

RESEARCH ARTICLE

Breast Cancer Awareness among Middle Class Urban Women - a Community-Based Study from Mumbai, India**Anita Gadgil¹, Catherine Sauvaget^{2*}, Nobhojit Roy¹, Kirstin Grosse Frie², Anuradha Chakraborty³, Eric Lucas², Kanchan Bantwal³, Indrani Haldar³, Rengaswamy Sankaranarayanan²****Abstract**

Targeting breast cancer awareness along with comprehensive cancer care is appropriate in low and middle income countries like India, where there are no organized and affordable screening services. It is essential to identify the existing awareness about breast cancer in the community prior to launching an organized effort. This study assessed the existing awareness about breast cancer amongst women and their health seeking practices in an urban community in Mumbai, India. A postal survey was undertaken with low or no cost options for returning the completed questionnaires. The majority of the women were aware about cancer but awareness about symptoms and signs was poor. Women were willing to accept more information about cancer and those with higher awareness scores were more likely to seek medical help. They were also more likely to have undergone breast examination in the past and less likely to use alternative medicines. High income was associated with better awareness but this did not translate into better health seeking behaviour. Organized programmes giving detailed information about breast cancer and its symptoms are needed and women from all income categories need to be encouraged for positive change towards health seeking. Further detailed studies regarding barriers to health seeking in India are necessary.

Keywords: Awareness - behaviour - breast cancer - questionnaire survey - India

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Introduction

Breast cancer is a growing concern worldwide and low- and middle-income countries are reporting increased incidence as well. More than half of the new cases and 62% of the deaths were estimated to occur in the less-developed countries in 2012 (Ferlay et al., 2013; Sankaranarayanan and Ferlay 2013; Sankaranarayanan et al., 2013). Women in these countries commonly present late, in advanced stages with large tumours, with the consequences being low survival rates and increases in treatment costs (Anderson et al., 2011; Saghir et al., 2011; Memon et al., 2013).

There are no organized breast cancer screening programmes in India (Agarwal and Ramakant 2008). Opportunistic screening by mammography is provided to those who can afford it, since mammography is available in most public hospitals. It is now a well-established fact that mammographic screening is not cost-effective in countries like India (Sankaranarayanan and Ferlay 2013) and prevention, based on cancer awareness and early

detection programmes, are more appropriate (Anderson et al., 2011). This has been emphasized in government-run programmes like 'Health for all' and 'national rural health mission', but data and findings from these interventions are not available (Agarwal and Ramakant 2008). Designing these interventions effectively requires knowledge about the prevalent awareness about cancer and women's health-seeking behaviour. A few studies were done among the slum dwellers in cities (Kumar et al., 2011b; Somdatta and Baridalayne 2008) and some in the rural areas (Rao et al., 2005) of India, but studies amongst middle-class urban women are few (Mayur et al., 2013; Mahendra et al., 2014). The incidence of breast cancer is rising more rapidly in urban areas (Chandramouli 2011) compared to rural areas (Takiar and Srivastav 2008) and hence attempts should be made to survey awareness about cancer amongst the urban women. We conducted a population-based questionnaire survey to further explore the baseline awareness about breast cancer and about cancer detection and screening in women from an urban middle-class community.

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Materials and Methods

Study setting and design

The study was conducted in a community covered by the Employees' Health Scheme for the Department of Atomic Energy (Government of India). The community comprises of middle class beneficiaries and their dependents (Saxena 2010; Banerjee and Duflo 2008), residing in urban and suburban areas (Chandramouli 2011) of Mumbai. The employees are provided with universal healthcare through primary care dispensaries and with referral facilities to a central hospital which provides free tertiary healthcare. The healthcare scheme covers beneficiaries from birth to death. As the healthcare is free and equitable in this community, it provides a unique setting to assess baseline awareness and responses about cancer (i.e., without access or cost considerations). This health scheme covers a population of approximately 25,000 women in the 30-69 year-old age group. We conducted a questionnaire-based mail survey on women in this age group between April and June 2013.

Protocol and data collection

A computer-generated random selection was done from the list of patient identification numbers. There is currently no information on prevalent awareness about breast cancer amongst Indian women based on large mailed surveys, hence sample size calculations could not be done and a random number sequence was used on the 25,000 women aged 30 to 69 years to select 10% (N=2500) as the study size. A questionnaire was mailed to each of these women at their home addresses with a request to deliver the responses to the nearest dispensary in their district. Multiple and free-of-cost options, as detailed below, were made available to the women to return the completed questionnaire to the lead researcher. We collected the questionnaires from the dispensaries across the city. We also provided a collecting centre in the vicinity of the work places of the employees where the women themselves, or the spouses, could deliver the questionnaires. We organised a designated centre in the central hospital. We waited for a period of one month and resent the questionnaires to the non-respondents as the response rate to the first round was only 5%. We gave a further period of one month before concluding the data collection. Age information was completed from the employees' centralized database of information. The hospital and satellite dispensaries are connected through the 'Hospital Information System Network'. This system contains demographic information along with the beneficiaries' salary and other employment-related information. On-going and past medical records of all the beneficiaries are also available. The age and income status used in this study were checked by visiting the records of the respondents.

Staff from the Screening Group, International Agency for Research on Cancer (IARC), Lyon, France developed the questionnaire, as no pretested or standardized questionnaire to assess awareness about breast cancer was available for the Indian context. The questionnaire was translated into Hindi (official language) and back-

translated into English to check for consistency. It consisted of two sections. The first assessed the woman's awareness about breast cancer signs, symptoms and its curable nature, if detected at an early stage. They were asked to comment on whether they were willing to accept more information about breast cancer. The second section explored the health-seeking behaviour of these women, whether they ever experienced a breast-related problem. This section also assessed whether they had undergone clinical breast examination or any other form of screening, prior to the survey. Multiple responses to behavioural practices were possible. The complete questionnaire is given in Table 1.

Data analysis

The study participants belonged to the urban middle class with incomes ranging from 2 to 10 USD per capita per day (Banerjee and Duflo 2008). This was converted to be rupees 18000 to 72000 per family per month, considering a family of four members. The responders were divided into three tertile groups of higher-income group (HIG) (Rupees (INR) 54,000-72,000 per family per month), middle-income group (MIG) (INR 36,000-53,000 per family per month), and lower-income group (LIG) (INR 18,000-35,000 per family per month).

To assess the awareness on breast cancer, we gave a score of 1 point for each correct answer in the first section that assessed the prevalent awareness. Highest score was 4. We grouped women with scores 0, 1 and 2 into inadequate awareness and scores 3 and 4 into adequate awareness. For health-seeking behaviour, since multiple responses were possible, answers were analysed accordingly.

Frequency distribution for different health seeking behaviours was done and chi-square test was used to assess categorical variables. SPSS version 22 was used for the analyses.

Results

We received 411 responses to the mailed questionnaires. A total of 389 (15.56%) women returned a completely filled questionnaire. Respondents belonged more frequently to the younger age-group as compared to the non-respondents (Table 2). The mean age was 48 years (Range 30-69). A majority of women (59.6%) were below the age of 50 years.

More than half (57%) of the respondents showed an overall adequate awareness with scores of 3 and 4. Eighty-three percent of the women were aware that breast cancer is curable if detected at an early stage. 'Breast lump' was the most commonly known symptom of cancer (70%), whereas hereditary nature of breast cancer and the fact that it can be present as a painless lump was known to just half of the respondents (48% and 51%, respectively). Eighty-three percent of the women were willing to receive more information about cancer. Women older than the mean age of 48 years were significantly more aware about breast cancer than the younger women (63% vs 50% p=0.01).

Amongst the 389 respondents, income information was available for 369 women. Among those, 147 (40%) were from HIG, 140 (38%) from MIG, and 82 (22%)

from LIG. When we compared the adequacy of awareness according to the income groups, higher awareness scores was significantly associated with the HIG (Table 3).

We assessed the health seeking behaviour in case of any breast abnormality. Ninety-five percent of the respondents chose to consult a doctor; 30% considered approaching nurses. According to the income category, the higher the level the more likely they were to consult a doctor for breast symptoms; inversely the higher the

level the less likely they were to use alternative medicines (Table 4). The level of awareness was also significantly associated with the health-seeking behaviour of the respondents; the more aware were more likely to seek medical advice.

A total of 102 out of 389 respondents (26.2%) had sought breast examination by a doctor for various breast complaints or for screening purposes prior to the survey. A total of 76 women (19.5 %) noticed some change in their breast(s) at some point of time in their lives, but only just over half (55%) actually visited a doctor to seek advice. We analysed the responses of women who had 'sought medical help for breast examination'. Those women who had adequate awareness about breast cancer (32% vs 18%, $p<0.01$), or who were willing to accept more information about breast cancer (27% vs 23%, $p<0.01$) were more likely to have undergone breast examination previously as compared to those with a low awareness or not willing to accept further information. The distribution of the respondents who were previously seen by medical doctor, across income groups was 31%, 27% and 15% for HIG, MIG, and LIG, respectively ($p<0.01$).

Table 1. List of Questions Asked

A. Awareness about breast cancer	
Breast lump is a symptom of breast cancer	
Cancer can be present in absence of pain	
Cancer can be hereditary	
Cancer is curable if detected in early stages	
Would you like to have more information about breast cancer?	
B. Health seeking behavior (what would you do if you found a lump in the breast)	
Would you consult a doctor?	
Would you consult a nurse?	
Would you share with a family member or a spouse?	
Would you choose an alternative therapy?	
C. Status of screening	
Have you ever noticed a lump or any change in your breast?	
Have you undergone a clinical breast examination?	

Table 2. Comparison between the Respondents and Non-Respondents According to Age-groups

Age groups	Non-respondents (%) (N=2111)	Respondents (%) (N=389)	P-value*
30-39	471 (22.3)	106 (27.2)	
40-49	571 (27.0)	118 (30.3)	
50-59	533 (25.2)	83 (21.3)	
60-69	536 (25.4)	82 (21.1)	P=0.026

*p-value for chi-square test

Table 3. Adequacy of Breast Cancer Awareness According to Income Groups

Monthly income categories	Number of women with income data n=369 (%)	Number of women with high awareness scores (%)	p-value
HIG (INR 54,000-72,000)	147 (40)	104 (71)	
MIG (INR 36,000-53,000)	140 (38)	67 (48)	
LIG (INR 18,000-35,000)	82 (22)	39 (48)	P<0.01

HIG: high income group; MIG: middle income group; LIG: low income group; INR: Indian rupees; p-value for chi-square test

Table 4. Health Seeking Responses if Breast Abnormality

In case a woman had breast swelling or developed breast complaints	Number (n=389)	%	p-value
She would consult a medical doctor for lump	370	95	
According to awareness level			
High awareness (N=221)	218	99	
Low awareness (N=168)	152	90	P<0.01
According to income level			
HIG (N=147)	144	97	
MIG (N=140)	134	96	
LIG (N= 82)	75	91	P=0.05
She found appropriate to consult a nurse	118	30	
She would discuss with spouse/friend	132	33	
She would use alternative medicines (homeopathy/Ayurveda /Indian medicines)	32	8	
High awareness (N=221)	14	6	
Low awareness (N=168)	18	11	P=0.03

LIG: low income group; MIG: middle income group; HIG: high income group; p-value for chi-square test

Discussion

Breast Global Health Initiative has stressed upon and recommended awareness-based early detection as an intervention for improving breast cancer survival in low- and middle-income countries (Anderson et al., 2011). We conducted this exploratory study to assess the breast cancer awareness in our community as a first step towards designing the awareness-based breast cancer early detection program. We chose postal survey to collect the data, as interview-based surveys are more expensive (Cummings et al., 2001; Gibson et al., 1999), and may not be appropriate in the Indian context. Health-related

surveys are not common in India (Gupta et al., 2011) and most of them aim to gather information from the physicians or medical students and use multiple methods for data collection (Gupta et al., 2007; Meherishi et al., 2010). Community-based cancer-related health surveys are scarce and most of the literature available regarding cancer surveys have included personal interviews, but not self-reported information (Mayur et al., 2013; Rao et al., 2005; Mahendra et al., 2014; Garg et al., 2010). This study is the first attempt in India to collect information about cancer awareness through mail survey in the community. A little over half of the women had higher scores for breast cancer awareness and more than three-fourths knew that breast cancer is curable if detected at an early stage. These figures correlate well with an interview-based study done in Mumbai, at the Tata Memorial Cancer Centre (Kumar et al., 2011b), where they found that awareness about cancer in general amongst slum dwellers was as high as 84.6% and cancer was perceived as curable by 66% of the women. Both our study, as well as the study done by Tata Memorial Hospital, showed a high level of awareness regarding cancer and its perception as a curable disease. When we compared our results with the other Indian studies, we observed a wide variation in breast cancer awareness across cities (Somdatta and Baridalyne 2008; Garg et al., 2010; Grosse Frie et al., 2013; Mahendra et al., 2014; Sreedevi et al., 2014). The awareness figures ranged from 53 to 84% and breast cancer was perceived as curable by a larger percentage of respondents (62 to 89%). The most encouraging findings from our data was that most of the women were aware that lump is a symptom of breast cancer although in other Indian studies, lump was not so commonly considered as a symptom of cancer (32% to 49%) (Somdatta and Baridalyne 2008; Mayur et al., 2013; Mahendra et al., 2014).

Only about half of the respondents were aware that cancer can be present even in absence of breast pain and that history of breast cancer in the family is associated with higher risk. These findings indicate that populations across the country may have heard about cancer or may be aware of its potential curability, but knowledge regarding signs and symptoms of breast cancer and its hereditary nature is still poor. Eighty-three percent of our respondents were willing to accept more information regarding breast cancer. There were no figures available from Indian studies to compare this. The studies regarding acceptance of screening reported primarily after the intervention (Rao et al., 2005; Kumar et al., 2011a) and hence information prior to intervention from our study is important to plan further awareness programmes in the community.

Older women were more aware about breast cancer. In a study among slum dwellers in Delhi, India (Seth et al., 2005), the authors also documented higher awareness in older women. Another study from Delhi in women from an urban resettlement colony (Somdatta and Baridalyne 2008) did not report any difference on breast cancer awareness among the old and young age groups. The association between age and awareness does not seem to be consistent.

We documented that the women from higher income groups were significantly more aware about breast cancer

and its symptoms than the middle- and lower-income groups. Our data showed a significant gradient across the income categories for response, as well as for awareness scores. These findings were in accordance with other similar studies from Mumbai (Kumar et al., 2011b) as well as from Europe and Africa (Akhigbe and Omuemu 2009; Hvidberg et al., 2014). These results indicate that efforts need to be made to increase awareness, especially in women from middle- and lower-income classes.

If they found a breast lump, 95% of the women preferred to visit a medical doctor. While the women who opted to consult a doctor did not show variation or gradients across income groups, the low income group did show a higher use of alternative medicines. The respondents from the Delhi study (Seth et al., 2005) involving a similar urban population reported a comparable response, where 96% would consult a doctor if they encountered a lump. Seth et al also showed that income groups had no statistically significant difference in positive attitude towards cancer. Our results showed that significantly more women with adequate awareness about breast cancer chose to see the doctor if they found a lump and those with higher awareness scores were also less likely to seek alternative medicines for treatment. We could correlate awareness with health seeking behaviour positively. A study from South Africa (Maree and Wright 2010) expressed that women in patriarchal societies may not prioritize their health, treatment or spending money on it. Health expenditure for their own health may be challenging, moreover permission from the husband is often needed (Maree and Wright 2010). This study concluded that health awareness and understanding of cancer does not facilitate early detection. A patriarchal society also exists in India, similar to that mentioned by Maree and Wright, and hence a further detailed study in the factors affecting the health seeking behaviour in the Indian scenario may be needed. Factors other than health and cancer awareness may be involved in health-seeking and barriers to health-seeking behaviour in Indian communities.

Our study demonstrated that 9% of the respondents would opt for alternative and contemporary medicines if they found a lump or any change in the breast. This is very relevant in the Indian scenario, where multitudes of alternative medicines are traditionally practiced. A mailed survey conducted among breast cancer survivors in Canada reported that 66% survivors used alternative medicines at some point and only half of them reported the use to their physicians (Boon et al., 2003). We do not have a similar study on cancer survivors in an Indian population. This Canadian study also documented an increase in the use of alternative medicines over years. A study from France (Saghatchian et al., 2014) recently reported usage of alternative medicines in 37% of breast cancer patients, while they were 80% in China (Wang et al., 2014). Though the percentage of women using these therapies is very low 9% in our study, this information could be utilized while conducting awareness programmes. These studies from different socio-economic and cultural backgrounds suggest that use of alternative medicines is prevalent across the globe and this issue needs to be discussed while planning screening strategies.

Our results about breast cancer awareness and health seeking behaviour were encouraging, but the actual number who visited a doctor and sought help was low. Only 26% of the respondents had been examined by a doctor previously. This highlights the present status of screening in our community. Women with higher knowledge about cancer and willingness to be informed in detail about it were significantly more likely to have undergone breast examination by a doctor. At the same time, there was a gap between high knowledge scores and actually receiving breast examination. This underlines that awareness about cancer does not always translate into health-seeking behaviour. This is an important finding in planning further screening programmes and again reiterates the need to properly examine health-seeking behaviour of Indian women. Very few Indian studies were available on women who had been previously screened. A study from Manipal, in rural women, showed that awareness measure had positively affected self-breast examination (Rao et al., 2005). A study conducted after screening in Mumbai slums (Kumar et al., 2011a) showed that acceptance of screening was encouraging in that community. However, figures of exactly how many women were screened before this study were not available.

The limitation of our study was that the low overall response rate in the community (16%) as compared to Western studies where responses up to 80% have been noted (Edwards et al., 2009). Average response rates have shown to vary between 52% for large sample surveys (>1000 participants) and 61% for small sample surveys (Gibson et al., 1999; Cummings et al., 2001). A large telephone survey from Denmark with 3000 respondents (Hvidberg et al., 2014), showed a 36% response rate. This survey was conducted to assess breast cancer awareness and acceptance of screening. There were few postal surveys from India to compare with (Gupta et al., 2011). The low response rate is partially explained by the fact that mailed surveys is a novel method for this community and also there were no prior breast cancer screening programmes available to the employees of this health scheme while in Western countries, national screening programmes are in place. It may have led to a selection bias; the respondents being more health-conscious and/or more aware of breast cancer than the non-respondents.

In conclusion, women from urban community had good awareness about cancer and its curable nature, but not about its clinical presentation. High income women, in spite of being more aware, did not differ in health-seeking behaviour from the middle-income group. Higher awareness in general correlated with better health-seeking behaviour, but did not always translate into women seeking breast examination. This emphasizes the need for giving more detailed information regarding breast cancer to women of all age groups and income categories and calls for further detailed studies dedicated to health-seeking behaviour and barriers to seeking health in urban women.

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