

Barriers for early detection of cancer amongst Indian rural women

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Abstract

Context: Breast and cervical cancer are the most common causes of cancer mortality among women worldwide, but actually they are largely preventable diseases. Healthcare providers in developing countries regularly see women with advanced, incurable cancers. Health of a rural Indian women and her access to health facility is compromised due to sociocultural, economical, and environmental factors. **Aims:** To know the problems associated with early detection of cancers in rural women. **Settings and Design:** Rural area and cross-sectional. **Subjects and Methods:** Study subject: Women of 35 years and above. Exclusion criteria: Not willing to participate. Sample size: All eligible women of selected villages. **Sampling Technique:** Random selection of villages. Study duration: 2 months. Study tools: Pretested questionnaire. **Statistical Analysis Used:** Percentages, χ^2 test, analysis of variance (ANOVA), multivariate analysis. **Results:** Awareness about symptoms, possibility of early detection, available tests, possibility of cure of disease was low. Main barrier for screening was cognitive, that is, 'don't know' answer by 83.99% women for cancer cervix, 84.93%, for cancer breast, and 67.26% for oral cancer. Awareness score was significantly associated with age ($\chi^2 = 17.77$, $P = 0.001$), education ($\chi^2 = 34.62$, $P = 0.000$), and income ($\chi^2 = 16.72$, $P = 0.002$); while attitude score with age ($\chi^2 = 16.27$, $P = 0.012$) and education ($\chi^2 = 25.16$, $P = 0.003$). Practice score was significantly associated with age ($\chi^2 = 11.28$, $P = 0.023$), education ($\chi^2 = 32.27$, $P = 0.003$), and occupation ($\chi^2 = 10.69$, $P = 0.03$). Awareness, attitude, and practice score of women having history of cancer in family or relative was significantly high than women without history. **Conclusions:** Cognitive barrier was the important barrier which has to be taken care of.

Key words: Barriers, early detection, rural, screening

Introduction

Cancer is a leading cause of death globally. Every year, millions of cancer patients could be saved from premature death and suffering if they had timely access to early detection and treatment.^[1]

Breast and cervical cancer are the most common causes of cancer mortality among women worldwide, but actually they are largely preventable diseases. In India, high incidence rates were reported for breast cancer, cervix, and ovary; which together accounted for 59% of all cancers in women.^[2] Breast cancer accounts for 19-34% of all cancer cases among women in India.^[3] Worldwide, cervical cancer claims the lives of 231,000 women annually, over 80% of whom live in developing countries.^[4] Oral cancers are one of the leading cancers in India today, with an age-standardized incidence rate of 12.6 per 100,000 population.^[5] More than two-third of the cancer patients are already in an advanced and incurable stage at the time of diagnosis.^[3]

The results from the Indian studies of 'downstaging' indicate that it is not suitable as an independent primary screening modality for cervical neoplasia and should not be considered for early detection.^[6] Screening facility like Pap smear is now available at Community Health Centers, while breast self-examination (BSE) can be done by woman herself if she knows about it. In spite of that, healthcare providers in developing countries regularly see women with advanced, incurable cervical cancer. The currently available evidence suggests that a shift towards early stages may be achieved at considerably lower costs by health education and improved awareness, as revealed by the findings from Sweden and Barshi, India.^[6]

Health of a rural women and her access to health facility is further compromised due to sociocultural, economical, and environmental factors. Nearly 72% of India's population stays in rural area. So the proportion of rural women is high. That is why there is need to know the problems associated with early detection of cancers in rural women.

Subjects and Methods

A cross-sectional study was planned in a randomly selected village from the villages under rural health training center (RHTC) of a medical college in Sangli district. A semistructured questionnaire was formed for this purpose with the help of published articles and experts. It was then peer reviewed and translated into Marathi language. Translated version was peer reviewed again. Questionnaire included close-ended questions like what is cancer?, curability of cancer and its reasons, risk factors, and screening tests for cancers and various

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reasons for the tests not being done. Pilot study was conducted using lady clerical staff of the medical college coming from nearby villages. Appropriate changes were made in the questionnaire on the basis of felt requirements. Approval from the Institutional Ethical Committee (IEC) was obtained. Permission was obtained from the Sarpanch (Head) of village by explaining him importance of study. Women above the age of 35 years were included in the study. House-to-house visit was paid for collection of data by using questionnaire. Those women who did not wish to participate were excluded. For illiterate women help was provided.

Three visits were paid between 11 am and 1 pm and another three visits on different days between 1 pm and 3 pm, as most of the women were farmers by profession and returned from the fields only in the afternoon. Later, full 2 days visit were paid to include any woman who was left out.

A lady clerk and medical social worker from RHTC were asked to supervise data collection, so as to avoid bias.

Data analysis was done by using Statistical Package for Social Sciences (SPSS; trial version 19). To study the association of sociodemographic factors with awareness, attitude, and practice; score was calculated for each of them. Out of 31 questions, 24 were about awareness, three of attitude, and four of practice. Total score for awareness was 47 as some questions had multiple correct answers, 3 for attitude, and 2 for practice. Age, education, occupation, family type, and per capita income were included in analysis.

To find out the effect of history of cervical, breast, or oral cancer in family, relative, or neighborhood of women on their awareness, attitude, and practice scores; association between them was checked.

For the same scores were divided as <50% and >50%.

Results

A total of 281 women were interviewed.

Awareness about cancer in general

All women were aware about cancer, but only 24 (8.54%) women knew correctly what cancer means. According to 87 (30.96%) women, cancer is curable and for 78 (27.76%) women, cancer is incurable, while 116 (41.28%) said they do not know about it.

Only four (4.59%) out of 87 women said cancer is curable, knew correctly that it is possible only when early diagnosis and right treatment for right duration is provided. While 58 (66.66%) opined that only early diagnosis is needed for curing cancer and for 45 (51.72%) women right treatment for right duration is required.

Some women gave multiple answers for symptoms, risk factors, and screening test.

Awareness about cancer cervix, breast, and oral

All women were aware about these three cancers.

Awareness about symptoms, screening test, early detection, and risk factors

Cancer cervix

Only 46 (16.37%) women were aware about its symptoms. Irregular per vaginal bleeding (37, 13.16%) was the most commonly known symptom followed by blood-stained discharge (34, 12.1%) and bleeding after intercourse (12, 13.95%).

Total 87 (30.96%) women answered positively for the possibility of early detection of precancerous lesions and early cancer, 56 (19.93%) were not able to answer, while remaining 138 (49.11%) answered negatively.

Only 40 (14.23%) women knew tests. Pap smear was known to 10 (3.56%), internal examination to 32 (11.38%), and colposcopy to four (01.42%) women. Only 80 (28.47%) women had awareness about risk factors. Most common answer was 'don't know', given by 201 (71.53%) followed by early marriage (43, 15.3%), poor personal hygiene (21, 07.47%), having more number of children (19, 6.76%), having first child at an early age (17, 6.05%), irresponsible sexual behavior by both partners (seven, 2.49%). None was aware of human papillomavirus.

Correct age for undergoing screening was known to only 50 (17.79%) women.

Attitude about and practice of early detection or screening

In case of availability of screening test, 141 (50.18%) women feel every woman should undergo testing. There was a negative answer for the same question by seven (2.49%), while 133 (47.33%) preferred don't know option.

Total 13 (4.63%) women gave history of undergoing screening.

Barriers for screening

According to women, reasons for not undergoing screening were as follows: Most common reason was 'don't know' (236, 83.99%), economic constraints (11, 3.91%), don't know the place where to do (three, 1.07%), feel shy (three, 1.07%), distance (three, 1.07%), not permitted (one, 0.36%), fear for diagnosis (10, 3.56%), no time (12, 4.27%), and no one to accompany (zero).

Cancer breast

Awareness about symptoms, screening test, early detection, and risk factors

For symptoms of carcinoma breast, only 98 (34.88%) women were aware, while don't know option was preferred by 183 (65.12%). Most common answer was lump in breast (94, 33.45%) then lump in axilla (15, 5.34%), discharge from nipple (nine, 3.2%), change in the skin of breast (six, 2.14%), and change in the position of nipple (two, 0.71%).

For 109 (38.79%) women, early detection of carcinoma breast is possible. According to 93 (33.10%) women, complete freedom from carcinoma breast is possible if

detected early, answer was 'no' by 40 (14.23%) women, while 148 (52.67%) said they don't know.

Only 88 (31.31%) women knew at least one test. Only 20 (7.12%) women knew about BSE. Most common answer was examination by doctor or nurse (66, 23.48%) followed by mammography (five, 1.78%). Only 57 (20.28%) women answered for it. Most common answer was 'not giving breast feeding' 36 (12.81%) followed by birth of a child at late age (28, 9.96%); no children (26, 9.25%); duration of breast feeding less than 6 months (23%, 8.19%); late marriage (23, 8.19%); history of breast cancer among mother, sister, and close relatives (24, 8.14%); and early menarche and late menopause (18, 6.41%).

Early detection or screening: Attitude and practice

There was a positive attitude for screening by 134 (47.69%) women, while 18 (6.41%) said, there is no need. But 129 (45.91%) women failed to give their opinion.

Correct age for undergoing screening for cancer breast was known to 61 (21.61%) women. There were total 19 (6.76%) women who had undergone screening. Four (1.42%) women had examination by doctor.

Barriers for screening

There were 19 (6.76%) women doing BSE regularly, 43 (15.30%) irregularly, and never by 219 (77.94%). Reasons for not performing breast examination or doing irregularly were as follows. Most common reason was don't know how to perform examination (186, 84.93%), don't have time (33, 15.07%), fear of getting mass (four, 1.83%), forget (3, 1.37%), and lack of privacy (1, 0.46%).

Oral cancer

Hundred and sixteen (41.28%) women were aware of the fact that even women can suffer from oral cancer.

Awareness about symptoms, screening test, early detection, and risk factors

There were 85 (30.25%) women having awareness about the symptoms. Most known symptom was difficulty in opening mouth and swallowing (67, 23.84%), recurrent bleeding gums (61, 21.71%), ulcer (59, 20%), and bad breath (49, 17.44%).

Detection of precancerous lesion is not possible for 34 (12.10%) women. Sixty-one (21.71%) women knew about detection of precancerous lesion by doing oral examination, while 189 (67.26%) were unaware.

Causal role of tobacco, gutkha chewing, and misri use in oral carcinoma was known to 160 (56.94%), 144 (51.25%), and 146 (51.96%) women. While remaining women either said no or do not know.

Awareness, attitude, and practice score and sociodemographic factors

Range of age was 35-80 years. Education wise largest group of women (116, 41.28%) was illiterate. As there were only nine women having 12 years of schooling, they

were added to the group having education 5-10 years of schooling. Four women had professional diploma and being a small group, it was combined with the graduate group. Majority of women were housewives. Others were farmers except three, who were teachers. They were not included in the analysis. There were four 'three generation' families which were added in joint family group. Getting information of family income from women was very difficult. Large number of women, that is, 144 (51.24%) were unaware of family income. Those who have answered had given approximate figures of income. After calculating per capita income, three groups were formed.

Awareness

Range of awareness scores was 0-33 out of 47. Median score was 6. There were 149 women having either 6 or <6 score. Six out of 47 means 12.75% score. This means more than 50% women were having score of 12.75% or less than that.

There was significant association between awareness score and age ($\chi^2 = 17.77$, $P = 0.001$, degrees of freedom (df) = 4), education ($\chi^2 = 34.62$, $P = 0.000$), and income ($\chi^2 = 16.72$, $P = 0.002$) [Table 1].

Attitude

Linear trend was observed in attitude score and age. Significant association was observed between age ($\chi^2 = 16.27$, $P = 0.012$, df = 6), education ($\chi^2 = 25.16$, $P = 0.003$, df = 0.9), and attitude score [Table 2].

Practice

Significant association was found in practice score and age ($\chi^2 = 11.28$, $P = 0.023$, df = 4), education ($\chi^2 = 32.27$, $P = 0.003$, df = 6), and occupation ($\chi^2 = 10.69$, $P = 0.03$) [Table 3].

History of cancer in family or relative and its association with awareness, attitude, and practice score

History of cervical, breast, or oral cancer in family or relative or neighborhood was present in 56 (19.93%) out of 281 women. Total 23 (8.19%) women gave history of breast cancer, 11 (3.91%) of carcinoma cervix, and 22 (7.83%) women oral cancers either in their relation or neighborhood.

None of the women having such history scored '0' for awareness.

Awareness score above 50% was significantly high in women with history (14, 25%) than without history (4, 7.8%) ($\chi^2 = 36.552$, df = 1, $P = 0.000$). Attitude score above 50% was significantly high in women with history 39, 69.64%) than without history (93, 41.33%) ($\chi^2 = 20.34$, df = 1, $P = 0.000$). Practice score above 50% was significantly high in women with history (28, 50%) than without history (47, 20.89%) ($\chi^2 = 17.961$, df = 1, $P = 0.000$).

Discussion

Early detection both by screening and early clinical diagnosis is an important intervention to control cancer in low- and

Table 1: Association between awareness score and sociodemographic factors

Sociodemographic factors	Awareness score			Total	
	0	<50%	>50%		
Age group (years)					
<45	24	124	14	162	$\chi^2=17.77$, $P=0.001$
	14.81%	76.54%	8.64%	100.00%	
45-55	11	30	3	44	
	25.00%	68.18%	6.82%	100.00%	
>55	28	46	1	75	
	37.33%	61.33%	1.33%	100.00%	
Education					
Illiterate	38	77	1	116	$\chi^2=34.62$, $P=0.000$
	32.76%	66.38%	0.86%	100.00%	
Up to primary	8	24	3	35	
	22.86%	68.57%	8.57%	100.00%	
Up to HSC	17	88	9	114	
	14.91%	77.19%	7.89%	100.00%	
Grand Pr	0	11	5	16	
	0.00%	68.75%	31.25%	100.00%	
Occupation*					
Farmer	25	68	3	96	$\chi^2=2.87$, $P=0.237$
	26.04%	70.83%	3.13%	100.00%	
Housewife	38	129	14	181	
	20.99%	71.27%	7.73%	100.00%	
Income group					
Don't know	43	98	3	144	$\chi^2=16.72$, $P=0.002$
	29.86%	68.06%	2.08%	100.00%	
<1,000 Rs	13	73	10	96	
	13.54%	76.04%	10.42%	100.00%	
≥1,000 Rs	7	29	5	41	
	17.07%	70.73%	12.20%	100.00%	
Family type					
Joint	40	113	9	162	$\chi^2=1.42$, $P=0.492$
	24.69%	69.75%	5.56%	100.00%	
Nuclear	23	87	9	119	
	19.33%	73.11%	7.56%	100.00%	
Total	63	200	18	281	
	22.42%	71.17%	6.41%	100.00%	

Gr and Pr=Graduate and professional, HSC=Higher secondary school. *Three teachers not included in analysis

medium-income countries. The main objective of it is to detect cancer cases early enough to provide less toxic and less expensive curative treatment. Most of the cancer patients seek medical advice when disease is fairly advanced. Regular mammogram screening and Pap smear testing have been utilized to detect breast and cervical cancer at early stage and have been shown to be effective in reducing breast and cervical cancer deaths. Pap smear testing is available in government hospital but it remains underutilized, while for breast cancer screening program is not available in India.^[3]

The success and effectiveness of an organized cancer screening program is largely dependent on obtaining

Table 2: Association between attitude score and sociodemographic factors

Sociodemographic factors	Attitude score				Total
	0	1	2	3	
Age group (years)					
<45	60	15	29	58	162
	37.04%	9.26%	17.90%	35.80%	100.00%
45-55	17	4	12	11	44
	38.64%	9.09%	27.27%	25.00%	100.00%
>55	42	11	10	12	75
	56.00%	14.67%	13.33%	16.00%	100.00%
	$\chi^2=16.27$, $P=0.012$				
Education					
Illiterate	64	14	19	19	116
	55.17%	12.07%	16.38%	16.38%	100.00%
Up to primary	13	3	6	13	35
	37.14%	8.57%	17.14%	37.14%	100.00%
Up to HSC	40	12	23	39	114
	35.09%	10.53%	20.18%	34.21%	100.00%
Gr and Pr	2	1	3	10	16
	12.50%	6.25%	18.75%	62.50%	100.00%
	$\chi^2=25.16$, $P=0.003$				
Occupation*					
Farmer	46	7	17	26	96
	47.92%	7.29%	17.71%	27.08%	100.00%
Housewife	72	23	33	53	181
	39.78%	12.71%	18.23%	29.28%	100.00%
	$\chi^2=2.78$, $P=0.425$				
Income group					
Don't know	70	12	25	37	144
	48.61%	8.33%	17.36%	25.69%	100.00%
<1,000 Rs	39	14	17	26	96
	40.63%	14.58%	17.71%	27.08%	100.00%
≥1,000 Rs	10	4	9	18	41
	24.39%	9.76%	21.95%	43.90%	100.00%
	$\chi^2=10.87$, $P=0.092$				
Family type					
Joint	73	18	30	41	162
	45.06%	11.11%	18.52%	25.31%	100.00%
Nuclear	46	12	21	40	119
	38.66%	10.08%	17.65%	33.61%	100.00%
	$\chi^2=2.40$, $P=0.493$				
Total	119	30	51	81	281
	42.35%	10.68%	18.15%	28.83%	100.00%

Gr and Pr=Graduate and professional, HSC=Higher secondary school. *Three teachers not included in analysis

high participation rates through effective recruitment and retention strategy.^[7]

This study was planned to find out the barriers for early detection of cancer in rural women.

Total 281 women of and above the age of 35 years were included in the study. All were aware about cancer, but only 8.54% knew exactly what cancer means, that is, uncontrolled growth of cell. More than two-third of women had belief that there is no cure for cancer. This indicates that in general women knew the 'name' 'cancer' and had fear about it. Only four out of 281 had correct knowledge that cancer is curable

Table 3: Association between practice score and sociodemographic factors

Sociodemographic factors	Practice score			Total	Significance
	0	1	2		
Age group (years)					
<45	110	41	11	162	$\chi^2=11.28$, $P=0.023$
	67.90%	25.31%	6.79%	100.00%	
45-55	30	11	3	44	
	68.18%	25.00%	6.82%	100.00%	
>55	66	7	2	75	$\chi^2=32.27$, $P=0.003$
	88.00%	9.33%	2.67%	100.00%	
Education					
Illiterate	94	21	1	116	
	81.03%	18.10%	0.86%	100.00%	$\chi^2=10.69$, $P=0.03$
Up to primary	29	2	4	35	
	82.86%	5.71%	11.43%	100.00%	
Up to HSC	78	29	7	114	
	68.42%	25.44%	6.14%	100.00%	$\chi^2=8.87$, $P=0.064$
Gr and PG*	5	7	4	16	
	31.25%	43.75%	25.00%	100.00%	
Occupation					
Farmer	77	19	1	97	$\chi^2=3.29$, $P=0.192$
	79.38%	19.59%	1.03%	100.00%	
Housewife	128	39	14	181	
	70.72%	21.55%	7.73%	100.00%	
Teacher	1	1	1	3	$\chi^2=8.87$, $P=0.064$
	33.33%	33.33%	33.33%	100.00%	
Income group					
Don't know	114	25	5	144	
	79.17%	17.36%	3.47%	100.00%	$\chi^2=3.29$, $P=0.192$
<1,000 Rs	68	20	8	96	
	70.83%	20.83%	8.33%	100.00%	
≥1,000 Rs	24	14	3	41	
	58.54%	34.15%	7.32%	100.00%	$\chi^2=3.29$, $P=0.192$
Family type					
Joint	125	28	9	162	
	77.16%	17.28%	5.56%	100.00%	
Nuclear	81	31	7	119	$\chi^2=3.29$, $P=0.192$
	68.07%	26.05%	5.88%	100.00%	
Total	206	59	16	281	
	73.31%	21.00%	5.69%	100.00%	

Gr and Pr=Graduate and professional, HSC=higher secondary school

if diagnosed and treated early. It makes clear that awareness about cancer in general is very very low.

Even though cancer cervix is the most common cancer affecting rural Indian women, awareness about symptoms, early diagnosis, and screening test was very poor. The prerequisite for early diagnosis is to have knowledge about the symptoms of cancer so as to consult doctor at the earliest.^[8] Similar type of findings are mentioned by other studies.^[9-11] Another study reports higher levels of awareness about symptom and risk factors. However, this study is from Myanmar.^[12]

Nearly two-third of the women was unaware of the risk factors for cancer cervix. Similar findings were noted by other study.^[13]

Cancer breast was also known to all. Awareness was low about symptoms (34.88%), but was better than cancer cervix (30.6%). Most known symptom was lump in breast. However, BSE awareness was very poor (7.12%). Similar findings were mentioned by other studies,^[3] which is very low as compared to a study from South African countries, where nearly half of women were aware.^[10] Nearly half of women failed to opine for availing the early diagnostic services may be because of lack of awareness. Awareness about risk factors for cancer breast was very low (28.47%), which may be hurdle for prevention. Similar findings were noted by other studies.^[14]

More than half of the women were not aware of the fact that they can also suffer from oral cancer if they use tobacco (chewing or mishri) and gutkha. Awareness about the precancerous lesions was low (21.71%). Oral cancers are ideal for screening, but awareness has to be raised.

According to women, main barrier for using early diagnostic services for all three cancers was lack of awareness about symptoms and availability of tests, and therefore, the possibility of early diagnosis. In this study, awareness was significantly associated with age, education, and income; attitude with age and education; while practice with age, education, and practice. Age and education was common to all. Scores of all three aspects were better in young women and if they had better education. Similar findings were mentioned by other studies.^[13] Poor awareness lowers the possibility of early diagnosis in spite of availability of screening test. Most of the older women were illiterate. So education may be having important role in awareness. Similar types of findings have been noted by other studies.^[10] Nearly half of the women have shown attitude or willingness for using the early detection method if they are available. Hence, lack of awareness was the main hindrance for early detection.

It was observed that, history of cancer in family or neighborhood has significantly improved not only awareness but also attitude and practice. Similar type of observation is noted in another study which was done on nurses from a rural region of Turkey.^[15] Usually the incidence of cancer in family or in relative initiates lot of discussion and people try to probe more information, which may be useful for improving not only awareness but attitude and practice also.

In the cognitive (knowledge) barriers, women were not only unaware about possibility of cure of cancer but also about the possibility of early detection of cancer, availability of test, awareness of risk factors, and symptoms of disease also. It was true for all three cancers, common in women.

In this study, important barrier for utilization of cancer screening was found to be cognitive barrier. First level

of cognitive domain is awareness, which the women were lacking. When they were made aware about the test availability for early detection, nearly half of the women were not sure about its utilization and they answered 'don't know' for their use. As women are usually not involved in decision making even in the issues related with their own health, they must have found it difficult to opine on the use of test or they did not feel comfortable in taking the decision on the basis of knowledge available to them (inadequate knowledge), so they may be in need of more understanding of the given test, for example, purpose of test and benefits of testing. This may be the reason why women having history of cancer in relatives or neighborhood had better attitude and practice than women without such history.

It suggests that awareness through mass media may not be sufficient in changing attitude or practice. But contributing more information to them by conducting discussions by the people in whom they have faith may be helpful, for example, local doctors, Accredited Social Health Activist (ASHA), auxiliary nurse midwife (ANM), etc.

Few women have mentioned emotional barrier like fear or shyness, which can be taken care by conducting health education sessions for delivering higher level of knowledge.

Other barriers were economic barrier (time and money), logistic barriers (child care, transportation, waiting times, etc.), and can be taken care by developing structural screening programs.

Social barrier like lack of family support can be taken care by involving male members of family in the health education sessions along with the women.

Similar types of barriers were reported in studies involving Asian women living in western countries. Breast and cervical cancer screening rates are consistently low among Asian women, both in Asian and western countries. According to a meta-analysis, 'Access Enhancing Intervention' (e.g. mobile vans and reduced cost mammograms) were shown to be most effective.

In this study, main barrier was the cognitive barrier as awareness about the symptoms, screening, and risk factors for prevention was low. There is a need of effective health education programs, especially in the rural parts of India.

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