Oncologist Perspectives on Breast Cancer Screening in India- Results from a Qualitative Study in Andhra Pradesh

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Abstract

Background: It is important to understand the perceptions of oncologists to understand the comprehensive picture of clinical presentation of breast cancer. In the absence of clear evidence, clinical practice involving patients of breast cancer in India should provide insights into stages of breast cancer with which women present to their clinics and mode of screening of breast cancer prevalent in Andhra Pradesh. Materials and Methods: A qualitative study was conducted to understand the perceptions of oncologists regarding clinical presentation of breast cancer, stages at which women present to clinics, and mode of screening of breast cancer prevalent in Andhra Pradesh. In-depth interviews (IDI) were conducted with ten practising oncologists from various public and private cancer hospitals in Hyderabad city to understand their perspectives on breast cancer and screening. The data were triangulated to draw inferences suitable for the current public health scenario. Results: Late presentation was indicated as the most important cause of decreased survival among women. Most women present at Stage 3 and 4 when there is no opportunity for surgical intervention. The results indicate that there is a huge gap in awareness about breast cancer, especially in rural areas and among poor socioeconomic groups. Even despite knowledge, most women delay in reporting due to reasons like fear, embarrassment, cost, ignorance, negligence, and easy going attitude. Conclusions: It is important to improve awareness about breast cancer and screening methods for promoting early screening. The study inferred that it would be beneficial to establish cancer registries in rural areas. Also, the policymakers need to make key decisions which among three methods (breast self examination (BSE), clinical breast examination and mammography) can best be used as a screening tool and how to successfully implement population wide screening program to prevent mortality and morbidity from breast cancer in India.

Keywords: Breast cancer screening - oncologists - factors causing breast cancer - preventive measures - Andhra Pradesh

Introduction

The urban cancer registries at 5 metropolitan cities located at Bangalore, Bhopal, Chennai and Mumbai in India are important sources of data regarding breast cancer in India (Kamarana et al., 2003). The data from these registries tend to focus greatly on the cancers near surrounding urban areas and have very limited inclusion of rural geographic areas (Babu, 2009). The pooled data on the number of Breast cancer cases among females in (Takiar and Vijay, 2010) indicates that the absolute numbers of breast cancers grew by 38% from 1998-2005.

However, the available evidence does not provide useful interpretations for identifying local prevalence of breast cancer and plan public health actions accordingly. It is not possible to answer one putative question: whether breast cancer is highly prevalent or not in rural areas of Andhra Pradesh or other such states in India, as we just do not have sufficient information to tackle this question.

In order to understand the epidemiological correlates, we followed two prong approach. One, we conducted a systematic review of evidence available on epidemiologic correlates of breast cancer addressing incidence, prevalence, and associated factors like age, reproductive factors, cultural and religious factors with specific focus on screening procedures in southern India (Babu et al., 2013). Second, we conducted a qualitative study to understand the perceptions of the oncologists regarding clinical presentation of breast cancer, stages of breast cancer with which women present to these clinics, mode of screening of breast cancer prevalent in Andhra Pradesh. The current article describes the results from qualitative study. The two prong approach was designed to understand comprehensive nature of determinants, which may be useful to plan for future public health programs.

Treating doctors from public and private tertiary oncology hospitals and institutes will have better insights into the problems of early screening among women and also provide inputs for betterment of the existing screening methods. Our study was planned to capture the opinion of these important stakeholders in cancer control. It is vital to understand their insights in order to understand the correlates of screening among women in Andhra Pradesh, India. This will help in planning educational programs,
prevention campaigns and also influence policy making for breast cancer screening in India.

Materials and Methods

The objective of this paper was to understand physician perspectives regarding current trends in clinical presentation, clinical features and screening methods followed by women with Breast cancer in Andhra Pradesh. Practicing Oncologists working in different public and private hospitals in Hyderabad city were approached for gathering information. They were selected as per their convenience and availability for the interview. Prior appointment was sought from the Oncologists after seeking their administrative approval. They were met at the date and time given by them. They were briefed about the study, taken consent for the interview. They were assured that anonymity will be maintained by the researcher and the information provided by them will be kept confidential. Permission for audio recording the interview was sought from them. The interview was conducted in English language as per the Guidelines developed (Table 1) and recorded both in the tape as well as transcribed by note taking. Each interview lasted for 10 min to 40 min duration with an average duration of 20-25 min, based on the response of the Oncologist and their available time. Like this, 10 interviews were conducted with different types of Oncologists (refer Results section).

Following questions were asked in the interview guide (Table 1) for conducting the interviews: Epidemiology of Breast Cancer in Andhra Pradesh, Presentation of Breast cancer by women in AP, Prognosis of Breast Cancer, screening, Risk & Recommendations to Health Perceptions and Knowledge and recommendations for Improved Practices.

Data management

MS-Excel was used to code the qualitative information from each of the interview. From each interview, the data was divided into Key themes with many subthemes under it, based on the guidelines used for conducting the interview. The information was then coded into these themes and subthemes. Where possible, relevant quotes used by the Oncologists were used for supplementing the information provided under each sub theme. The coded information was analysed and the themes emerging out of the information were identified. Transcripts were studied repeatedly to identify and list important and recurrent themes in women’s accounts of their experiences. This framework of themes and patterns generated an index of major themes and sub-themes, each of which was assigned a number so that the index could be applied systematically to all the transcripts.

Results

A total of 10 Oncologists were interviewed for the purpose of the study, of which 4 were Radiation Oncologists, 2 Medical Oncologists, 2 Surgical Oncologists and 2 were Gynec Oncologists. There were 4 Female Oncologists and 6 Male Oncologists among the group. Among the 4 hospitals visited, one hospital was public sector Oncology Institute, which caters to the rural low and middle socio economic groups while the remaining 3 hospitals were private Institutes which mainly cater to the middle and high socioeconomic groups. Two of the Oncologists did not give consent for audio recording of the interview while the remaining 8 of them consented. The summary of the results is presented in Table 2.

Epidemiology of breast cancer

Lack of Cancer Registries: In India, lack of proper cancer registries was the major barrier in providing estimate on Cancer epidemiology. However, Breast cancer has now become more an urban disease as compared to rural areas, Reasons include, life style factors, availability of facilities for screening.

Majority of Oncologists commented that Breast cancer is more an urban disease than rural. Major factors for increased urban incidence are due to increase in awareness levels and also facilities for diagnosis.

Current incidence

Three of them could not comment on the incidence figures as they felt that there are no tumour registries in India.

‘I cannot comment on the incidence and prevalence of breast cancer as we do not have a tumour registry in Andhra Pradesh. What I see is many younger women are being affected’ Medical Oncologist, 38 years.

The average number of new cases in a month were reported to be around 15-20, we get 15-20 cases per month in this hospital. Prevalence is 10 cases. Age group affected is 40-50 years- Radiation Oncologist, 52 years, Govt Cancer Hospital.

‘Our hospital will get about 10000 cases every year, out of which people with breast cancer are around 1500. 20 to 50yrs age group. Largely of middle age. In Andhra Pradesh, women of the age group 40-55 are more affected’ One of them mentioned the incidence to be 1 in 12-15 women, which is higher than globally reported figure of 1 in 10. Depending on the size and accessibility of the hospitals, the new case load in private hospitals was reported to be 20-50 (which is related to the reported high urban incidence). Among the rural poor, the incidence was reported to be 5-8%’ Radiotherapist, 35 years.

Current prevalence

Only one Oncologist has given a prevalence figure of 10 cases per month who are already diagnosed with breast cancer.

“We get 15-20 cases per month in this hospital. Prevalence is 10 cases. Age group affected is 40-50 years’ Radiologist, 50 years.

Age group of women affected

Most (7 out of 10) of the Oncologists said that Older age group (40-60 years) of women are being more affected than those in younger age. However, Breast Cancer is seen targeting more towards younger age group women (22-40 years also), mainly from urban background due to various modifiable risk factors outlined by them.
Thank you so much for your time and valuable information for the study.

‘It is affecting 25-40 years group. Most young women’
Medical Oncologist, 38 years.

‘Ductal carcinoma, globular carcinoma, depending on the type of origin in the breast tissue. Common is ductal carcinoma. In govt set up advanced stages are seen. In corporate set up, we get early stages’
Radiation Oncologist, 35 years.

Mortality from breast cancer
One of them reported the mortality among women due to breast cancer to be 4-5%. However, the survival...
Table 2. Summary of Recommendations with Suggested Strategies

<table>
<thead>
<tr>
<th>No.</th>
<th>Strategy</th>
<th>Methods/Processes</th>
<th>Stakeholders</th>
</tr>
</thead>
<tbody>
<tr>
<td>1.</td>
<td>Health Education on Self Breast Examination</td>
<td>Promoting breast cancer awareness</td>
<td>Government</td>
</tr>
<tr>
<td>2.</td>
<td>Breast Cancer Screening</td>
<td>Breast cancer high risk groups (genetic predisposition, family history of BC)</td>
<td>Government</td>
</tr>
<tr>
<td>3.</td>
<td>Maintenance and Streamlining of Cancer Registries</td>
<td>Clinical Examination by Physicians at PHC level, followed by mammogram</td>
<td>Government, Public and Private Health care providers</td>
</tr>
<tr>
<td>4.</td>
<td>Screening for early breast cancer</td>
<td>Screening of high risk groups (genetic predisposition, People with obesity, hormonal imbalance etc)</td>
<td>Government, Public and Private Health care providers</td>
</tr>
<tr>
<td>5.</td>
<td>Promoting mammography using Digital Mammograms</td>
<td>Providing subsidies for screening facilities</td>
<td>Government</td>
</tr>
<tr>
<td>6.</td>
<td>Promoting breast feeding, Regular exercise, smoking and alcohol ban</td>
<td>Providing information on a continuous basis</td>
<td>Government</td>
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Government, Primary level to tertiary
Method/Process
Target group
Traditional risk factors like Nulliparity, obesity etc are non-modifiable. Presence of BRCA1 genes in the women also contribute to the risk among those with family history of BC. Two types of risk factors are accounted to be responsible for the stage at which women are presenting to them with Breast Cancer. Our focus should be early detection. Only in 10% of women is breast cancer genetically inherited, whereas in 90% of women, cancers are non-genetic. There are two genes BRCA1 and BRCA2 which are predominant among the 10% of women with genetic predisposition. If they are cancer +ve, prophylactic removal and/or very close observation can be done. Some of the factors like obesity, diabetes mellitus, nulliparity, stress etc can contribute to the breast cancer, but it is not generally caused by a single factor.” Surgical Oncologist, 43 years.

Other modifiable risk factors
‘Breast cancer, unfortunately like cervical cancer is not a preventable disease. It is not possible to prevent the disease. Every woman can get it. Our focus should be early detection. Only in 10% of women is breast cancer genetically inherited, whereas in 90% of women, cancers are non-genetic. There are two genes BRCA1 and BRCA2 which are predominant among the 10% of women with genetic predisposition. If they are cancer +ve, prophylactic removal and/or very close observation can be done. Some of the factors like obesity, diabetes mellitus, nulliparity, stress etc can contribute to the breast cancer, but it is not generally caused by a single factor.” Surgical Oncologist, 43 years.

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Presentation of breast cancer by women in AP

Late presentation is the cause of decreased survival among women. All the Oncologists expressed their concern for the stage at which women are presenting to them with Breast Cancer. They said that women present at Stage 3 and 4 when there is no opportunity for surgical intervention. They have to go for radical treatment, with radiotherapy and chemotherapy being the options left for them. In locally advanced stages, it is very challenging to treat the cases. The survival rate in Stage 1 is 90%, since the breast cancer is not aggressive while the survival rates decrease as the stage progresses from stage 2-4 and falls to 15% in stage 4.

In some conditions, the women wait till the fungating growth appears on the breast with foul smelling discharge. This is more so among Muslim communities and women living in joint families. Reasons outlined for late presentation is Fear being an important factor.
Prognosis of breast cancer

‘Older age, ER PR positive status determine good prognosis. Patient factors like old age, absence of comorbid conditions (like Diabetes Mellitus, Hypertension, no family history of BC). ERPR+ receptor status have good prognosis. Among the treatment factor, molecular treatment and targeted therapy have good prognosis. Age of the women, stage of presentation, ER PR+ status, nodal positivity determines the systemic spread of the disease. Apart from this, aggressiveness of the tumour itself, hormonal status, gene mutations, family history, incomplete treatment also determine poor prognosis.’ Radiation Oncologist, 35 years.

Screening

Five Key preventive measures to prevent the incidence: Primordial prevention is the only way to reduce the incidence of breast cancer, as suggested by the Oncologists. Key preventive measures suggested by them include; Awareness generation on Breast cancer detection and screening method screening through Self breast examination, clinical examination followed by mammogram, Fine needle aspiration cytology test (FNAC), Genetic markers test for confirmation, lifestyle modifications- like regular exercise, dietary modifications, decrease intake of Oral contraceptive pills. Improvement in screening facilities and treatment facilities at the secondary level

Consistency in awareness generation efforts

Awareness on Screening limited to higher socioeconomic strata: Oncologists expressed that urban women have good awareness regarding screening and also access to facilities. Commonly used Screening procedure is Mammogram. Breast Self Examination is being done, but only among women who have attended awareness camps. But in practice it is not being done much. Those women with a malignancy of one breast, those who are at risk of breast cancer (family history) are advised for self breast examination at the facilities when their family member/relatives come for treatment.

Other modalities of screening currently in use are Sonomammogram, Fine Needle Aspiration Cytology (FNAC)test which is again confined to Tertiary hospitals. Other advanced tests like testing for ERPR positivity status, BRCA1 genes in blood are also done, but confined to the higher end corporate hospitals.

‘We don’t know the affect of screening for breast cancer women. So is it economically viable to do? Is it cost effective? Does it really improve mortality from breast cancer? We don’t have answers for all these. So what we can do is only extrapolate from the western data. If or if not applied to others, conditions’ Medical Oncologist, 38 years.

Currently American Cancer Society Guidelines (ACS) are being followed for screening, which says that every woman above 40 years need to be screened. Other than this, National Cancer Control (NCC) and WHO screening guidelines are also being followed.

Side effects caused due to screening

There are no documented side effects due to screening, except for the pain and embarrassment for the women during the process.

‘Repeated exposure to radiation increases risk of sarcoma, which is another malignancy because of repeated radiation, but again the radiation level is been so low, that comes to 30 40 mammograms done in a life time will not be a very high exposure.’ Medical Oncologist, 38 years.

Most of the Oncologists advised Clinical Examination by a Physician to be the best option for Population based screening, as it does not require a specialist doctor and can be done by Physician or trained nurse. This should be followed by Mammogram, in case of any suspicion by the Physician.

‘They imagine it as grave disease. They get panicky and fear about further treatment’ Radiation Oncologist, 52 years.

Risks and costs of screening: No risks are involved with screening. Cost of Mammogram ranges from Rs800-3000 in Private facilities while in Government tertiary hospital it is only Rs300.

Risk to health perceptions and knowledge

Huge gap in awareness about breast cancer is seen by different socioeconomic groups. Awareness among urban women was found to be more about screening. Where as in rural areas, there still exists a huge gap, as is felt by most of the Oncologists. Sometimes, fear is the major barrier which is causing delay in screening and treatment, since women feel cancer is dangerous and there is stigma associated to the fear of losing hair, breast and cosmetic appearance

‘They are ignorant. They think lumps formed are those seen during pregnancy and lactation. Not that somebody advices them but they themselves think that way. Rural women neglect the disease due to fear and ignorance. Where as urban women come running to the hospital once they see any lump, since they watch TV’ Radiation Oncologist, 52 years.

‘I think the culture of screening is not there here. Anyone doesn’t go even my mother doesn’t go when I say her to go. many women think that if they have breast cancer they will have their entire breast removed’ Medical Oncologist, 38 years

Expected delays in case reporting of BC and reasons for the delays.

Despite knowing, most women delay in reporting
due to reasons like fear, embarrassment, ignorance, negligence, easy going attitude.

‘Women feel, anyway it’s something which don’t get better so why bother others. So it’s got to do with the culture of our women also. They don’t want to put other family members into any kind of trouble, whatever happens that happens.’ Medical Oncologist, 38 years.

**Barriers for the delay in case reporting**

Cost, fear and negligence are the major barriers for delay in case reporting. Cost is the major barrier, especially among rural women. Apart from this, Fear, stigma, negligence, lack of facilities for early screening and diagnosis are other barriers outlined.

‘They imagine it as grave disease. They get panicky and fear about further treatment.’ Gynec Oncologist, 50 years.

**Recommendations for improved practices**

Early Screening should detect more number of Cases, thereby rising the incidence. They opined that they expected rise in Breast Cancer if the barriers are not addressed. Oncologists felt that through early screening and detection, incidence of breast cancer should be more, which help in identifying more women in Stage 1. Hence barriers need to be removed to promote more screening among women, especially self breast examination

‘Mammogram is not available everywhere but sonomammogram is available everywhere. Self breast examination is also being done by women, as we are advising them during the visits here. If they have tumour in one breast, we advice them to examine the opposite breast also’ Radiotherapist, 52 years.

**Discussion**

As found from our study results, the incidence of breast cancer in developing countries is rapidly on the rise. It is alarming that breast cancer is generally detected at advanced stages when a cure is not possible. The incidence of breast cancer increases with increasing age across the globe. However, the average age of presentation for breast cancer in the Indian population is widely reported to be around 10 years younger compared to the developed world and can have devastating effect on this predominantly young population (Sabu et al., 2010).

It is important to detect the breast cancer early to save millions of lives. Stigma, limited awareness, knowledge and lack of population wide screening program have led to late detection of most breast cancers (Gakwaya et al., 2008). Early detection of breast cancer makes more treatment choices available and also there are greater chances of long-term survival (Chong et al., 2002). If detected earlier, breast cancer has better survival rate than other cancers (Sharif et al., 2010). When detected at the early stage, breast cancer is curable, with a 100% survival rate for stage 0 and 1 (Thomas et al., 2002).

Studies have suggested that in the Indian scenario, the shift to routine use of mammography as a screening tool may not be justified (Smith et al., 2006; Okonkwo et al., 2008). Economically viable strategies would be to promote Breast Self Examination and Clinical examination at the primary health care level (Babu et al., 2011).

Our study findings showed that the women in Andhra Pradesh present predominately at either stage III and IV. Stage at diagnosis is an important determinant of the overall survival rates. On average, 50% of breast cancer cases in India present at late stage (stage III and IV) (Chopra, 2001). As found in our study, it is very important when women with breast cancer are aware of their disease and how early the treatment can be given. In developed countries like the United states, only 12% of the breast cancer cases are diagnosed at an advanced stage (Goel et al., 1995).

Our qualitative study found that early detection of genetic mutations in BRCA1 and BRCA2 genes among women with a family history of breast cancer helps in better prognosis. Earlier, it was thought that the contribution of BRCA2 mutations seems rather low among Indian women (Saxena et al., 2006). However, the contribution of environmental factors are equally important to address in India. More than 80 studies looking at the association of physical activity and breast cancer have found physical activity to have a protective effect (Marmot et al., 2007).

This protective effect is due to a multitude of factors which include reduction in circulating levels of and cumulative exposure to sex steroid hormones, changes to insulin-related factors and adipocytokines, modulation of inflammation and immune system and hormonal and cellular metabolism pathways (Friedenreich and Cust, 2008). Hence, we infer that modification of lifestyle including obesity reduction through physical exercise, diet regulation and consumption of low caloric diet might have beneficial effect in preventing breast cancer.

This study also reports the association between Estrogen receptor positive status and decreased breast cancer risk. The controversial effects of oral contraceptives (OCPs) on breast cancer have been extensively studied but there is a conflicting epidemiological evidence regarding the role of OCPs in causation of breast cancer (Calle et al., 1996). Our results from systematic review and qualitative interviews also noted the protective effect of breast feeding in reducing risk for breast cancer (Babu et al., 2013). There are several studies done in India showing similar results (Gajalakshmi et al., 2009; Meshram et al., 2009).

As found in our study, the late presentation is the cause of decreased survival among women in south India. This was due to presentation at Stage 3 and 4 when there is no opportunity for surgical intervention.. This can be addressed by improving awareness about breast cancer especially in rural areas and among poor socioeconomic groups. On the other hand, despite having the knowledge, most women delayed in reporting due to reasons like fear, embarrassment, ignorance, negligence, easy going attitude. These need to be addressed by reinforcement of knowledge and Adating interventions to bring changes in behavior among these women. Studies can be piloted in Urban India to understand how successful behaviour change interventions can be done. Other reasons for later reporting were due to cost. This can be addressed by inclusion of breast cancer treatment costs in existing health schemes such as Arogyashri and Yeshaswini. Though the
oncologists opined for BRCA gene screening, the country has a long way to go in implementing this. High costs of genetic screening is the major limitation prohibiting the wide use of this method. To begin with, genetic mutations in BRCA genes can be done among women with a family history of breast cancer.

In conclusions, based on the qualitative study, the most reasonable way forward would be to establish cancer registries covering rural areas. Alternatively, doing national representative surveys (annual, repeated every year) to estimate the serial cross sectional data on cancer incidence might be helpful. Next logical step would be to examine age-wise, gender wise cancers and establish national priorities. It is also important to improve the awareness among women to be aware of the importance of early screening. Concurrently, the policymakers need to make key decisions which among three methods (Breast self examination (BSE), Clinical Breast Examination and Mammography) can be used as a screening tool and how to successfully implement population wide screening program to prevent mortality and morbidity from breast cancer in India.

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