



Barriers to Early Diagnosis and Treatment among Breast Cancer Survivors: Qualitative Study in Tertiary Care Hospital, North Karnataka

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ABSTRACT

Introduction: Around the World, Breast cancer has become one of the common cancers among women. Prevalence and mortality of Breast cancer in India are 18 lakh & 12.7 per lakh cases respectively. One of the important reasons behind late presentation & high death rate is the lack of breast cancer awareness.

Objectives: To assess the barriers in diagnosis and treatment among breast cancer patients and to explore the perception about cancer prevention among them.

Methods: A qualitative study was done among women with confirmed breast cancer who were admitted to KIMS, Hubballi, and Cancer hospital, Navanagar in April 2019. Data collection was done by the In-depth interview method and analyzed as per qualitative study protocol standards.

Results: The data was collected among 14 participants. Themes were generated accordingly. The findings showed lack of awareness, myths, financial constraints, negligence were the major barriers to the early presentation of breast cancer.

Conclusion: This study showed barriers such as lack of awareness, negligence, fear, financial constraints, myths and misconceptions, social stigma, lack of family support. Measures taken to reduce mortality by early diagnosis and treatment.

Keywords: Qualitative study, In-depth interview, Breast cancer survivors, early diagnosis

INTRODUCTION

Around the world breast cancer has become one of the common cancers in women with more than 1.6 million new cases every year and 6 lakh deaths according to the Globocan 2018.¹ Prevalence of breast cancer in India is 18 lakh and mortality is 12.7 per lakh cases.¹ However, the rise in breast cancer incidence has been steeper in low and middle-income countries², including India, & reports indicate rising trends in breast cancer incidence.³ The high number of Breast cancer deaths is due to the fact that ~70%

of women with breast cancer present at late stage.⁴ This is also reflected in the fact that the five-year survival rate of breast cancer in India has not changed much from ~60% since 1995.⁵

The major risk factors for breast cancer are female gender, age more than 50, family history of breast carcinoma, BRCA 1 and 2 mutation.⁶ Increasing urbanization and westernization associated with changing lifestyle and food habits has lead breast cancer to attain top position in all major urban can-

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cer registries.⁷ Exercise and breast feeding are the important protective factors against breast cancer.⁶

One of the important reasons behind late presentation and high death rate is lack of breast cancer awareness. Mammography, clinical breast examination, monthly breast self-examination are the important methods for screening.⁸ Early diagnosis of breast cancer gives greater chance of long term survival and a better quality of life.⁹

There are still many myths and misconceptions related to breast cancer. Most of the women are not aware of common symptoms of breast cancer and hence do not consult doctor, resulting in low screening rates, and present at advanced stage of the disease causing increase in mortality.¹⁰ Breast cancer survivors are threatened with various problems due to disease itself or its treatment. These problems include fatigue, pain, osteoporosis and early menopause, inability to cope with the disease, traumatic stress, distress, depression, fear of recurrence, and family worries, sexual problems and infertility.^{11,12,13}

There are barely enough studies that explore the various factors behind the lack of awareness and other factors in India which prevent early prevention and early approach to medical care. The current qualitative study was undertaken to assess the barriers to early diagnosis and treatment of breast cancer & to explore the perception of prevention on Breast cancer mortality among breast cancer patients

METHODOLOGY

A Hospital based qualitative exploratory study conducted in KIMS Hospital and Navanagar Cancer Hospital, Hubballi in April 2019 among histopathologically confirmed breast cancer patients. Convenient sampling was used to recruit the patients during the study period.

Women with histopathologically confirmed breast cancer in KIMS Hospital, Hubballi and Navanagar Cancer Hospital, Hubballi were included in the study and women with advanced stage of breast cancer with severely ill, were excluded from this study.

Informed oral consent was taken assuring that their confidentiality will be maintained before approaching the patients and briefed about the study and permission was taken for audio recording. In depth interview was conducted in a separate chamber in a comfortable place & maintained their privacy. Socio-demographic details like age, education, occupation and family income. Initially we allowed the patients to speak regarding their illness, later to extract the information we needed, relevant questions were put forth. We interviewed about 30 to 40 minutes and relevant observations were made. The same procedure was followed for 14 participants. All audio interviews were translated into English and transcribed in Codes were intently revised by discussion with team members and converted into verbatim.

The data was read and re-read thoroughly to develop codes. Codes were intently revised by discussion with team members and themes were generated after thorough analysis of data. This information was used to frame barriers in comprehensive manner and depicted in tables and figures.

RESULTS

Out of 17 Breast cancer patients contacted during the study period, 3 of them refused to give consent. In depth- interview was conducted for 14 Breast cancer patients and also audio recorded. Characteristics of participants are depicted in Table 1. Among 14 patients 6 patients were >50years and 2 were Nulliparous women. Among them 2 were in stage 1 & 4 were in stage 2. After reviewing audio recording verbatim and codes were generated. With codes themes were framed which is mentioned in Table no 2.

Table 1: Demographic profile of the participants

Characteristics	Participants (%)
Age	
>50	6 (42.9)
<50	8 (57.1)
Religion	
Hindu	11 (78.6)
Muslim	3 (21.4)
Parity	
Multiparous	12 (85.7)
Nulliparous	2 (14.3)
Literacy status	
No formal education	10 (71.4)
Primary Education	4 (28.6)
Occupation	
Home-maker	3 (21.4)
Daily wager	11 (78.6)
Stage of disease	
Stage 1	2 (14.3)
Stage 2	4 (28.6)
Stage 3	6 (42.9)
Stage 4	2 (14.3)

Theme I: Awareness about Breast cancer:

This study shows that knowledge about Breast cancer is less among all the participants. There was lack of awareness among the participants. They believed cancer could spread from one part to other or it could recur. There is lack of awareness regarding treatment of cancer. (Fig1)

Theme II: Myths and Misconceptions:

Myths and misconceptions are one of the major factors leading to delay in presentation of patients. Irrespective of education and occupation they believed pain is the initial symptom of Breast cancer. They believed trauma to the breast, collection of milk in breast, poor hygiene, and food faddism were causes of Breast cancer

Table 2: Codes and verbatim of the participants

Themes/subthemes	Codes/verbatim
Awareness about Breast cancer	Knowledge: "I don't exactly know what Breast cancer is."-34 year old A Costly Treatment: "I just knew that treatment would be costly."-38 year old B
Myths and Misconceptions	Belief: "Pain is initial symptom of Breast cancer."-60 year old C "I had endured trauma to the breast. I think this caused Breast cancer."-48 year old D
Negligence	Care free attitude: "I Thought the lump will regress on its own."-46 year old E "I had a wedding in my family so I did not show early."42 year old F Prioritising family: "My daughter had delivered recently so to help her I did not consult doctor."40 year old G
Fear of Disease	Fear of Diagnosis: "I did not consult fearing that doctor would say it to be cancer."-46 year old E Fear of recurrence: "If cancer occurs in one part of the body then it can occur again in other part of the bodytoo."-52 year old H
Social Stigma	"People say cancer occurs to bad person."-51 year old I "I did not go out of home for many days as I had foul smelling water coming out of nipple."-38 year old B
Family support	Positive support: "My sons and husband took me to doctors and helped me get admitted here."-54-year-old J Negative support: "My husband did not support me at all. He started telling everyone in the community that I have cancer and if I die, he did not kill me."-44 year old K
Financial constraint	"I have spent around 60,000 rupees in last 6 months for treatment. My family is facing difficulty to get even 2 meals a day."-60 year old L "Even if I have BPL card travel charges, tablets from outside cost are high that affects my family."34 year old A "I should be accompanied by my brother or husband for which they do not get that day's wages."-44-year-old K
Post diagnosis reaction	Disbelief: "I cannot believe I have cancer. It is like I am in a bad dream."-38 year old M Sadness: "I feel sad that I have Breast cancer."-46 year old E Burden: "I feel like I am Burden on my family."-34 year old A
Post treatment reaction	Relief: "I am relieved that the cancer part is removed from my body."-42 year old F Body disfigurement: "Breast is pride of women; operation was to remove the whole breast. I feel depressed.-34 year old A "I cried for about 2 days when there was hairfall."-38-year-old E
Perception on prevention of Breast cancer mortality	"People fear Breast cancer. The fear among the people should be eliminated so that women can consult the doctor early."-54 year old J "If any lump is felt in breast consult as early as possible."-60-year-old "Both men and women should be made aware about Breast cancer."-44-year-old K

Theme III: Behavioural factors that prevent early detection of Breast cancer.

Negligence: There is delay in early consultation even after noticing lump in the breast. They thought the lump would regress on its own. They prioritize their family over their health. **Fear of Disease:** The patients were scared to hear about their condition and due to fear of recurrence there is delay in consulting a doctor.

Social Stigma: Patients restrict themselves & stay at home due to foul smelling nipple discharge. They be-

live cancer is due to their bad deeds

Family support: This study showed good physical and emotional support from the family. They also experience ignorance from their family

Theme IV: Financial Constraint.

Financial burden was most common domain for delay in treatment and missed regular follow-up. Even though all participants received treatment in government facility, they faced financial problems because they could not afford other expenses like travel, food, and drugs from outside medicals.

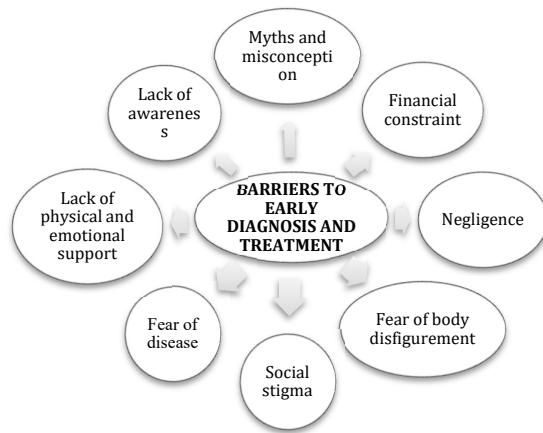


Figure 1: Barriers to early diagnosis and treatment of breast cancer survivors

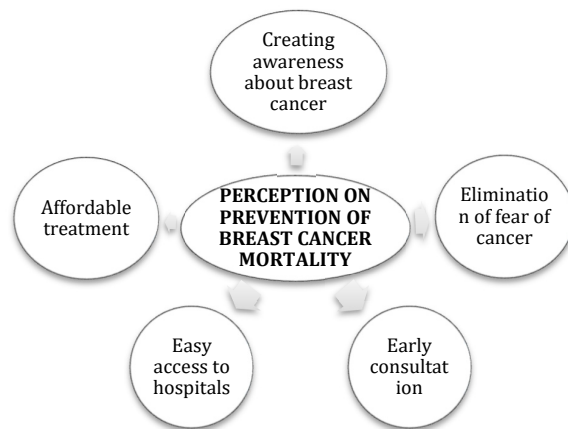


Figure 2: Perception on prevention of breast cancer mortality

They missed regular follow ups due to loss of daily wages not only of theirs but also of the person accompanying them.

Theme V: Post-diagnosis and post-operative reactions.

Participants felt sad and burdened post-diagnosis due to which they delayed treatment. Even though symptoms were relieved for most of them, but they were emotionally became weak because of body disfigurement or post-operative changes.

Theme VI: Perception on prevention of Breast cancer mortality.

Survivors believed increase in awareness and early consultation can reduce the mortality of Breast cancer. They also suggested eliminating fear of cancer goes a long way in helping women consult doctor at

the earliest. Providing affordable treatment will decrease financial burden on them. (Fig2)

DISCUSSION

The study was conducted to explore the barriers for early diagnosis, treatment and to know the perception about breast cancer prevention among breast cancer survivors. In-depth interview was conducted with 14 participants for this purpose.

The study revealed that most of the women are unaware about the disease and treatment so they ignored their symptoms, until these symptoms affected their routine activities which lead to delayed consultation. Similar results found in previous study^{14, 15} such as lack of awareness among rural and low socio-economic groups is the important reason for late presentation of breast carcinoma in women.

Myths and misconceptions among people regarding breast cancer symptoms like, considering pain as the initial symptom and regarding etiological factors like trauma, collection of milk in breast, consumption of certain vegetables etc. all these factors contribute as one of the main hindrance for early diagnosis of breast cancer. Patients also believed that curse by god or parents, have caused breast cancer in them.¹⁶

Participants in this study expressed, financial expenses for medication, travel charges loss of daily wages of the partner who was accompanying them caused burden their family. This led to barrier in early treatment, similar to previous study.¹⁵

This study revealed that participants had fear of diagnosis and recurrence of breast cancer; even after diagnosis they were negligent about their condition. Participants approached in the late stage, as they prioritise their family over themselves. Similar findings were found in a another study.¹⁴ where in spite people being aware of breast cancer, presented at late stage due to fear, ignorance and easy going attitude.

Family support is the key role in early diagnosis and treatment. Physical & emotional support is necessary to the participants. Most of the participants had good family support while some were neglected due to stigma. These findings were similar to previous study.¹⁶

Breast cancer survivors had fear of post-diagnosis and post-treatment reactions. They had fear of acceptance & post-treatment complications like, hair fall body disfigurement, due to which they skip treatment and regular follow-up which is similar to previous study.¹⁶

During the study participants suggested that awareness should be created about breast cancer, its symptoms and treatment. Financial support should be provided to rural and poor people through health schemes.

All these above factors lead to delayed approach to medical care. If these barriers are removed and misconceptions among people will be clear, then mortality due to breast cancer will be reduced.

CONCLUSION

This study brought out the barriers to early diagnosis of breast cancer, such as lack of awareness, negligence, fear, financial constraints, myths and misconceptions, social stigma, lack of family support. Lack of knowledge is a potential factor in delayed consultation. Necessary measures to be taken to break the barriers of early diagnosis and treatment of breast cancer. Measure like increasing awareness, large scale affordable screening, early consultations, treatment at reasonable prices, breast reconstruction surgery at low prices are main stay for the betterment of such patients.

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