

# Assessment of community inquisitive insight towards carcinoma breast and cervix among adolescent girls in a city of Chhattisgarh, India: A qualitative study

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## ABSTRACT

**Background and Aims:** Breast and cervical cancers are two of the most common cancer diagnosed and are leading cause of death among females. Mortality and complication rates are higher in countries with lower awareness regarding breast and cervical cancer. The aim of this study is to assess the community inquisitive insight regarding breast and cervical carcinoma after sensitising them with health education. **Setting and Design:** This is a qualitative research done on adolescent school going girls. The analysis is done using the verbal and written queries during group interaction sessions after the health education regarding breast and cervical cancer was imparted. **Results and Conclusion:** A community specific health education material regarding breast and cervical cancers should include information regarding normal physiological process like menstruation, available preventive, and screening and management modalities of common cancers, the explanations for myths and redressal of stigma prevailing in the specific community.

**Keywords:** Breast cancer, cervical cancer, community inquisitive insight, health education

## Introduction

Breast cancer is the most common cancer diagnosed and is the leading cause of death among females. Each year among all the patients newly diagnosed with breast carcinoma, around 60% are diagnosed in low- and middle-income countries and around 70% of breast cancer deaths also occur in these countries.<sup>[1]</sup>

In India, the incidence of breast carcinoma ranges from 19-34% which is less as compared to UK (around 25%), but the mortality rates in both the countries are similar (12.7% vs 17.1%). Mortality increases among the breast cancer patients in advanced stages.<sup>[2]</sup>

The reasons may be lack of awareness among the population, inadequate accessibility of quality diagnosis and lack of community screening programmes along with others factors responsible for delay in diagnosis of the disease.

In recent years, there have been many initiatives for raising health awareness among the population by government and non-government agencies in India. The National Programme for prevention and control of Cancer, Diabetes, Cardiovascular diseases and stroke has a significant component in the form of community level screening and prevention of commonly prevalent cancers including breast and cervical cancers. It has been assisted by many private and NGO efforts to raise the awareness regarding breast cancer among general population.<sup>[3]</sup>

The assessment of knowledge and awareness regarding breast cancer is usually done using KAP (knowledge, attitude, practice)

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studies. After several efforts of health education sessions in the Indian population, the awareness can be assessed alternatively through assessing the inquisitive questions put forward by the beneficiaries. This is also indicative of the amount of interest the particular disease raises through its perceived importance in the community. The future health education interventions can be tailor-made on the basis of prevailing knowledge gaps and the myths among the community members.

The present study intends to assess the Community Inquisitive Insight (CII) regarding breast cancer among the school going adolescent girls.

## Methods

### Study design

This study was a qualitative research on adolescent school and college going girls. The qualitative analysis was done using the written and verbal queries and opinions put forward by the adolescent girls during group interactive session after health education regarding breast and cervical carcinoma was imparted.

### Study population

Adolescent girls attending four government schools selected conveniently. Health education regarding carcinoma breast and carcinoma cervix was imparted in all the 4 schools. The health education was done through power point presentations prepared by the researchers and validated by 6 independent subject experts. The health education intervention encompassed information regarding the anatomy of breast and cervix, burden of the disease, risk factors associated, common presentations, management available, screening and prevention modalities available. Post-health education session, group discussions were arranged. The objective was to assess the existing knowledge gap after the health education and incorporate the feed backs to produce a regional, need based, culture sensitive adolescent health education material regarding breast and cervical cancer. A total of 621 adolescent girls (Age 12-19 years) participated in the group discussions.

### Study tools and measures

To accomplish the assessment, a guide was developed for the group discussion. Attempt was made to avoid leading question to any participants. Broad opening questions like “Do you have anything to ask after all you heard or saw?” or “Do you want to clarify something or to know more about something?” or “Do you have any suggestions to improve such health education in future?”. The discussion was done in vernacular language. With due consent from the participants and the school authority, the statements were noted down in verbatim. Each discussion session was 45-60 minutes in duration. The transcript was compiled and revised with recall of missing information just after each session was over.

Analysis of data: Qualitative data management, analysis and visualisation was done by using ATLAS.ti (version 7.1.8).

The final verbatim transcriptions of written statements in group discussions were analysed through thematic analysis in following steps [Figures 1 and 2].

## Results

Assessment of frequently asked questions and feedback statements of the participants was done through word crunching and it showed the most discussed word was cancer (frequency = 72) followed by breast (f = 38) ad cervix/cervical (f = 29) [Figure 3]. Hence, it can be concluded the participants are sensitised and curious to know about breast and cervical cancers. Period/menstruation (f = 59) was next most common discussed topic which raised curiosity. Participants were interested to know about frequency, periodicity and abnormalities arising or related to menstruation. Among the general symptoms most commonly discussed ones were abdominal (f = 8), pain (f = 17) and vaginal discharge (f = 10). It reflects the felt need among the adolescent girls to know more about normal physiological changes in menstruation, which should be a part of any health education imparted on them [Figure 3].

Questioning was enthusiastically done by the sensitised adolescent girls, what (f = 30), how (f = 14), why (f = 13) and when (f = 4) were cumulatively used 61 times. Words PAP (f = 7), test (f = 11), examinations (f = 5) and screening (f = 3) were frequently present among the queries. HPV (f = 16) was also one of the most common topic to be queried. Medicine (f = 10), treatment (f = 8) were discussed less than prevention (f = 7) and vaccination/vaccine (f = 18). Good/excellent was used 12 times in appreciation of the programme.

The discussion with the participants was done in two parts (Themes); [Table 1, Figure 4]

- a. Theme 1: Knowledge Gap – the first part was when the participants asked the researchers all their questions which were less understood or they were curious about knowing more about certain topics after the health education was imparted. [Table 1]
- b. Theme 2 – Feedback regarding the health education Imparted: The second part was a feedback on the health education session [Table 1]

All the queries were categorised into two major domains i.e. inquisitive queries (verbosity = 93) and apprehensive queries (verbosity = 32). The inquisitive queries were those questions which were asked because of curiosity or extreme interest into the topic with suggestive expressions and enthusiasm. The apprehensive queries are questions asked with some hint of fear or stigma in mind. These major domains were further classified into sub domains [Table 1]. All of the above domains and sub domains constitute the existing knowledge gap after the health education regarding 3 major areas of Interest. Those are as follows



**Table 1: Themes, domains, sub domains and derived domain grounded in data from 4 group discussion sessions among adolescent girls in a city of Chhattisgarh, India**

Themes	Domains	Sub domains	Derived Domain
Knowledge Gap	Inquisitive queries Apprehensive queries	Duration of menstruation Regularity of Menstruation Symptoms of menstruation Associations with menstruations Causation Treatment Prevention Myths Stigma Awareness Complaints	Menstruation
Feedback regarding Health Education Imparted	Positive Reviews Health education related Knowledge Gap Management Improvement related.		

*“I Feel tired during periods, what should I do?”*

*“Is it normal to have pain in stomach before periods come?”*

Some were asking regarding medications for relief of

*“Should we take a tablet if there is pain during periods?”*

b. Domain 2: Apprehensive queries:

There were apprehensions over heavy bleeding during menstruation. One of the participants stated:

*“Earlier there was more blood loss during menstruation. Now bleeding is less than before and only for 3 days? Can this lead to any problem?”*

There are various manifestations which the participants thought were associated with menstruation. One of the statements was:

*“I get pain in breast during periods, is it normal?”*,

*“Why do pimples come before periods?”*.

Some of the participants were apprehensive and wanted to know if there is any relation between irregular cycles and cancer.

One participant stated:

*“Is there any relation between irregular cycles and cancer?”*

Another one stated

*“If there is pain and heaviness in breast 2-3 days before periods come, can it lead to cancer?”*

Another participant asked:

*“If clots come during periods, is it dangerous and can it be a symptom of cancer?”*

II. Knowledge gap in Carcinoma Cervix:

a. Domain 1: Apprehensive queries:

The discussion regarding cervical cancer was around the diagnosis, causes, prevention, signs and symptoms. Participants had apprehensive queries related to causation of cervical cancer.

One of the participants asked:

*“Patients with history of repeated abortions, is the chance of cervical cancer more in them?”*

Another participant stated:

*“Is there anything related with male genital organ (as it is having this virus) so it infects female?”*

One of the participants asked apprehensively:

*“Is there any way to test cervical cancer at home without going to the doctor?”*

This indicates the stigma prevalent in the community in seeking care for cervical carcinoma.

b. Domain 2: Inquisitive queries:

The inquisitive queries regarding the cervix mostly were regarding the availability of screening test/PAP smear, its relevance, the preventive vaccine available and its effectiveness. The participants were very interested to know the early diagnosis and prevention. One of the participants expressed:

*“In spite of the high cost, what is the effectiveness of the HPV vaccine? Should we really get vaccinated considering that most of us will get married late?”*

III. Knowledge Gap in Carcinoma of Breast:

a. Domain 1: Apprehensive queries 1:

The apprehensive queries regarding breast was most commonly pertaining to pain in breast. Many of the participants wanted to know if there is any relation between mastalgia/pain and heaviness in the breast during periods.

One of the participants stated:

*“If there is pain and heaviness in breast 2-3 days before periods come, can it lead to cancer?”*

Similar queries were echoed from several participants.

b. Domain 2: Inquisitive queries:

The inquisitive queries regarding breast cancers were centered on the possible associations of common breast problems such as unequal sizes of nipple, watery discharge from nipples with breast cancer. One of the participants asked:

*“If one side nipple is big and other side nipple is small, can this be a symptom of breast cancer?”*

There were also queries regarding probable associations of oral contraceptive pill and types of brassieres according to their fitting and color with breast carcinoma.

One statement was:

*“Should I wear tight bra or not?”*

Another stated:

*“Should we wear the bra at all times or not?”*

Another participant asked:

*“Should we not wear black colored undergarments?”*

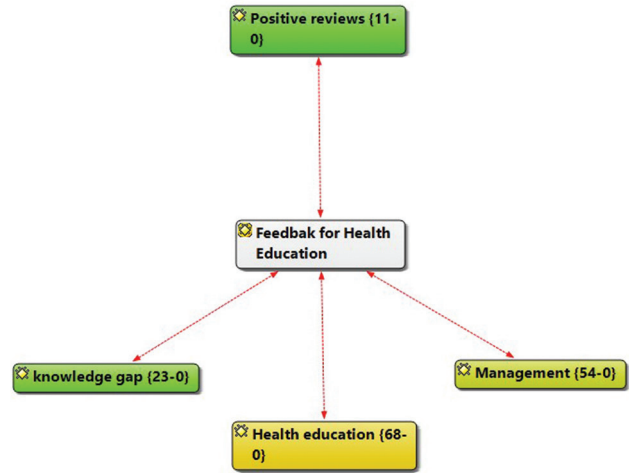
**B. Feedback regarding Health Education Imparted:**

The feedback session for the health education generated a lot of curiosity among the participants. Many of the participants praised the health education given, while others suggested a lot of to improve the same.

The improvements suggested were segregated into 3 domains, i.e. [Figure 5]

- i. Knowledge gap existing post health education
- ii. Improvements needed in program management
- iii. Health education related

These can be assimilated to prepare community sensitive, need based health education material regarding the commonly prevalent cancers among the adolescent females. The knowledge gap or the inquisitive knowledge need of the participants covered a lot of issues.



**Figure 5:** Domains identified (along with their verbosity) from feedback received from adolescent girls in 4 group discussion sessions in a city of Chhattisgarh, India

One of the participants rightly suggested:

*“Information should also be given about the cost and duration of treatment for breast cancer”*

Some of the participants expected more practical demonstrations and life models to have a better understanding the causation of the cancers. Other suggested there should be detailed discussion on the preventive measures available including the feasibility of the HPV vaccination and if possible vaccination camps can be conducted along with the health education. One of the participants suggested:

*“Provide us with the vaccination camps”*

The time management of the health education session has to be improved to have better impact in generating awareness. Finally the suggestions for improving the health education material also elicited enriching responses. These included the use of use of common vernacular language, easy wordings, less use of medical jargons, shorter time of presentation with more interactive sessions with use of audio visual aids, simultaneous practical demonstration sessions of simple screening examinations (PAP, self breast examinations etc.), involvement of community members including teachers through panel discussions, personal counseling sessions for needy girls. The statements which corroborated the same are:

*“Common Hindi language should be used so that illiterate people can understand it”*

*“Invite general public too”*

*“If practical is done and showed through the medium of hospital, then we will remember it better”*

## Sub domains: Myths and Stigma

There are many population specific stigma, myths and false beliefs prevalent among the adolescents of the community which came out during discussion session.

The notable query among all the questions was:

*“Why is cancer spreading so much in females?”*

Some of the participants believed that the cancers are affecting females more than the males.

*“Does shaving of pubic hair lead to change in bacterial flora of vagina? Can it lead to vaginal cancer?”* One of the participants asked:

Most common myths were related to use of inner wears and its associations with cancers. Some asked if there are any remote chances of cancer after HPV vaccination.

There is high level of stigma existed among the participants which hinders early diagnosis and treatment of the same. One of the participants asked:

*“If we are suffering from cancer should we tell this to anyone or we should not tell to anyone other than doctor?”*

Another participant asked:

*“Is there any way to test cervical cancer at home without going to the doctor?”*

There were several indirect suggestions in forms of queries which show some solutions to reducing the stigma among the community members. One of such queries was:

*“Why aren't male students invited in this awareness program? Aren't they supposed to learn about it?”*

## Discussion

There have been various studies assessing the knowledge of the adolescent girls regarding commonly prevalent cancers among the females. Various studies concluded health literacy improves shared decision making.<sup>[4]</sup> Studies have also been done to evaluate the health education interventions among the adolescent girls. But the present study is one of the first qualitative studies in the community inquisitive insight after sensitizing the adolescent girls through health education.

The results obtained revealed that there is a felt need in community to know various aspects of breast and cervical carcinoma along with other reproductive information such as normal menstruation, associated symptoms of menstruations etc., Dey *et al.* in 2016 did a qualitative study on breast cancer awareness and prevention in India and concluded that women's

ambivalence in prioritizing their own health and social/behavioral hurdles should be addressed in a breast cancer awareness programme.<sup>[5]</sup> Monn *et al.* in 2019 concluded Awareness of the risk factors associated with breast cancer can alleviate fear and anxiety, and can lead people to pursue prevention.<sup>[6]</sup>

The participants of the study were of the view that the inclusion of general population and males in the health education sessions will improve the health literacy regarding the carcinomas among them and also help to reduce stigma related to it. Gupta *et al.* in 2015 did a review of breast cancer awareness among women in India. They concluded there is an urgent need for nation and state wide awareness programmes, engaging multiple stakeholders of society and health systems to help improve health literacy in India.<sup>[7]</sup> Dey *et al.* 2015 did a study on breast cancer awareness at community level in Delhi and concluded that awareness must be drastically increased via community outreach and use of media as a first step in fight against breast cancer.<sup>[8]</sup>

Most of the participants in the study wanted to know various presentations of breast and cervical cancers in detail even after the health education session. Dr Gadgil *et al.* in 2015 did a community based study in Mumbai, India, and concluded that the women in the community were aware about breast cancer but not about its presentation.<sup>[9]</sup>

The participants were of the view that practical demonstrations of examinations like breast self-examination (BSE) and PAP smear should be included in the health education sessions to improve its quality. Leading agencies working for BC prevention have recommended monthly BSE to women.<sup>[5,10,11]</sup> Study done by Kim *et al.* in 2019 concluded oral and listening literacies are contributing factors to lifetime breast cancer screening and up-to-date cervical cancer screening.<sup>[12]</sup>

## Conclusion and Recommendations

Felt need based Health education intervention regarding breast and cervical cancer, specific for a community can be developed through assessing community inquisitive insight after sensitizing them. This will be a more effective and acceptable tool to address the stigma and low awareness pertaining to a specific health condition as compared to Health education developed by researchers or specialists. A community-specific health education material regarding breast and cervical cancers should include information regarding normal physiological process like menstruation, available preventive, and screening and management modalities of common cancers, the explanations for myths and redressal of stigma prevailing in the specific community.

The revised community specific health education regarding breast and cervical carcinoma should be used as a health education tool in primary care setting as an effective preventive measure by the primary care physicians. This will not only help in reduce the stigma associated with the carcinoma and improve the health

seeking behavior but also encourages community participation envisaged through primary care approach in Alma Ata.

### Declaration of patient consent

The authors certify that they have obtained all appropriate patient consent forms. In the form, the patient (s) has/have given his/her/their consent for his/her/their images and other clinical information to be reported in the journal. The patients understand that their names and initials will not be published and due efforts will be made to conceal their identity, but anonymity cannot be guaranteed.

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### Conflicts of interest

There are no conflicts of interest.

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