras Medical College, Chennai-3. Email: shankarshaki@yahoo.com

ABSTRACT:

The diagnosis and treatment of breast cancer may have a significant effect on a woman's overall health. Breast cancer cases and survival rates have been steadily increasing, putting an added strain on healthcare needs and facilities. Thus, thorough and in-depth understandings of the perceived needs of breast cancer survivors are critical for enhancing their quality of life. **Aim:** To explore the perceived needs of the breast cancer survivors. **Methods:** This qualitative phenomenological design was conducted involving breast cancer survivors attending medical & Radiation Oncology outpatient department using purposive sampling technique. A semi structured open ended questions for in-depth interviews and Focus Group Discussion were used to elicit data. **RESULTS:** The core themes which emerged as a result of thematic analysis were Physical and Psychosocial Need, Coping Strategy, Treatment Compliance and Quality of Life. **CONCLUSION:** Clients suffering with breast cancer should be assessed for perceived needs to enhance their quality of life. Oncology nurses play a critical role in breast cancer survivor's care. Nurse led management seemed to be effective in providing specific evidence-based practice pertaining to the perceived needs that could help the patients to improve and lead a life in a productive and peaceful manner.

KEYWORDS: Breast cancer Survivors, Nurse led, Perceived needs, Quality of Life.

Article Received: 10 August 2020, Revised: 25 October 2020, Accepted: 18 November 2020

INTRODUCTION:

Breast cancer contributes to a high incidence of mortality and morbidity among women. Breast cancer is a rapidly growing disease with an estimated 19.3 million new cancer cases by 2020, with breast cancer accounting for 11.7 percent of all new cancer cases, even surpassing lung cancer^[1]. The projected incidence of cancer patients in India among females was 7,12,758 for 2020, and 1 in 29 females develop breast cancer^[2]. Moreover, 14% of women, i.e., 1 in 28 females, are affected with breast cancer, and urban women are more affected than rural women. Cancer survival is more difficult in higher stages, and 50% of Indian women suffer from the 3rd and fourth stages of cancer. Breast cancer prognosis has significantly improved over time, and currently, 90% of them were in 5-year survival rates and 80% of them in 10-year survival. The crude Incidence Rate (CIR) of breast

cancer among women in Chennai was 47.7 for one lakh population^[3]. The Tamil Nadu Cancer Registry report (2012-2015) and ICMR's National Cancer Registry Programme 2020 showed that at Chennai, 52/ 1 lakh were affected with breast cancer, which contributes a two-fold increase from a decade ago, which was only 26 or 27 per lakh population and it accounts for 25% - 30% of all female cancer. The survival rate of breast cancer patients has increased due to advancements in medicine^[4]. Breast cancer diagnosis and treatment produce a profound effect on a woman's physical, psychological, social, and spiritual well-being, which produces an adverse effect on the QOL of survivors of breast cancer^[5].

The quality of life and patient satisfaction are contingent on cancer morbidity outcomes, which do not take into account the survivor's view of their condition and treatment processes^[6]. The assessment

of the survivors had several positive sides in improving their quality of life. To begin, it is critical to understand the patients' perceived needs in relation to their needs and outcomes, as this assists in determining the necessary resources. The actual needs of the survival do not reflect only on the problems and symptoms^[7,8]. Next, it allows in the identification of the need for help; hence by scrutinizing the needs and allocating the resources^[9]. Analyzing unmet perceived needs is critical for improving their quality of life, which is critical throughout the breast cancer survivor journey^[10-12]. Late identification of unmet needs has a detrimental impact on the quality of life of breast cancer survivors, thus lowering their treatment needs and costs^[13-17].

Although breast cancer patients have a better prognosis, it was well known that they suffer from long-term distress and stress. Hence the elucidation of the differences in breast cancer survivors' perceived needs is important for healthcare workers in planning care. Survivors may also need ongoing monitoring for cancer recurrence and the development of new cancers. Thus cancer can be perceived as a chronic condition, and recommendations are emerging for long-term survivorship care. Cancer survivors who have other chronic conditions or health risk factors may face additional challenges during cancer treatment and follow-up care at the time of diagnosis. Very few studies are present in

India exploring the perceived needs of breast cancer survivors. Hence the researcher felt it was necessary to assess the perceived needs on an in-depth basis by qualitative research basis.

MATERIALS AND METHODS:

Study Design and Patients: A qualitative phenomenological research design was conducted to explore breast cancer survivors' perceived needs. The purposive sampling technique was used to choose the samples. The participants were selected from those attending the Medical & Radiation Oncology Department, Tamil Nadu Government Multi Super Specialty Hospital, Chennai – 02.

The inclusion criteria were a) diagnosed as Breast cancer patients seeking treatment for at least six months, b) able to understand and speak Tamil c) patients attending the cancer Outpatient and Inpatient department.

The exclusion criteria were a) Not able to speak Tamil, b) Not willing to participate, c) Having Comorbidities.

Data Collection:

Interviews:

The study participants were informed about the study in their known language; both oral and written consents were obtained. The interviews were conducted with a semi-structured interview guide as a three Focus group discussion and five in-depth one-to-one interviews to explore breast cancer survivors' perceived needs. The interviews are conducted to explore the unrevealed areas concerning the impacts of perceived needs among breast cancer survivors. The interviews are digitally recorded and transcribed verbatim.

Ethical Approval: Ethical approval was granted by the Institutional Ethics Committee of Tamil Nadu Govt. Multi-Specialty Hospital vide ref. no. 1577/P&D-I/TNGMSSH/2017/PMS/ 003/07/2020. The study was also registered with the clinical trial registry of India no. CTRI/2020/08/027291.

Data Analysis: The material was transcribed verbatim, and the researcher independently read the transcripts multiple times to become familiar with the data and acquire an overview of the text. Then, the transcripts were reviewed for content. Text corresponding to the matrix categories was coded and transferred to these categories. Any coding inconsistencies were discussed until consensus was reached. A description of each category was then developed.

RESULTS:

Based on three focus group discussions and five interviews, the study results evolved with the themes of **Physical and Psychosocial Needs, Coping Strategy, Treatment Compliance, and**

Quality of Life.

THEME I: PHYSICAL AND PSYCHOSOCIAL NEEDS

Sub Theme 1: Loneliness

Most of them are under stress if they are alone. Some of the survivors feel that whenever they go to a function, they are talking about them and looking at them. So to avoid such a situation, they need company. In other words, it is difficult for most of the respondents to go out somewhere without someone accompanying them. However, the situation is different for a person who thinks people around her interact in a loving and caring way, giving her more confidence. However, she also needs someone to accompany her, and she feels people look at her with wretchedness.

Sub Theme 2: Low Self Esteem

The breast cancer survivors were affected by their physical disfigurement, which stigmatized them from societal functions. They lacked in their self-esteem, and some of the respondents explained that even though their family members and people were good to her, they might exhibit different thoughts when she was not present. Most of them found it reluctant to wear the sarees while going outside.

A participant verbalized that -*"Feeling sad is constant. If someone looks at us as an enemy, then I feel really bad. We do not know what they speak behind us. In front of us, they are all normal, and they do not hurt us. First, I had that hesitation, but later I did not feel anything as such. Got the courage saying this is what I have got because of fate, after that, I have not thought of it also"*.

Sub Theme 3: Sleeplessness

When it comes to peaceful sleep, the majority of the participants responded negatively. Many participants explained that they could not sleep well if there are any thoughts in their minds. Mental reasons were outweighing the physical reasons for sleep. Some take medications (not sleeping pills) to get sleep. For some, it is the body pain which doesn't give them sleep, and also, one of them has after-effects of sleep which include indigestion which results in sour burps. Another participant says if she doesn't sleep, she feels like a headache and feels dizzy.

The verbalization of one of the participants was, *"I cannot get sleep. I do not know whether it is because of the worry I have about this or because of my body's reaction to it; I do not know. That is the pain. I do not get much sleep. I do not get sleep because of this hand pain; that is why I take sleep tablets. I will take it once a week, then the next day, the whole day will be drowsy, so I stopped taking it. Sleeping is not okay because of pain. If I do not sleep, then I do not feel energetic or become lazy. Whether I eat or not eat, I do not get sleep"*.

Sub Theme 4: Fatigue

Most of the respondents say that although they can work, they cannot work more because of pain, and some explain their day was painful and fatigued even by doing simple household works. Their treatment's side effects had a profound impact on their well-being, and they were verbalizing that they had no strength to do their works. Some of them felt dizzy, and every time she stands, she feels to sit immediately. Drowsiness is also there among them.

Based on the participant's verbalization, *"I am not able to lift this hand at all. They say if we operate*

and then give current (radiation), it will be okay. If I wash too many utensils, I will become breathless. Now I do not know any difficulty as such. The only problem is this hand pain. Only after physiotherapy is I able to lift it so much. We are spending on small treatments like this—no worries as such. Pain is there, and the hand is weak. It would be there for 4 to 5 days, drowsiness. I can do small household chores, but I do not scrub and wash utensils because if I do, I will get chest pain. I will not be able to lift this hand. I am not able to put any workload on this hand."

Another respondent verbalized, *"Compared to earlier, it is better now. I go to physiotherapy and do some exercises. Now it is better. When I got my first chemotherapies, I felt that area was a bit rough. Now it is okay to an extent. When we have undergone such major surgery, we cannot be as usual. The work gets late because they have told me I should not lift any weight on this side. Cutting vegetables, household chores will all get delayed; I will be able to do it late only."*

THEME II: COPING STRATEGY

Sub Theme 1: Stress Management

The coping strategies followed by the participants vary significantly from person to person. Most of the respondents agreed that they manage their mental stress by talking to their near ones, while some of the participants concentrated on their business to feel relaxed, and it acts as a diversion.

The participant's narrations were *stroke their hand on my head and ask "Granny, when will your hair grow? It is like this" and makes fun (enjoying kind of tone), they are small kids. I feel very happy then"*.

Another participant's narrations were, *"I feel happy when my children, daughters-in-law, and grandchildren come. Yes, they all visit once a week. Then I feel very happy. In between, also when I am watching serials or speaking to neighbors, I feel happy. One 10th standard girl got admitted, even though she had the disease. At least we are elderly, but that small girl has got it, she is a student, she is suffering, seeing all that I consoled myself. What to do, God has given this"*.

Sub Theme 2: Spiritual Well-Being

Understanding how the participants connect themselves with God is significant with the coping strategies adopted by them. Most of them considered God as a reason for their condition, for some out of it said that God had given them this, so they have to bear it. At the same time, some others think God could have given more, but he is grateful enough not to do that. Some other survivors think they survived

only because of God's grace. For others going to the temple or praying would give them satisfaction. Most of them agreed that their belief in God has increased to an extent.

"I am alone. I feel happy when I go to the temple. I go there and sit for a while and feel relaxed."

Whatever we have got is the fate written by God. With the grace of God I am happy. I pray God saying, "Let me get sleep, let my hand pain get relieved," pray for half an hour and then go and lie down.

THEME III: TREATMENT COMPLIANCE

Sub Theme 1: Health Wise Needs

Even though the participants feel uneasy and pain while taking medications. However, to prolong their lives and lead a better living, they consistently followed their treatment regimen. The majority of the respondents describe how "the treatment starts with eight chemotherapies and then radiation and further injections and as last step tablets are prescribed which should be taken consistently."

Another respondent who suffered because of COVID-19 said, *"After coming here (the present hospital), I got operated. There was water oozing from it, but I stayed at home as there was Corona. Now I have come, and I am taking further treatment. A problem in pain, they did physiotherapy and gave a current (maybe ultrasound). They gave tablets for chemotherapies, that is it. I will do exercise for at least half an hour. Since the time I started physiotherapy, I have been exercising. I eat, and I will sleep"*.

Sub Theme 2: Health Care Needs

Most of them agree that the hospital service and care are good, and they are satisfied with it. An opinion from the respondents furnished the information that they were aware of their condition and followed that to a moderate level.

"After coming here, the senior doctor took good care of me. I got admitted for one month. That is when the doctor spoke to me, saying, "Do not get scared. This is what is to be done." He filled me with courage, saying if everything is done, I will be all right. That courage is still there in me. Nevertheless, further information will help us."

Regarding care in the hospital, one of them says that doctors tell her not to worry, which gave her confidence. Whereas another person says, everyone including the staff, speaks and interacts well. Also,

one person mentioned that no special preference or bias is shown to anyone. Everyone is treated equally.

Sub Theme 3: Acquisition of Information

Although this was not exclusively asked, most of them said they follow the instructions told by the hospital correctly. However, they were not provided with adequate information to their expectations.

A person says that the doctor gave her an instruction pamphlet which you are supposed to follow. She says

"finish the chemotherapies and come, the doctors will give a paper (instruction pamphlet), "Be like this, do all this, if you notice anything like this get it checked." They have not told you what you should not eat; they say you can eat whatever you like, there is no problem, but avoid non-veg, that is because post-surgery might cause infection if it turns to a wound it will be difficult. Other than that, you can eat everything good".

THEME IV: QUALITY OF LIFE

Sub Theme 1: Financial Crisis

Financial concerns have a major effect on the quality of life of breast cancer survivors. For others, it has a direct effect on their healthcare costs. In contrast, for others, their disease condition influences the nature of their caretakers' job and job loss, which indirectly influences their source of income and livelihood.

A person commented on her daily hardships *"For me, it is my daughter only. I lost my husband. My son also passed away and should depend on her for my needs."*

Another respondent said that "All kids are staying in different, different places. Only me and my husband have come here. Even he does not have a job. He was working. As he started taking leave very often, he lost that job. He is accompanying me in bringing me and taking me back."

Sub Theme 2: Family Reinforcement

Most of the participants insisted that they shared their condition with their family members and friends, which reduced their burden due to their condition. However, on the other hand, they were disturbed that their condition impacted a lot and changed their family members' routine and which in turn imposes a burden on the family's financial factor. However, all of them responded that they received greater support from their family members.

A participant verbalized, *"Even though it was tough for the mind, children solaced me, even my husband was very solacing. I do not wash clothes or any such*

work, and the daughter does it. The siblings were the support for me. They filled courage, saying, "Do not get scared. Nothing will happen. Everything will be fine." Even the neighbors also said the same. About the help, it was relatives who gave some money and helped with the expenditures".

Sub Theme 3: Impaired Physical Relations/ Sexuality

The physical relations and the sexual function among the breast cancer survivors were majorly concerned or obligated to satisfy their husbands than themselves. Some of them expressed fear of being in a relationship, but in some other cases, the respondents have been told by their relatives to stay away from the husband as it may harm him. Some respondents expressed guilt as their husband started drinking without expressing his sexual desire, which she cannot satisfy, and some of them expressed they had pain during intercourse. However, overall the sexual relationships among the breast cancer survivors were greatly affected.

"I feel like asking about it with the doctor, but here I am not able to speak to them freely. First, the body has to get recovered. We have not thought about it as of now. That is because we have two kids, and we have reached the age of 40, so he says, "give importance to health, take care of it." If you tell me about the relationship, I will learn about it".

DISCUSSION:

The study results revealed that the physical and psychosocial needs, coping strategy, treatment compliance, and quality of life themes were an outcome of the perceived needs of breast cancer survivors.

Fear, low self-esteem, and stigma were the most commonly observed patterns among the respondents. These, in turn, lead some towards **mental stress**. Fear was there because before getting this disease, the respondents have pictured breast cancer as a danger or death. Their past experiences have created this fear, the people around them, and the whole society.

Another factor is **low self-esteem** which was visible in most of the respondents. This can be observed when they interact in society. This low self-esteem builds with each function or social interaction. They think that others are talking behind their back. This means that they gossip when the respondents are not present, which creates an **inferiority complex**.

Moreover, another significant aspect is the breast, which is removed post-operation, yet another symbolization of women culturally and biologically. Some of them use pads, cloths, or other materials to

fill the removed breasts' void. This further raises their inferiority complex.

Stigma is not experienced by most but a few. However, the stigma here is discriminating against the person or treating them differently and affecting the next generation in their family. **Loneliness** is another significant aspect concerning the subjects. That being alone increases their stress. Thus they always require a company. These patients always need someone to accompany them. In addition to all of this, a theme found common among the participants is **guilt**. They believe that it is because of them the overall situation of their family got worsened. Another observation is that some of the respondents hesitate to touch or come closer to the relatives, who do not disagree with their approach. One of the most used methods to relieve themselves from the pain and mental stress is talking to someone. As mentioned earlier, being lonely creates a tense environment, whereas conversing or spending time with others could soothe them.

Family support is a feature that has a massive effect on these respondents. In the family, it is mostly the closest kin to whom the respondents first shared their experience. They separate themselves from society, and this further could be a reason for stress.

Sleeping is arduous for some, whereas others have their mechanism to get a peaceful sleep. However, no one takes any sleeping pills. There are physical as well as mental reasons for them not to be able to do so. Drowsiness, body pain, breathlessness are found to be common concerning the health of the respondents. Regarding the physical relation, according to the interviews, the respondents are more concerned or obligated to satisfy their husbands than themselves.

Nearly all the participants do not know detailed knowledge about the disease, treatment, and treatment duration. However, they followed all the instructions received by them through doctors. These include chemotherapies, radiation, and medicines to be taken.

A greater number of the respondents receive much love and care from their family members and hospital staff. The **financial situation** is deficient and poor for most families, but they are working hard to meet ends and give them a quality life. Concerning diet, the respondents inclined more towards fruits and vegetables and hot beverages like tea and coffee. Doctors are very supportive and ensure the patients do not worry. However, it is astonishing that only a few doctors have suggested using pads. These pads, which would help fill the void as the breast is

removed, are not suggested by most doctors. Thus, most of them do not know, or those who wear clothes are in a dilemma whether to use them or not.

We have already mentioned the situations of the respondents in their daily life. More information is to be given to the patients or survivors to cope with the people around them. Explaining them in subject matters of disease, treatment, and its after-effects is to be prioritized. Apart from these, certain measures should be taken: counseling to reduce their mental stress, teaching to use pads and wigs, physical relations, and courses to deal with the people who are not aware of it. Moreover, lastly, to approach people with confidence, the survivors themselves should not be in tension. They should be taught to eliminate their inferiority complex in public places.

With this, we can understand that the most significant aspect they require is acceptance. Acceptance in society and family gives them a pleasant environment. The first step is to make people much more aware, which includes men and women. Breast examinations should be promoted in remote areas that don't have much knowledge. This awareness is to be cautious when this disease would occur and learn to accept such people.

The present study findings were consistent with the study, which evolved with the themes of supportive relief and therapeutic support, which implies their symptomatic relief and informational needs^[18]. The study results among male breast cancer also revealed the themes of living with the women's disease, barriers, coping, and supportive care needs^[19]. The breast cancer survivors' needs were based upon financial burden, informational needs, family support and counseling, and emotional support^[20].

CONCLUSION:

Breast cancer is a dreadful condition, and living through that is hectic. They need physical and psychosocial support, all of which contribute to breast cancer survivors' improved quality of life. As a result, the oncology nurse's role in developing supportive networks and policies is critical in meeting their needs. A nurse-led survivorship program has to be developed in each health sector in assessing and rectifying the perceived and actual needs of the breast cancer survivors.

REFERENCES:

1. Sung H, Ferlay J, Rebecca L, Siegel, Laversann M, Soerjomataram I, Jemal A, Bray F. Global cancer statistics 2020: GLOBOCAN estimates of incidence and

- mortality worldwide for 36 cancers in 185 countries. CA journal for A Cancer clinicians .2021. doi: 10.3322/caac.21660
2. Mathur P, Sathishkumar K, Chaturvedi M, Das P, Sudarshan KL, Santhappan S, Nallasamy V, John A, Narasimhan S, Roselind FS. Cancer Statistics, 2020: Report From National Cancer Registry Programme, India.JCO Global Oncology .2020; 6: 1063-1075
3. Incidence of breast cancer high among women in Chennai: Study.https://images.newindianexpress.com/images/FrontEnd/images/new_logo.jpg. Published: 13th October 2020 04:35 AM
4. Akca M, Ata A, Nayir E, Erdogan S, Arican A. Impact of Surgery Type on Quality of Life in Breast Cancer Patients. J Breast Health. 2014; 10: 222-8.
5. Li J, Humphreys K, Eriksson M, Dar H, Brandberg Y, Hall P, et al. Worse quality of life in young and recently diagnosed breast cancer survivors compared with female survivors of other cancers: A cross-sectional study. Int J Cancer .2016;139:2415-25.
6. Cossich T, Schofield P, McLachlan SA. Validation of the cancer needs questionnaire (CNQ) short-form version in an ambulatory cancer setting. Qual Life Res. 2004; 13: 1225-33
7. Bonevski B, Sanson-Fisher R, Girgis A, Burton L, Cook P, Boyes A. Supportive Care Review Group Evaluation of an instrument to assess the needs of patients with cancer. Cancer. 2000; 88: 217-25
8. Osse BH, Vernooij-Dassen MJ, Schade E, Grol RP. The problems experienced by patients with cancer and their needs for palliative care. Support Care Cancer. 2005; 13: 722-32
9. Fiszer C, Dolbeault S, Sultan S, Bredart A. Prevalence, intensity, and predictors of the supportive care needs of women diagnosed with breast cancer: a systematic review. Psychooncology. 2014; 23:361-74
10. Adler NE, Page AE, editors. Cancer Care for the Whole Patient: Meeting Psychosocial Health Needs. National Academies Press; 2008.
11. Osse BH, Vernooij-Dassen MJ, Schade E, Grol RP. The problems experienced by patients with cancer and their needs for palliative care. Support Care Cancer. 2005;13(9):722–32.
12. Epplein M, Zheng Y, Zheng W, Chen Z, Gu K, Penson D, et al. Quality of life after

- breast cancer diagnosis and survival. *J Clin Oncol*. 2011;29(4):406–12.
13. Akechi T, Okuyama T, Endo C, Sagawa R, Uchida M, Nakaguchi T, et al. Patient's perceived need and psychological distress and/or quality of life in ambulatory breast cancer patients in Japan. *Psycho-Oncology*. 2011;20(5):497–505.
 14. Husson O, Mols F, Van de Poll-Franse L. The relation between information provision and health-related quality of life, anxiety and depression among cancer survivors: a systematic review. *Ann Oncol*. 2011;22(4):761–72.
 15. Shim E-J, Mehnert A, Koyama A, Cho S-J, Inui H, Paik N-S, et al. Health-related quality of life in breast cancer: A cross-cultural survey of German, Japanese, and South Korean patients. *Breast Cancer Res Treat*. 2006;99(3):341–50.
 16. Mehnert A, Koch U. Psychological comorbidity and health-related quality of life and its association with awareness, utilization, and need for psychosocial support in a cancer register-based sample of long-term breast cancer survivors. *J Psychosom Res*. 2008;64(4):383–91.
 17. Carlson LE, Bultz BD. Efficacy and medical cost offset of psychosocial interventions in cancer care: making the case for economic analyses. *Psycho-Oncology*. 2004;13(12):837–49.
 18. Ghaemi SZ, Keshavarz Z, Tahmasebi S, Akrami M, Heydari ST. Explaining Perceived Priorities in Women with Breast Cancer: A Qualitative Study. *Asian Pac J Cancer Prev*. 2019 Nov 1;20(11):3311–3319. doi: 10.31557/APJCP.2019.20.11.3311.
 19. Nguyen TS, Bauer M, Maass N, Kaduszkiewicz H. Living with male breast cancer: A qualitative study of men's experiences and care needs. *Breast Care*. 2020;15:6–13. doi: 10.1159/000501542
 20. Dsouza SM, Vyas N, Narayanan P, Shradha S, Manisha GM, Sharan K. A qualitative study on experiences and needs of breast cancer survivors in Karnataka, India. *Clinical Epidemiology and Global Health*. 2018;6:69–74. <http://dx.doi.org/10.1016/j.cegh.2017.08.001>
