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Breast Cancer Awareness among Urban Indian Women: An Internet Survey

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I. Introduction

The estimated incidence and mortality of cancer in recent years in India is 1.015 million and 0.683 million respectively. Breast cancer is the second most common cancer in Indian women with an estimated annual incidence of 0.145 million and mortality of 0.070 million, as reported in 2012 Globocan database [1]. According to 3 year report of the Population-based Cancer Registry (PBCR):2012-2014, it is the commonest cancer among women in 21 out of 34 PBCRs with the highest Age-adjusted incidence rates (AARs) in Delhi (AAR 41), Chennai (AAR 37.9) and Bangalore (AAR 34.4) [2]. The consolidated report of Hospital-based Cancer Registry (HBCR): 2012-2014 also enlists breast cancer to be the commonest cancer in females of 7 out of 8 HBCRs with the highest in RCC Trivandrum (28.3%), TMH-Mumbai (27.6%) and BRAIRCH Delhi (26.1%) [3]**.** Moreover, data from PBCRs and HBCRs from 1980s onwards show an increase in the incidence of breast cancer which has overtaken cervical cancer [4]. According to 2012 breast cancer statistics, 1 out of 2 ladies suffering from breast cancer dies while the figure is 1 out 5-6 in the Unites States [5]. This is chiefly due to presentation at later stages owing to social taboos, lack of widely implemented screening programs, etc. There is urgent need of information and education regarding awareness of breast cancer.

Use of the Web to perform an epidemiological survey was first reported in 1996 [6]. This method has since been applied to national-scale surveys in various countries. According to Internet and Mobile Association of India (IMAI) November 2015 reports, India has the second largest internet user's base in the world behind China. Quite significantly, female internet users are growing at a rate of 39% compared to 28% among males [7]. Among the female Internet users, the highest growth has been in the segment of non-working women which grown by 97% over last year [7]. Also, 75% of the working women access in urban areas was found to access the Internet daily [7].

In our study we have tried to assess the level of awareness regarding breast cancer among Indian educated females using internet-based surveys.

II. Materials And Methods

In this cross sectional observational study we tried to find out the level of knowledge, attitude & awareness about breast cancer among urban educated females aged 20-60 years. We included Indian urban females of age more than 21 years with a graduation as minimum educational qualification with having regular internet access and not related to healthcare either by education or profession. Woman having past history of malignancy were not included.

The participants responded to an internet-based cross-sectional survey conducted through an online survey [8]. The study population was accessed from social networking sites like facebook[9], instagram[10], twitter[11], etc. Potential respondents were blindly invited to participate in the internet-based survey via e-mail. The invitation e-mail contained an URL directing them to a protected area of the website using their unique log-on ID and password. The nature and purpose of the study were explained in information brochure along with an online informed consent form. A demographic data sheet was also sent to the participants to collect information about their age, marital status, educational level, occupation, and family history of breast cancer. Data were collected from December 2015 to June 2016.

The self-administered questionnaire, English version of the modified Breast Cancer Awareness Measure (Breast CAM) version 2 (Cancer Research United Kingdom, King's College London and University College London, 2009, updated on 09/02/2011) [12] has been used for this study. The Breast CAM comprises of

seven domains: 1.) Symptoms 2.) Confidence, skill and behavior in relation to breast changes, 3.) Anticipated delay in contacting doctor, 4) Barriers to seeking medical help, 5.) Knowledge relating to age related and lifetime risk, 6) Knowledge regarding breast screening,7) Knowledge regarding risk factors.

The Breast-CAM has been found to be a valid and reliable instrument for measuring breast cancer awareness in women. Test-retest reliability is moderate to good for most items. Data was analyzed using Statistical Package for Social Sciences version 20 [13]. Frequency distribution statistics were used to assess demographic variables and responses for each domain of the questionnaire.

III. Results

Questionnaire was mailed to 862 candidates of whom 212 (24.6%) women responded (till June 2016) to all its domains .The median age of respondents was 24 years (range 21-54 years). Most of them (41.4%) were from Kolkata, followed by Bengaluru (25.6%), Delhi (19.4%) and Mumbai (13.6%). 129 (60.8%) respondents were post-graduates while rests were undergraduates. The results for each domain of the questionnaire are discussed in terms of percentage of responses under the following headings.

A) Domain 1: Knowledge of symptoms:

Results are detailed in Table 1.Majority of women were able to identify common symptoms of breast cancer like lump or thickening (84.4%),discharge or bleeding (53.7%),changes in the shape of either breast or nipple (42.5%).

B) Domain 2: Confidence, skills and behavior in relation to breast changes:

The results are detailed in Table 2. Majority women rarely/never check their breasts (42.4%) and 25 % have no idea/do not know about self-examination. Majority women (41.7%) said that they are not at all confident to notice changes in their breasts.47.2% women said that they never been to see doctor for their changes in breast. 34% never noticed change in breast.

C) Domain 3 : Anticipated delay in contacting the doctor:

Results are detailed in Table 3.Majority women (51.4%) said that they will consult a doctor within 1month if they notice any changes in breast.29.2% will seek early consultation (within a week).

D) Domain 4: Barriers to seeking medical help

Results are detailed in Table 4. Majority women said that they do not feel embarrassed (85.5%), sacred (75%), or worried (87.7%) to seek consultation of doctor. Interstingly 16.5% said they feel sacred to go and seek medical consultation.

E) Domain 5: Knowledge of age-related and lifetime risk:

Details are detailed in Table 5. Majority (38%) have no idea about age related risk of breast cancer. According to 22.5% women breast cancer can occur at any age. 45.4% women said that they do not know the lifetime risk of breast cancer. 24% said that the risk is in 1:9 ratio in lifetime

F) Domain 6: Knowledge of Breast Screening:

This particular domain has been customized for this study since NHS Breast Screening Program is not available in India. We have used only two questions. Responses are detailed in Table 6. 71.7% women never heard about breast cancer screening. 60.3% women said that they do not think breast cancer screening will decrease breast cancer occurrence.

G) Domain 7: Knowledge regarding risk factors:

Results are detailed in Table 7.The responses were inconsistent and incoherent mostly. So, only the positive responses (‘agree’ and ‘strongly agree’) for each risk factor have been presented. Majority women agreed (35.8% agreed and 25% strongly agreed) that past history of breast cancer is a leading risk factor followed by family history (28.3% agreed and 12.7% strongly agreed) and drinking more that one unit of alcohol (23.6 % agreed and 16.9% strongly agreed).

IV. Discussion

As mentioned earlier, all the PBCRs show a significant increase for annual average of AARs for breast cancer over the last three or five years [4]. This rising risk is attributed to socioeconomic and life-style changes like childbearing at later age, modern dietary habits and also associated changes in menstrual patterns [14, 15]. Quite naturally, screening may be thought to be our defense in such a scenario. However, contrary to the initial enthusiasm with mammography as a screening procedure, Cochrane review has suggested little benefits of

mammography in reducing mortality and morbidity from breast cancer [16]. The recent studies also support this review and show more chances of over-diagnosis and hence over-treatment with screening mammography but small effect on breast cancer mortality [17, 18]. The other screening tool, Clinical Breast Examination (CBE) reportedly has a poor sensitivity of 54%, but a specificity of 94% [19]. The threat posed by the rising trends is greater in developing countries like India where screening is all the more difficult to implement on a large scale owing to economic reasons. There is also low cancer literacy of breast cancer risk factors among Indian women, irrespective of their socio-economic and educational background [20]. As a result of all these factors, breast cancer mortality is increasing in India as opposed to Western counterparts [4].

Educated women are reported to be more aware of breast cancer [21]. In fact, women from lower socio-economic status present at later stages in diagnosis and experience a higher mortality rate than those from an affluent background [22]. This study was conducted to assess the level of awareness among educated urban females having access to internet. Of late, internet based surveys on awareness of behavioral patterns linked to breast cancer have been successfully implemented [23]**.** We chose to use the Breast-CAM v2 tool for our study. The tool was earlier used to collect data from Saudi females about their knowledge of breast cancer warning signs, risk factors, screening programs and breast self-examination (BSE) [24].

As far as the psychometric properties of Breast-CAM v2 [12] tool is concerned, it has high readability (i.e., widely acceptable by women), quite sensitive to different degrees of intervention, good test-retest reliability quotient and good construct validity [25].

In our study, we found nearly 43-85% of women had knowledge of breast cancer symptoms. Compared with the study by Somdatta et al. [26] where 79%, 13% and 3% women mentioned breast lump, nipple discharge and skin changes respectively to be at least one of the symptoms of cancer, we witnessed a higher level of cumulative awareness at 84.4%, 53.7 % and 42.9% for the corresponding symptoms. For the same aforesaid symptoms, the level of awareness was reported to be 50.5%, 47% and 35% among Saudi females of Jeddah [24]. Health professionals like nurses are known to have higher levels of awareness at around 90% for all these symptoms as shown in the study by Khokhar A et al. [27]. However, ours being a mixed population, we did not observe such results. As far as awareness about self-checking of breasts, 42.4 % rarely/never did it and 25% didn't know about it at all; however, the highest frequency of checking was once a month reported by 19.8% women. Also, 71.7 % women were aware of breast cancer screening procedure. The results are comparable, if not better than earlier studies both in terms of awareness about Breast self-examination (BSE) and correct frequency of once a month BSE [24, 26, 28, and 29]. However, our questionnaire considered only breast self-checking which may not adhere to proper BSE methodology or frequency.

The knowledge about various risk factors observed in our study is compared with the results of previous studies done in urban populations in the Table 8. (

More than 50% of women mentioned about reporting to doctor within a month of detection of changes in breast and most of the women didn't feel embarrassed or apprehensive or worried about visiting a doctor if required. To summarise the above discussion, the level of awareness among educated urban females are not satisfactory. Keeping in mind that our study reflects only the 'tip of iceberg', the overall scenario among Indian females seems to be quite despondent. However, our study has a few limitations too. Firstly, the probability of taking second opinions before sending responses always remain in absence of a personal meeting; this may have confounded the results. Secondly, it is difficult to take study subjects in confidence when web-based mails are sent. In our study, less than 30% responded completely to all the domains of the questionnaire. Thirdly, the Breast-CAM v2 module isn't customized to Indian population. All the psychometric properties have been tested and validated for use in foreign populations.

Clearly, national screening programs with wide scale implementation are not achievable in near future. But interventions are urgently required to increase the awareness level about breast cancer in Indian females. Various such approaches have been suggested in the 2012 review article on recent breast cancer scenario by Khokhar A et al., viz. awareness campaigns by Govt. agencies and NGOs, strengthening breast cancer related curriculum in medical schools, targeting women in late thirties for mammographic screening, public health worker training in clinical breast examination, developing indigenous guidelines for breast cancer management, etc. We sincerely believe that these interventions are practically feasible and can certainly bring a change in the current level of awareness.

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Table 1:

A) Domain 1: Knowledge of symptoms:

Questions	Yes (%)	No (%)	Don't know (%)	Refused (%)
Do you think a lump or thickening in your breast could be a sign of breast cancer?	84.4	11.1	4.5	0
Do you think discharge or bleeding from your nipple could be a sign of breast cancer?	53.7	10.8	35.5	0
Do you think changes in the shape of your breast or nipple could be signs of breast cancer?	42.9	34.4	22.7	0

Table 2:

B) Domain 2: Confidence, skills and behavior in relation to breast changes:

How often do you check your breasts? (%)		**Are you confident that you will** notice a change in your breasts? (%)		Have you ever been to see a doctor about a change you have noticed in one of your breasts? (%)	
Rarely or never	42.4	Not at all confident	41.7	Yes	17.9
At least once every 6 months	5.8	Slightly confident	30.1	No	47.2
At least once a month	19.8	Fairly Confident	9.2	Never Noticed	34.9
At least once a week	7	Very Confident	4.2	Don't know	0

Don't know	25	Don't know	14.8	Refused	0
Refused	0	Refused	0		

Table 3:

C) Domain 3:Anticipated delay in contacting the doctor :

If you found a change in your breasts, how soon would you contact your doctor?	Within a week (%)	Within a month (%)	Within six months (%)	Don't know (%)	Refused (%)
	29.2	51.4	15.7	3.7	0

Table 4:

D) Domain 4:Barriers to seeking medical help :

Questions	**Yes-often (%)**	**Yes-sometimes (%)**	**N**o (%)	Don't know (%)	Refused (%)
Too embarrassed to go and see the doctor	1.4	13.3	85.3	0	0
Too scared to go and see the doctor	6.2	16.5	75.9	1.4	0
Worrying about what the doctor might find may stop me from going to the doctor	2.6	9.7	87.7	0	0

Table 5:

E) Domain 5:Knowledge of age-related and lifetime risk :

The next question is about who you think is most likely to get breast cancer.		How many women will develop breast cancer in their lifetime?	
Questions	% of responses		% of responses
A 30 year old woman	3.7	1 in 3 women	2.8
A 50 year old woman	17	1in 9 women	24
A 70 year old woman	18.8	1 in 100 women	21.2
A woman of any age	22.5	1 in 1000 women	6.6
Don't Know	38	Don't Know	45.4
Refused	0	Refused	0

Table 6:

F) Domain 6:Knowledge of Breast Screening :

Questions:	Yes (%)	No (%)
Have you ever heard of breast cancer screening	71.7	28.3
Do you think screening can decrease breast cancer occurrence?	60.3	12.2

Table 7:

G) Domain 7:Knowledge regarding risk factors:

Risk factors	Agree	Strongly Agree
Having a past H/O breast cancer	35.8	25
Using Hormonal agents(Hormone Replacement Therapy / Oral Contraceptive pills)	26.4	4.2
Drinking more than 1 unit alcohol a day	23.6	16.9
Being overweight(BMI>25)	25	8.9
Having a close relative with breast cancer	28.3	12.7
Having children later on in life or not at all	12.3	8.9
Starting your periods at an early age	9.4	3.3
Having a late menopause	8.47	6.1
Doing less than 30 mins of moderate physical activity 5 times a week.	8.9	2.8

Table 7: Comparison of study results with published researches on level of awareness of breast cancer among women.

	Awareness levels(%) of different risk factors							
STUDIES	Family history	Hormonal agents (viz.HRT/OC	Alcohol	Overweight/ Obesity	Age at 1st child birth	Nulliparity	Early menarche	Late menopause

		P)						
Somdatta et al[26](2008)		8%		11%				
Khokhar (2009)[30]	58%			11.6%	21.3%		7.7%	
Garg[31] (2010)	39%			51%				5%
Oza et al[32] (2011)	40.8%		52.8%	34.4%	37.6%	42.4%		27.2%
Bala and Gameti[28] (2011)	27.6%	27.6%		26%	29.6%	25.2%		21.2%
Khokhar[27] (2012)	98.06%	85.3% (HRT) / 90.3% (OCP)	98.4%	76.4%	90.34%		52.1%	29.3%
Fotedar et al[33] (2013)	93.9%	74%					73.1%	
SM Radi[24] (2013)	57.5%	35.5%	41%	28.5%	23%		17%	18.5%
Index study	41%	30.6%	40.5%	33.9%	21.2%		`12.7%	14.6%

Studies written in italics were done among health care experts, viz. nurses; rest have professional heterogeneity.