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Barriers to Breast Cancer Screening In Young Indian Women: A Tale of Two Cities

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Abstract : Screening for breast cancer reduces mortality by 30 – 40% but there are many psychological barriers to screening. A comparative case study was undertaken in young well educated Indian women to map the barriers to screening and their relation to the socio-cultural milieu. Volunteers from two premier educational institutes of Ranchi and Chennai were required to respond to a self completion questionnaire recording their attitudes to breast cancer screening. The responses were marked on a scale of 1-5. The two cohorts were from similar social and economic backgrounds and had equally fair knowledge of Breast cancer but differed in their access to healthcare and their choice of dress. The significant differences in outcome variables of embarrassment, fear and barrier in the two cohorts were found to correlate to the centre of study only. The authors postulate that this may be the due the influence of their present social environment i.e. 'neighbourhood'.

Key Words: Breast cancer, Screening, Barriers, Socio-cultural parameters, Knowledge of breast cancer

Introduction

Regular screening for breast cancer reduces mortality by about 30 – 40 % (Vaino *et al.*, 2002; Tabar *et al*., 2003; Swedish Organized Service Evaluation Group, 2006). But there are many psychological, social and economic barriers to screening e.g. embarrassment, lack of access to health-care, or lack of physician referral. (McGarvey *et al*., 2005; Secginli *et al.,* 2006; Ansnik *et al*., 2008)

Patients undergoing mastectomy have a worse "Quality-of-Life" (The WHOQOL Group, 1994; Fleck *et al.,* 1999; Kluthcovsky *et al*., 2007;) compared to those undergoing Breast conserving surgery, especially the physical and social components (Ganz *et al*., 2004; Pandey *et al*., 2006;), with a poorer body image (Falk Dahl *et al.*, 2010).

Screening uptakes in US and UK are 75 – 80 % (Cole and Bryant, 1997; Patnick, 2008 ;), but it is almost nil in India. This study attempts to define the barriers that prevent Indian women from volunteering for breast cancer screening and compare the magnitude of those barriers in young women from a metropolitan city and a state capital. The authors have interviewed several educated women with a fair knowledge of Breast cancer who have been advised breast self-examination but refuse to practice even that. What prevents them from undergoing screening?

In this backdrop the present study aims to:

1. Map the barriers to screening in young, educated, well-off Indian women with good access to healthcare facilities and,
2. Define the influence of the socio-cultural environment of the subject on the barriers to screening.

Materials and Methods

A comparative case study (Hantrais, 1996) was designed, selecting women from two premier educational institutes of Chennai and Ranchi with the following inclusion criteria:

1. Women less than 30 years with a graduate's degree.
2. Women with no breast diseases

38 females from Chennai and 40 from Ranchi, from two premier institutes, volunteered for the study. Embarrassment felt to activities relating to breast examination, fear of loss of breast and knowledge of breast cancer were tested through a self-completion questionnaire. They were also tested for their knowledge of breast cancer through ten questions answered in true/false format. A pilot study was carried out to establish the internal reliability of the questionnaire and Cronbach alpha scores of the various sections measured 0.919, 0.816 and 0.765 respectively (Cronbach, 1951).

Independent variables included age, annual family income, family history of breast cancer, and access to healthcare (access to family physician, history of previous gynecological consultation and access to Health insurance). The socio-cultural parameters included the preferred style of dress and the place of residence, now and as a child.

The pilot survey showed that some subjects who had consented to the study had not answered one or more questions. The possible reasons may be:

1. They did not know the answer
2. Perceptual Defense (Blum , 1955; Minard, 1965; Loiselle and Williamson, 1966;) caused them to ignore questions that evoked strong negative emotions

Therefore, "barrier", a third dependent variable was added to account for the unanswered questions. All variables were marked on a scale of 1-5 and final scores were obtained by taking the section mean.

The results were analyzed using PAST 2.17b (Hammer, Harper, and Ryan 2001) software. The statistical tests included Chi-square test, ANOVA, and Kruskal – Wallis test.

Results:

The demographic characteristics of the sample have been presented in table 1.The mean age of the respondents from Chennai and Ranchi were 20 years and 22 years respectively.78 per cent were graduates and 22 per cent post-graduates. The two cohorts were from comparable economic backgrounds (Family income, $p = 0.051$;).They were significantly different in their access to a family physician ($p < 0.001$) and access to health insurance ($p < 0.0001$) but similar in the number of volunteers who had visited a gynecologist ($p = 0.16$). 12/38 volunteers from Chennai had seen breast cancer in their family compared to 5/40 from Ranchi ($p = 0.041$).

Socio-cultural background

63 per cent respondents from Chennai were residents of a non – metropolitan city and 60 per cent had spent their childhood in one. In comparison, 95 per cent respondents from Ranchi had spent their childhood in a non – metropolitan city and 92 per cent were now staying in one. The difference did not reach statistical significance (Place of residence as a child, $p = 0.80$; present place of residence, $p = 0.86$). 87 per cent Chennai respondents preferred western dresses compared to 53 per cent from Ranchi ($p < 0.001$). Respondents from Ranchi also displayed a markedly heightened 'perceptual defense' response to uncomfortable questions – either due to embarrassment or lack of knowledge. In fact, 38 per cent Ranchi volunteers didn't know the size of their brassier cup compared to 0 per cent Chennai volunteers!

That, two cohorts of women of similar age groups, educational and economic backgrounds who have spent their lives in similar urban social environments should display such varied response to embarrassing questions points to the effect of their social environment i.e. the effect of the 'neighborhood'.

Knowledge of Breast cancer

The average score was 4.57/10 ranging from 0 – 9.The mean score of respondents with a family history of breast cancer was 5.12 and those without a family history was 4.41; the difference was not significant ($p = 0.22$).There was no correlation between the knowledge scores of the respondents and their embarrassment, fear and barrier scores. The difference in the knowledge scores between the respondents from Chennai and Ranchi did not reach statistical significance (Chennai = 4.79 Ranchi = 4.35, $p = 0.36$).

Measures of Embarrassment

Five questions measured embarrassment and the responses are shown in figure 1.Briefly, 35 per cent would refuse breast examination by a male doctor, 46 per cent will hide a breast lump from their sons, 40 per cent would refuse a Mammogram because it is too embarrassing, and 76 per cent may ignore any advice regarding breast examination due to embarrassment. The mean Embarrassment score in Chennai was 2.24 and in Ranchi was 3.01($p < 0.01$).This score did not vary in relation to any of the independent variables except the center of study.

Measures of Fear of mastectomy

The absence of fear of loss of breast (mastectomy) was used as a surrogate measure of resistance to screening and the responses are shown in table 2 and figure 2. Briefly, 49 per cent would not demand breast prosthesis, 62 per cent would not feel any restriction in their choice of dress, 77 per cent would not feel deformed, and 71 per cent fear the cancer more than the deformity after mastectomy. The mean Fear scores in Chennai were 2.50 and those in Ranchi were 3.14 ($p < 0.001$). None of the recorded independent variables correlated with the fear score except the center of study.

It is implicit from figure 3 that a significantly greater number of respondents from Ranchi than Chennai avoided consenting to mammograms ($Chi^2 = 16.56$; $p < 0.001$).Only 50 per cent respondents from both centers chose regular mammograms! The mean barrier scores in Chennai were 1.81 and Ranchi were 2.31 ($p < 0.001$).

Discussion

This survey attempted to define the emotional and psychological barriers against breast cancer screening in Indian women. Therefore, the respondents were chosen from a population which would face minimum practical or logistic problems in accessing healthcare services. The questions, too, were designed to strike deep emotional chords in educated women and were based on situations commonly encountered by the first author in his clinical practice.

The results revealed deep emotional distress to situations commonly encountered by breast cancer patients. For example, a woman often discovers a lump in her breast when she is a widow and dependent on her son. Our survey shows that in such situations 46 per cent respondents would hide the lump from their son and allow the disease to progress. When asked to react to the slogan 'if only women paid as much attention to their breasts as men do'; one out of four respondents ignored the question and a

similar number opined that it is a 'necessary evil' - men will ogle at female breasts! Very few respondents really understood that the slogan refers to breast-self examination as a means of cancer screening.

These deep –seated emotional barriers have been found in highly educated women. The conventional wisdom is to overcome them through education about cancer. Therefore, the respondents were also tested for their knowledge of breast cancer through ten questions answered in true/false format. The median score was five with most scoring between 3 and 6.Thus the respondents displayed a high level of emotional avoidance combined with fair knowledge of the disease and minimal practical or logistic barriers. Forbes *et al*. (2011) surveyed the health seeking attitudes of women from various ethnic communities in East London. They found that women of Indian origin reported emotional rather than logistic or practical barriers to seeking medical help. 59 per cent reported embarrassment as a barrier, 46 per cent worried about what the doctor might find, and 53 per cent reported not feeling confident talking about their symptoms. Another survey amongst South Asian women living in Canada (Bottorff *et al*., 1998) found that many respondents would not visit a doctor unless accompanied by a friend or relative.

These studies and the present study show that barriers to health – seeking behavior, in Indian women, in general and cancer screening in particular are predominantly emotional and may not be influenced by the subjects' health – related knowledge. Embarrassment, Fear and Barrier scores of the respondents were not associated with either their having a patient in the family or their knowledge of cancer (p values; 0.15, 0.79 and 0.14 respectively). Forbes *et a.l* (2011) and Scanlon and Woods (2005) both found that South Asian women have better knowledge of age-related risks of breast cancer but are less likely to examine their breasts than their western counterparts, same as the findings of our survey.

The volunteers for this survey were young women given to wearing western dresses and those from Chennai were students at a national fashion designing institute. It is expected that such women would pay more attention to their body image than the general Indian female. Cash, Melnyk and Hrabosky (2004) have postulated that body image includes an attitude of satisfaction or dissatisfaction in one's body that varies with two factors-self-evaluation and investment in appearance or the respondent's view of the importance of her appearance. Assuming that younger women are likely to invest more in their appearance we hypothesized that fear of disfigurement by loss of breast may prompt them to choose regular screening, but the results failed to support our hypothesis. Surveys in Indian women from low socio – economic strata (Khan *et al*., 2010) did find that such patients did not pay much importance to their appearance, but finding the same result in a group of young educated women was surprising. When specifically questioned if they would suffer the embarrassment of mammograms to avoid the deformity due to loss of breast 70 per cent respondents chose to 'get the tumor out anyhow'! This indicates that fear of a diagnosis of cancer overrides the fear of deformity. Therefore, fear of being detected with cancer would prove a barrier to screening rather than fear of deformity motivating them to undergo screening. A similar result was obtained by Tejeda *et al*. (2009) and Watts *et al.* (2009) when surveying women to find barriers to mammography and pap smears respectively.

The second aim of the study was to define the influence of socio-cultural differences on screening attitudes. Therefore, two groups of volunteers of comparable educational, economic and cultural backgrounds were chosen from a metropolitan city and a state capital. In spite of their comparable backgrounds more respondents from Ranchi preferred ethnic dresses than those from Chennai. Given that dress choices are vulnerable to peer pressures this change in style reflects the influence of 'neighborhood'. In the authors' opinion the differences in their embarrassment, fear and barrier scores are also due the effect of 'neighborhood', since we could not detect any correlation to either family history of breast cancer, ease of access to health care or knowledge of breast cancer.

Many authors have linked perceptions of neighborhood to general health status (Ross and Mirowsky, 2001; Hill, Ross and Angel, 2005; Wen, Hawkley and Cacoppo, 2006) .Schempf, Strobino and O'Campo (2009) were able to show that neighborhood structures and processes shaped maternal behavioral risks thus impacting infant birth weight. In the authors' opinion the social environment of a metropolitan city helps reduce the barriers to screening thus influencing health-risk behavior of respondents. At the same time, as more and more urban centers develop there is hope that tier two cities like Ranchi will also develop social environments like Chennai in the future to positively impact the health behavior of its residents.

Conclusions

The study seems to indicate that barriers to cancer screening are an emotional response of the subject and that 'neighborhood' i.e. place of residence may have an impact on the risk behavior of the residents.

Limitations of the study:

Being a comparative study, the results of this study can't be generalized. But the first author has come across many instances in his clinical practice when women of this socio-economic group avoided screening. The question; why are they avoiding screening, seemed to beg an answer!

The study asks young women to respond to situations they have not faced. But a majority has rightly said that mastectomy would result in a poorer body image

and dress restriction, similar to the results of Falk Dahl *et al*. (2010) and Ohsumi *et al.* (2009) Therefore the other responses are unlikely to differ significantly.

The study also suffers from small sample size but in a conservative society such as India it is very difficult to persuade women to answer intimate questions about their breasts.

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Table 1.Comparison of the demographic characteristics of the respondents from Chennai and Ranchi

Demographic characteristic	Chennai	Ranchi
Total number of respondents	38	40
Mean age (range)	20(17 – 23)	22(20 – 27)
Education		
Graduate (%)	37(97.4)	22(56.4)
Post – Graduate (%)	1(2.6)	17(43.6)
Annual Family Income (%)		
< INR 15000(%)	0	1(2.7)
INR 15000 – 500,000(%)	23(60.5)	27(73.0)
INR 500,000 – 1,000,000(%)	4(10.5)	9(24.3)
> INR 1,000,000(%)	10(26.3)	0
Positive history of Breast Cancer in Family (%)	12(31.6)	5(12.5)
Respondents having Family Physician (%)	27(71.1)	16(40)
Respondents who have seen Gynecologist (%)	13(34.2)	20(50)
Respondents with Health Insurance (%)	33(86.8)	9(22.5)
Dress Style		
Ethnic +/- dupatta (%)	5(13.2)	17(42.5)
Western +/- dupatta (%)	33(86.8)	21(52.5)
No response (%)	0	2(5.0)
Present place of residence		
Tier 1 city (%)	14(36.8)	3(7.5)
Tier 2 city (%)	9(23.7)	23(57.5)
Tier 3 town ((%)	15(39.5)	14(35.0)
Residence during childhood		
Tier 1 city (%)	14(36.8)	2(5.0)
Tier 2 city (%)	6(15.8)	19(47.5)
Tier 3 town (%)	17(44.7)	19(47.5)
Mean knowledge of cancer score(CI)*	4.79(4.13 – 5.42)	4.35(3.7 – 5.0)

* F (1, 73) = 0.8399p (same) = 0.3624Not Significant

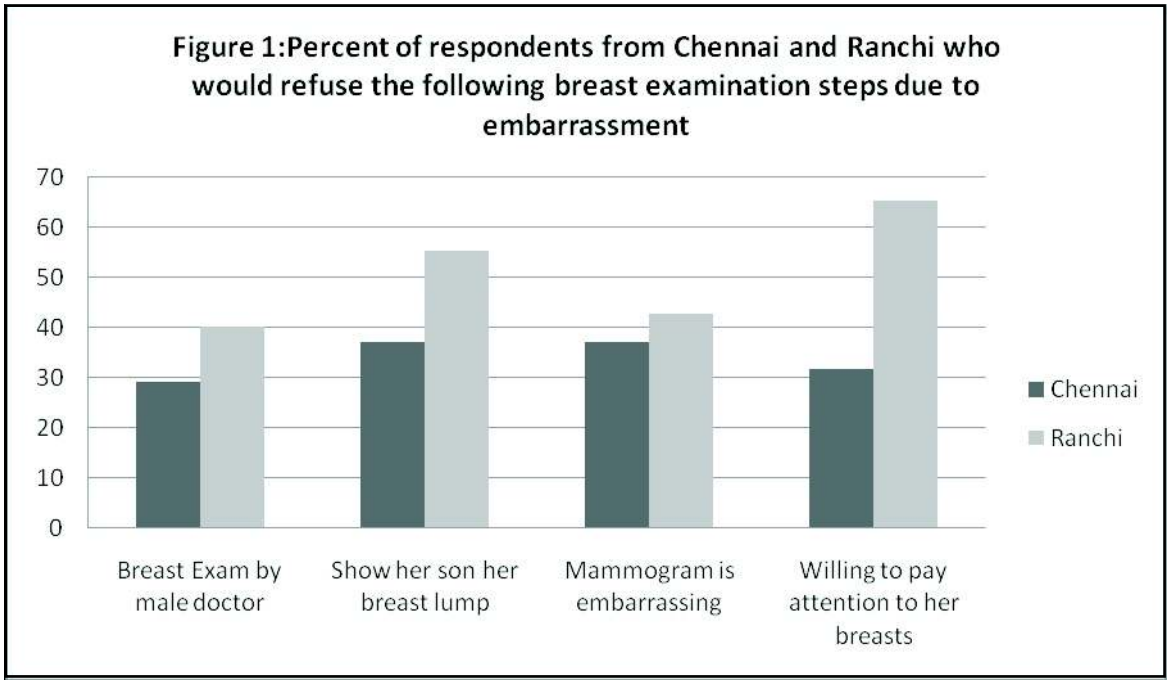
Figure 1:Percent of respondents from Chennai and Ranchi who would refuse the following breast examination steps due to embarrassment
70
60
50
40
30
20
10
0
Breast Exam by male doctor
Show her son her breast lump
Mammogram is embarrassing
Willing to pay attention to her breasts
Chennai
Ranchi

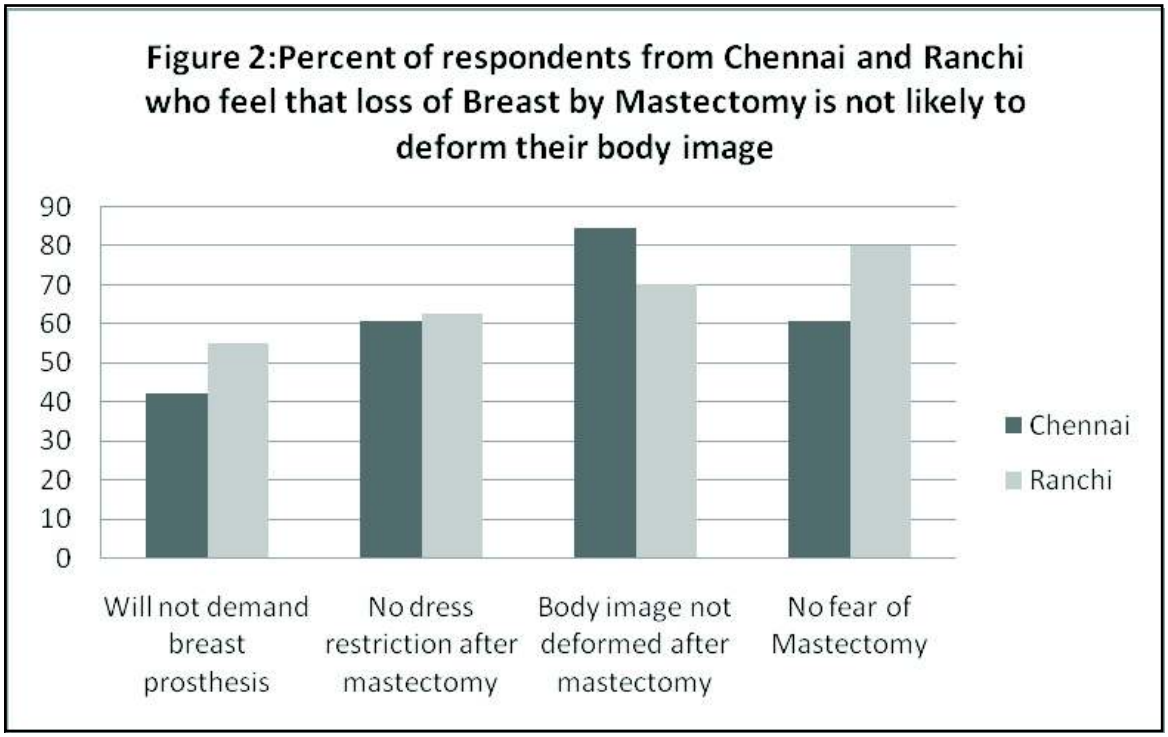
Figure 2:Percent of respondents from Chennai and Ranchi who feel that loss of Breast by Mastectomy is not likely to deform their body image
90
80
70
60
50
40
30
20
10
0
Will not demand breast prosthesis
No dress restriction after mastectomy
Body image not deformed after mastectomy
No fear of Mastectomy
Chennai
Ranchi

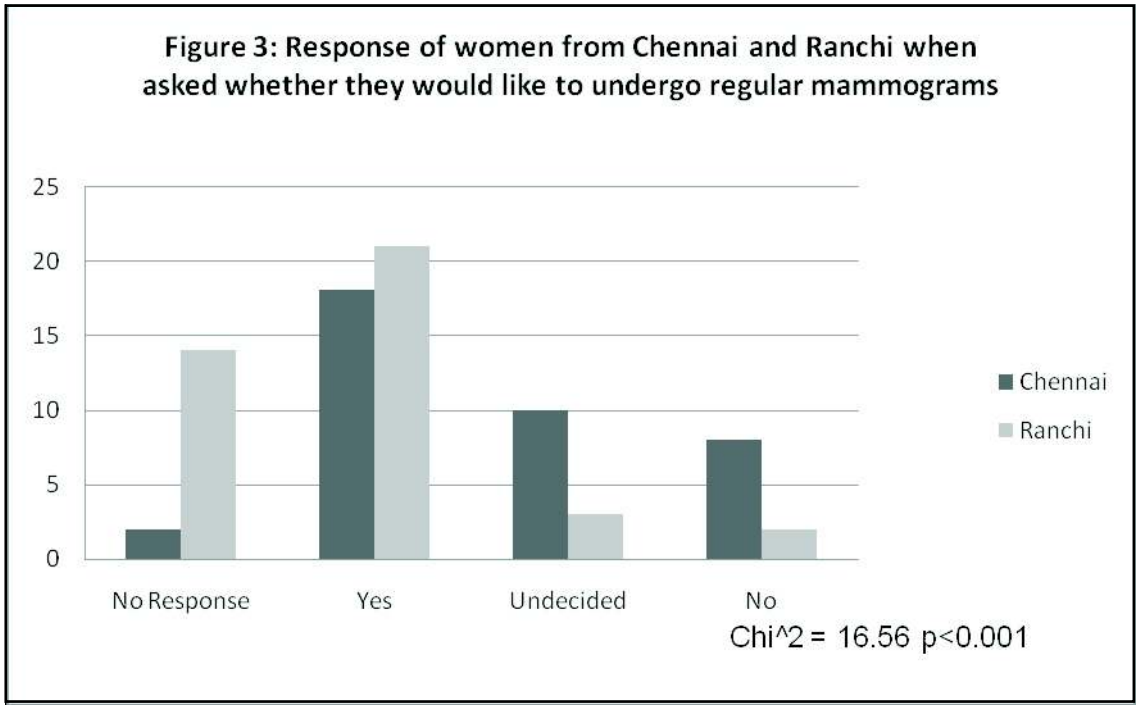

Table 2: A Comparison of Mean Embarrassment, Fear and Barrier scores of respondents from Chennai and Ranchi.*

	Chennai	Ranchi	P value
Embarrassment	2.237	3.096	<0.01
Fear	2.504	3.143	<0.001
Barrier	1.81	2.31	<0.001

*The respondents from Ranchi have significantly higher scores in spite of having similar scores when tested for knowledge of Breast cancer (ref: Table 1)

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