

## Original Research Article

# Factors affecting the participation and utilization of breast cancer screening services among health care workers Kolar: a qualitative study

Hogarehalli Jayanna Swathi<sup>1</sup>, Hogarehalli Jayanna Vinayaka<sup>2</sup>, Varsha R. Mokhasi<sup>3</sup>,  
Byrappa Nirmala Bhanuprasad<sup>4</sup>

<sup>1</sup>Department of Community Medicine, Kanachur Institute of Medical sciences, Mangalore, Karnataka, India

<sup>2</sup>Department of Gastroenterology, All India institute of medical Sciences, Raipur, Chattisgarh, India

<sup>3</sup>Department of Community Medicine, Sri Siddhartha Medical College Tumkur, Karnataka, India

<sup>4</sup>Department of Dermatology, Government general hospital Shikaripura, Shimogga, Karnataka, India

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### \*Correspondence:

Dr. Hogarehalli Jayanna Swathi,

E-mail: [swathi.hj27@gmail.com](mailto:swathi.hj27@gmail.com)

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## ABSTRACT

**Background:** India is going through epidemiologic transition with a shift of disease burden from communicable to non-communicable diseases. There is no organized screening programme for breast cancer in the country. Hence, a large proportion of women with cancer of the breast present in advanced stages of cancer. The integrated cancer control programme calls for early detection of cancer, opportunistic screening and cancer outreach camps that are to be promoted and carried out by health care providers. The objective of this study was thus designed to understand the various factors preventing the participation and utilisation of breast cancer screening.

**Methods:** It was a qualitative method with two groups. The study was conducted between two taluks out of 6, Kolar and Bangarpete. All Angawadi workers and helpers aged more than 30 years were invited and those who have history of breast cancer and family history of breast cancer were excluded from the study. All the subjects who did not attend the screening were included to elicit the reasons for non-attendance.

**Results:** The theme 'barriers to screening uptake' were broadly divided into three main categories- namely 'worry', 'transport' and 'work commitment'. The sub-category 'anxiety' (31.9%) was reported to be the highest barrier and least was in the sub-category 'no replacement' (4.3%). The frequency of response categorized into different sub-categories.

**Conclusions:** The reasons were identified by using 'single question' interview guide, and were categorized into 'worry', 'transport' and 'work-commitment'. Barrier in 'worry' category was found to be highest.

**Keywords:** Anganwadi workers, Breast cancer screening, Barriers for screening

## INTRODUCTION

Breast cancer is the most common cancer among females, world- wide.<sup>1,2</sup> The overall incidence of breast cancer is lower in Asia, age standardised rate (ASR) of 29 per 100,000 women compared to the average world level, ASR of 43 per 100,000 women, and even more so compared to some developed regions such as the European Union.<sup>3</sup> Over the past two decades, the incidence and mortality of

breast cancer is found to be relatively stable in developed countries, but increasing in developing countries like India.<sup>4</sup>

India is going through epidemiologic transition with a shift of disease burden from communicable to non-communicable diseases.<sup>5,6</sup> The main reason for this observed increase in India is not actually due to increased early screening of breast cancer but, due to increased

diagnosis of disease in advanced stages at various tertiary health care facilities. Cancer screening in developing countries is mainly opportunistic type, characterised by low coverage. There is no proper screening programme for breast cancer in the country. Hence, a large proportion of women with cancer of the breast present in advanced stages of cancer.<sup>6,7</sup> The integrated cancer control programme calls for opportunistic screening, early detection of cancer and cancer outreach camps that are to be promoted and carried out by health care providers.<sup>8</sup> The AWW and AWH who are the link to health care system for rural women must be brought into the domain of breast cancer screening, firstly, by themselves getting screened and then use them as mediators for further encouraging rural women in uptake of breast cancer screening. Testing various approaches and devising the approaches that improve the breast cancer screening uptake among AWW and AWH may help in further choosing a particular approach to upscale in the community they represent. This study was thus designed to understand the various factors preventing the participation and utilisation of breast cancer screening,

### Objectives

The objective of among AWW and AWH in Kolar district, Karnataka to assess the various factors preventing the participation and utilisation of breast cancer screening.

## METHODS

It was a qualitative method with two groups. The study was conducted between two taluks out of six Kolar and Bangarpete. The study was conducted between January 2023 to June 2023 for a period of 6 months. All Anganwadi workers and helpers aged more than 30 years were invited and those who have history of breast cancer and family history of breast cancer were excluded from the study. All the subjects who did not attend the screening were included to elicit the reasons for non-attendance.

### Sampling procedure

Out of six taluks in Kolar district, two taluks were selected randomly using a lottery method. There were 18 PHCs in Kolar and 13 PHC in Bangarpete. Among these selected taluks, four PHCs were selected in each of the taluk (a total of eight PHCs) by using random number table. All the randomization activity was performed by an expert in the Department of Community Medicine, SDUMC who was not related to the study. All anganwadi centres under these selected PHC's formed the sampling frame for the current study (anganwadi women and helpers). Those women (AWW and AWH) who did not attend the breast cancer screening camp were listed and contacted through mobile phone to find out the reasons for the same. Direct phone call was made to AWW and AWH to find the reasons for non-participation after obtaining verbal consent. AWH who did not have access to mobile phone were contacted through AWWs during their work hours (11am and 1 pm)

and requested to get the AWH on the line and the reasons were noted. If they were not responding to the call, a phone call was made again on the subsequent working day. Those who did not answer to the second call were labelled as 'non-responders'. The reasons were captured by using the 'single question' interview guide designed for knowing the reasons for non-participation. All reasons were noted down in a note book during the phone conversation. Also the socio-demographic details were captured using the same pre-tested question which was designed to capture the details during their visit for breast cancer screening. The telephonic conversation lasted for not more than five minutes.

### Statistical methods

Interview was transcribed into English language directly during the telephonic interview and quotes were noted down. This was later transcribed to the Microsoft word document for further analysis by the different investigators. Manual content analysis was done to derive categories and sub-categories to determine the barriers to screening uptake. The sub-categories were reported as frequency and percentage. Results were also reported using verbatim quotes. These quotes were derived independently by two different investigators and agreement was reached. Disagreements were further resolved in consultation with the third investigator. All investigators are trained in qualitative research.

## RESULTS

The theme 'Barriers to screening uptake' were broadly divided into three main categories- namely 'worry', 'transport' and 'work commitment'. These categories were further divided into eight sub-categories as shown in Figure 1. The sub-category 'anxiety' (31.9%) was reported to be the highest barrier and least was in the sub-category 'no replacement' (4.3%). The frequency of response categorised into different sub-categories is as reported in Table 1. The sub-categories are also supported.

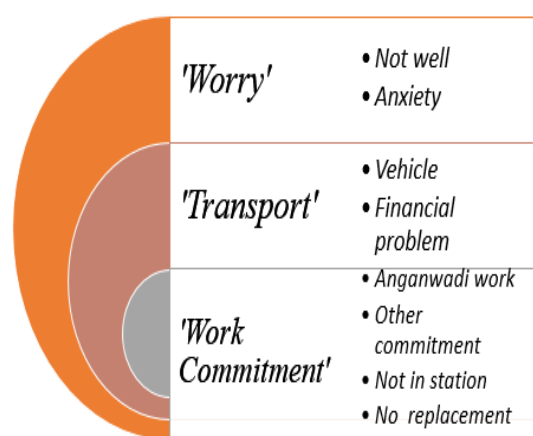
**Table 1: Barriers for breast cancer screening uptake according to the sub-categories among anganwadi women who did not undergo screening in Kolar district.**

Category	Frequency	Percentage*
<b>Anxiety</b>	44	31.9
<b>Work commitment</b>	31	22.5
<b>Lack of transport</b>	29	21.0
<b>Other commitment</b>	21	15.2
<b>Financial problem</b>	19	13.7
<b>Not well</b>	16	11.5
<b>Not in station</b>	09	6.6
<b>No replacement</b>	06	4.3

Note: \*- percentage calculated for N=138; Multiple responses were considered by verbatim quotes.

**Table 2: Verbatim quotes illustrating the barriers for breast cancer screening uptake among anganwadi women who did not undergo screening in Kolar district (n=138).**

Sub-category	Quotes
	"I got fever, back pain and headache for 3 days. I could not get up only and thatsy was unable to come for the examination..."(43 year old AWW)
<b>'Not well'</b>	
	"I had been admitted in the hospital during that time... I got severe blood loss, due to irregular menstrual cycle; I got blood transfusion done in the hospital!!"( 48 year old AWH )
	"Madam, I was very much worried regarding examination....What if it comes positive?... I got 3 children and my husband is a drunkard....!" (50 year old AWH)
<b>'Anxiety'</b>	"Myself already got the menopause, and I am divorce... I am anxious, what if it comes positive? No one is there to look after me....." ( A 55 year old AWH)
	"No one in my family had the history of breast cancer and I am 100% sure I won't get, and I am scared to get the check done...." ( 58 year old AWH)
<b>'Vehicle'</b>	"My village is 10 km away from the screening area and I got knee pain, could not walk for a short distance also... My son will go to work early in the morning and cannot ask him to drop me"(56 year old AWH)
<b>'Financial problem'</b>	"If I want to come for screening I have to spend 40 rupee and, and I am the only earning women in the family, my son and daughter are still studying...If I had that 40 rupee it will be helpful for me in some other time...!"(46 year old AWH)
	"I knew that there was a breast cancer screening camp, but because of work commitment I could not attend madam... I have to prepare food for children, as well for pregnant women here" (38 year old AWH)
	"There was sudden visit by the Taluk health officer to our anganwadi and I was instructed to stay in the anganwadi on that day..."(40 year old AWW)
<b>'Anganwadi work'</b>	
	"Madam.....I got some other work on that day and I was unable to attend..." (50 year old AWW)
<b>'Other commitment'</b>	"I have to clean my house, since next week was the Diwali, and not got the time to attend the screening programme..." (36 year old AWH)
<b>'Not in station'</b>	"I have to attend my cousin marriage on that day, so I could not attend"(30 year old AWW)
<b>'No replacement'</b>	
	"Anganwadi teacher (AWW) took leave on the day of screening, I wanted to come for screening, but because she was on leave I have to look after the Anganwadi..." (47 year old AWH)

**Figure 1: Barriers for breast cancer screening uptake among anganwadi women who did not undergo screening in Kolar district (N=138).**

## DISCUSSION

### *Barriers for breast cancer screening uptake among anganwadi women who did not undergo screening*

High response rate is an essential aspect for the success of any screening programme. The literature for barriers to breast cancer screening from qualitative studies is lacking from India. Studies conducted in countries like China and USA to identify the barriers were mostly based on utilising belief questionnaire models, finding barriers in specific groups who had disability or specific conditions like multiple sclerosis, or studied on culture specific population with more emphasis on migrants.<sup>9,10</sup> The current study is the first to look into barriers among anganwadi women which may not be generalizable to other women. But, few factors can be extrapolated and be a thought provoking for implementation of screening programmes in countries like

India.<sup>11,12</sup> In this study telephonic interviews were done for all the women who did not turn up to breast cancer screening and some of them who explained the reasons elaborately were documented in their own words as verbatim quotes to retain the depth of the barriers.<sup>13-15</sup>

These barriers were categorised into three main categories and eight sub-categories. Discussion of these categories will be done under these categories and sub-categories.

### **Worry**

In this category we have two sub-categories that depict the nature of barriers; one being a direct one 'anxiety' and other a proxy measure of worry 'not well' which could be the main reason expressed by the participants. This domain when explored showed various barriers and also gave insights which our quantitative results could not detect. The qualitative part gave insight that among this group of people the reasons for not attending could be more related to 'anxiety'.

'Anxiety' related to positive diagnosis was seen across various categories of women which is concurrent with reports from other studies done across different countries. Also another barrier identified was the knowledge and belief that only those who had family history of breast cancer must get checked and others need not. We have included reasons for 'not being well' to be a barrier under category of 'worry' as this is the most often quoted reason by women who are having anxiety to get screened. This reason was also found to be the most cited one as a reason for non-attendance in the current study.

These aspects emphasize the need for more awareness creation in these anganwadi women and also in the general community from which they come from as there could not be a much better scenario in the general public who in fact are less informed than our target population.

### **Transport**

This is identified as a most important barrier in most studies that assessed for barriers. Although the quantitative analysis showed that distance from screening facility was not significantly associated with screening uptake, the qualitative study gave a contradictory insight.

Almost one fourth of the women who did not undergo screening cited reasons related to this domain as a primary barrier. Some of the barriers were directly related to non-availability of transport whereas others were also related to 'financial problem' in reaching the screening place. Some gave the reason as money that is to be spent for transport could be utilised for some other purpose which carried more weightage than screening for them.

This call for inclusion of the distance from screening facility as a prime importance while planning for screening among women. Though the current study had chosen a

place which was well known to the anganwadi women and which they access at least once in a month; it was found that transport was available for them from various means for free as part of their duty which was not the scenario on the day of screening. Prior plan for travel and financial allocations must be considered in the breast cancer screening programme. This could actually result in a substantial increase in the screening uptake as most of these women were willing to get screened unlike those who were in the 'anxiety' domain.

### **Work commitment**

As per the screening plan we had taken necessary steps so as to make at least AWW or AWH available for anganwadi work on the day of screening (this was done by conducting screening on different days for AWW and AWH). Still due to the absence of one of them on the screening day the other could not attend the screening. Few of them also reported 'anganwadi related work' as a reason for not attending screening and some cited 'no replacement' for them at job and personal level factors. Some cited 'out of station' as a reason for not attending the screening camps.

An interesting reason cited by some women was 'diwali festival related work'. It was found that one of the screening days happened to be about a week before the Diwali festival which could be a barrier in attending screening in some women. Although the festival was taken into consideration while planning for screening, the drop out even before a week was not anticipated among the participants.

This domain gave various reasons cited by women, but none could actually be addressed at the planning level or be analysed at general population level. This barrier gave reasons which mostly varied from person to person and could be addressed only by increasing the awareness on the importance of screening in a way that women perceive it over and above the personal reasons cited. This also gave an important consideration in planning for a screening program which includes culture specific practices during festivals. As most of the women were Hindu by religion and thus 'diwali' being a major festival, 'work related to the festival' takes precedence in the lives of these women even a week or many days before the festival which is a common practice. Though this was anticipated, the 'work' taking overwhelming precedence even a week before the actual festival date was not anticipated. This can be a message for planning any further screening programme among these women.

### **Limitation**

Usage of a 'single question' interview guide for telephonic interviews could have resulted in lesser exploration of various domains associated with barriers to screening uptake.

Many barriers were involved in non-participation for breast cancer screening. The reasons were identified by using 'single question' interview guide, and were categorized into 'worry', 'transport' and 'work-commitment'. Barrier in 'worry' category was found to be highest.

## CONCLUSION

This study was done on anganwadi workers and helpers. If these people are educated regarding breast cancer screening services, they will convey the message to other people through their monthly meetings, various national programmes they celebrate. These health care workers will become main bridge to the general population.

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