Original Article

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Looking Beyond Knowledge and Accessibility-Exploring Barriers and Facilitators for Cervical Cancer Screening Services among Tribal Women in Tea Gardens of Darjeeling, West Bengal

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ABSTRACT

Introduction: Despite efforts to motivate all reproductive age women to avail cervical cancer screening services, many still do not utilise them. Most researchers have universally identified barriers like the lack of knowledge and lack of accessibility as the reason for not availing services. However, additional barriers also prevent women from making use of these screening services.

Aim: To explore the barriers and facilitating factors for cervical cancer screening beyond the lack of knowledge and accessibility of services.

Materials and Methods: This qualitative research was conducted among tribal women residing in the Kiranchandra Tea Estate and Atal Tea Estate (two tea gardens in the rural Naxalbari Block) West Bengal, India, from July 2018 to February 2019. Women aged 30-59 years, living in the garden for atleast the last five years, not suffering from obstetrics/gynaecological disease during last two years and willing to participate in the study were included, based on a purposive sampling method. Information Education Campaign (IEC) on cervical cancer and screening were undertaken and screening services arranged in the gardens on garden holidays for two consecutive weeks. Eight Focus Group Discussion (FGDs), four in each garden were conducted, with each FGD consisting of 5-8 participants (N=49). Data obtained was recorded and logged with the participants' permission and consent. A manifest content analysis was used to explore the perceived barriers and facilitators of cervical screening.

Results: The major barriers identified were lack of support, burden of responsibility and the lack of felt need. The facilitators found most frequently were provision of information, social motivation, easy accessibility and affordability of screening services.

Conclusion: The present study revealed that, there are various actual and perceived barriers to cervical cancer screening among tribal women in tea garden areas. Even after imparting knowledge and increasing availability and accessibility of a free program, familial support, burden of responsibility and lack of felt need, hinder increased uptake of the services.

Keywords: Burden of responsibility, Felt need, Opportunistic screening, Resource poor setting, Social support

INTRODUCTION

Due to advances in medical sciences as well as improved public health measures, the incidence of Invasive Cervical Carcinoma (ICC) has been decreasing through the decades. However, it remains the fourth most common cancer in women worldwide [1]. Furthermore, most of the burden of ICC is borne by the developing countries of the world, where it is one of the, if not the leading cause of cancer-related deaths among women. Of the approximately 300,000 deaths due to the disease worldwide in 2018, it has been estimated that over 90% were in low and middle-income countries [2].

India contributes significantly towards the burden of ICC, with approximately one of every five sufferers being from the country [3]. More than three-fourths of these patients are diagnosed at advanced stages of the disease. This leads to poor long-term prognosis and reduced prospects of cure [4]. Although strides have been made at the Government level, to bring cervical cancer screening to the masses, it has remained a largely unmet need, with most of the population of reproductive age women still having no access to proper diagnostic and management modalities [5]. Further complicating the situation is the fact that cervical cancer, much like maternal mortality, is a striking example of health inequity, with both the morbidity as well as mortality due to the disease showing wide disparities based on regional and socio-economic differences in accessing healthcare [6]. In low and middle-income countries, where health systems struggle to provide basic services, women don't have access to proper screening and often only learn of their diagnosis once it's too late, if at all. Thus, ICC hits poor and impoverished communities the hardest, setting off a vicious cycle of poverty, lack of access to healthcare and high morbidity and mortality due to the disease [7].

Screening for cervical cancer, a down staging screening procedure, aims to detect the disease at the pre-cancer stage when it is amenable to simple treatment and cure. Visual Inspection with Acetic Acid (VIA), done in population-based programmes remains the preferred mode of screening in resource poor settings because of the low costs. Again, since the procedure can be performed by trained technicians, it reduces the financial burden of the state, incurred by utilising qualified physicians for screening [8]. In many of the developed countries, the annual incidence and mortality from this cancer have gone down by 50-70% since the introduction of these screening programmes. Universal cervical screening in India still remains a mostly unachieved goal. However, there has been a national push towards mobilising women to access healthcare related to cervical cancer screening. This has been facilitated by the implementation of a national level mobile technology-based screening programme [9]. Apart from this, isolated efforts being undertaken either as opportunistic screening in hospitals or by Non Government Organisations (NGOs) in the district through locally organised cervical cancer screening camps are the major ways screening services are provided to communities in rural India [10].

Several studies in different parts of the world have reported a lack of awareness about cervical cancer, lack of easy access to

care and cost of screening and subsequent treatment, to be the primary reasons, why women don't seek cervical cancer screening [11,12,13]. On the other hand, higher level of education, low cost or free tests and supportive physicians and friends, and accessibility to the screening camps near their home were reported to lead to an increased chance of women availing screening services for cervical cancer [14,15]. Reports from cervical screening camps, conducted in tea gardens in the study area, suggest that despite regular information, education communication camps on cervical cancer over months among the population and the provision of screening services at the doorsteps, the participation of tribal women in these camps are far from satisfactory [16]. These women, who belong to some of the most impoverished and socio-economically deprived communities in the country, are more vulnerable to the disease and at the most need of screening services.

The perspectives of tribal women towards screening methods and services aimed at detecting ICC should be explored in detail, as they are keys to identify the unmet needs of the community and thus facilitate the expansion of screening services in the country. This study was conducted to explore the barriers that prevent tribal women residing in a tea garden of Darjeeling District, India from availing cervical screening, when lack of knowledge and lack of accessibility of the services are taken care of.

MATERIALS AND METHODS

A qualitative study design was used to explore the perceived barriers and facilitators of cervical cancer screening among tribal women. Focus Group Discussion (FGDs) were held to obtain the experiences of the participants with respect to cervical cancer screening. The study was done in consultation with Sumita Cancer Society (SCS), an NGO, involved in grassroots level carcinoma cervix screening activities in Darjeeling district over the last 10 years.

The present study was carried out in the Kiranchandra Tea Estate and Atal Tea Estate, two tea gardens in the rural Naxalbari Block of West Bengal, India from July 2018 to February 2019. The communities residing inside the tea estate also forms their main workforce, comprised mostly of people of the Munda and Oraon tribes. The two tea estates were chosen because of their convenience, ease of access and their population composition being similar to other tea gardens in Eastern and North-Eastern India.

Ethical clearance was obtained from the Institutional Ethics Committee of North Bengal Medical College and Hospital in Siliguri (ID-PCM/2.15-16/148). The participants were assured of their right to terminate their participation at any time during the study and were asked to only share information that they were comfortable sharing. The participants were informed and had agreed that the FGDs would be recorded, and they were assured that the recordings would be used only for research purposes and that their confidentiality would be ensured.

Inclusion and Exclusion criteria: A purposive sample of ever married women between the age groups 30-59 years were chosen for the study. All of the women were residents of their respective tea estates for at least five years were included in the study. Women who were pregnant, had undergone hysterectomy, or had been diagnosed with cervical cancer or pre-cancerous cervical lesions were excluded from the study. Women diagnosed with any obstetric/gynaecological disease in the last two years were also excluded.

All the study participants provided written informed consent regarding their participation. A total of 49 women volunteered for the study.

Data Collection

The FGD was guided by the researcher using an interview guide [Annexure 1], consisting of open-ended questions and probing question prompts, which were based on previously published literature [12]. The major topics that were explored were the participants' ideas and perceptions regarding cervical cancer, its screening procedure, and the perceived barriers or facilitators towards screening.

Information Education Campaign (IEC): To control for the lack of knowledge regarding cervical cancer and screening methods an Information Education Campaign (IEC) was designed in association with the SCS and undertaken in the two tea gardens. Two individual IEC events were conducted in each garden, seven days apart, and authorities of the tea gardens were intimated and coordinated with to ensure maximum participation of the residing female population. Furthermore, to control for the lack of accessibility to screening services, two cervical screening camps were conducted in each tea garden 15 days after the second IEC event. Similar to the IEC events, the cervical cancer screening camps were also conducted one week apart from each other. Thus, a total of four IEC events and four screening camps were conducted in the study areas in a span of 10 weeks. Line listing of women was done both in the IEC events as well as the screening camps.

Focus Group Discussion (FGDs): Participants for FGDs were identified based on consultation with local health workers and they were invited to share their views and participate in FGD, held in the corresponding tea garden hospital premises at timings based on their convenience. The FGDs were conducted within 10 days of screening. Eight FGDs, four in each garden were conducted, with each FGD consisting of 5 to 8 participants. One researcher acted as the facilitator in all of the sessions, and the interviews were recorded by the note taker.

Data analysis: The tape recordings were handled, coded and transcribed by the researchers ensuring anonymity. Transcribed texts were translated by a person having workable knowledge of the vernaculars spoken in the areas (Bengali and Sadri).

STATISTICAL ANALYSIS

Manifest Content analysis after network mapping of the transcripts was performed by the researchers to analyse the data using ATLAS.ti software (version 7, ATLAS.ti scientific software development GmbH) for coding and categorisation [17].

RESULTS

The data analysis and network mapping of the obtained data led to two broad categories of responses, viz., barriers towards cervical cancer screening, and facilitators towards the same. These categories were subdivided into further sub-categories based on the varieties of the responses obtained [Table/Fig-1].

Categories	Sub-categories
Barriers	Lack of support
	Burden of responsibility
	Lack of felt need
Facilitators	Provision of information
	Social motivation
	Easy accessibility and affordability of services

[Table/Fig-1]: Participant's responses-categorisation.

Barriers Towards Screening

Participants elucidated a complex interplay of different factors which acted as barriers when availing cervical cancer screening services. The principal factors that were put forward included lack of support, burden of responsibility and lack of felt need for screening.

Lack of support: The lack of familial and social support was put forward as the key factor that determined whether the participants would avail the screening services. A number of FGD participants were either discouraged or prevented by their families from attending the screening camps. Families not only prevented women from going to the screening camps but also from attending the IEC camps.

"My husband said, "What you will do going there, are you sick?"" (FGD 8)

"I wanted to come, but my husband and his mother told me that there is no need because I was not sick." (FGD 1, 3)

The participants also felt that, they were not in a decision-making position in the family and were therefore influenced by their family member's indifference to their situation. Some women felt that their family didn't care even if they got affected by cervical cancer and were not concerned whether they availed treatment or health check-up for the same. This indifference also played a role in their discouragement of the women from availing the screening camps.

"Even if they are informed they won't remember, they turn a deaf ear to us" (irritated) (FGD 4)

"Whether I have the disease or not, they are not bothered" (FGD 1, 5)

Burden of responsibility: Tribal women living in the tea gardens, in addition to being responsible for the household and familial duties, are very often employed as workers in the gardens themselves. Therefore, participants felt that they had very little time for themselves after taking care of their work as well as household duties. Several participants felt that interrupting their daily routine of work, household duties and taking care of their children to go and attend screening camps where they would have to stand in long queues would be very difficult for them.

"We are labourers, if we don't work we earn nothing, if we are late or don't go for our duties, we won't get work in the tea garden in future." (FGD 2,3)

"I was hungry, there was too much household work. I also have three children… I thought I will go next time" (FGD 7)

Lack of felt need: Women who attended neither the IEC nor the screening camps as well as those who attended the IEC camps but not the screening ones were of the opinion that there was no need for them to do so because they were healthy. Participants, even a few of those who attended the IEC camps believed that screening was only needed when and if they were feeling unwell or were showing symptoms of the disease. Some of the women also believed that cervical cancer was a disease of the elderly, and there was no need for them to get themselves tested because they were young and healthy.

"I do not understand why I need to test for cancer. I am young." (FGD 6)

"Tests are for sick people. I am healthy. Why should I get tested?" (FGD 4, 7)

These women felt that as long as they 'feel' healthy, they need not worry about cancer. Some of the participants felt that since none of their family members had any problems with the disease, they were also protected.

"No one in my family ever had this disease (cancer). So, I do not need to get tested, because I will also not have cancer. It's a waste of time." (FGD3)

Some of the participants who attended the IEC but did not attend the screening camp told that they didn't want to know the result of the test. They argued that they have to alter their lifestyle significantly and might even face excommunication from their families if the result comes positive. They said that it was better for them to get treated once symptoms appear than take the stress of a positive result.

"I don't want to know the result of the test. You don't understand what will happen if positive results come… my family will disown me." (FGD4)

Facilitators

The participants pointed out factors that they perceived to be ones that made them undergo the screening procedure. The main factors that the participants identified were provision of information, social motivation, and easy accessibility and affordability of services.

Provision of information: The information received about the IEC and screening camps either through attendance in the same or through their neighbours and friends encouraged the attendance of these women to the camps. The latter was evident from the fact that a substantial number of women not attending the awareness camp knew about the disease and had come for screening. All of the participants who had attended the IEC camps knew about cervical cancer and how screening for cancer can help them. Furthermore, the information provided in the camps allayed much of the fear among the participants, and a few of them felt emboldened to attend the screening camps.

"I got to know a lot about the disease from the camps that you conducted." (FGD3, FGD4)

"My friend attended the camp… told me about the disease, that's why I attended this (screening) camp" (FGD3)

Social motivation: Another important facilitator that the participants identified was social and familial motivation. Several unwilling women were encouraged by their family as well as their friends or neighbours to take part in the IEC as well as screening camps. This was mostly seen in younger women, who were motivated by their older peers.

"I didn't want to come but my friend's mother insisted that we must go as we will be benefitted" (FGD3)

Support from their husbands or the other members of the family boosted the confidence of the women, and encouragement from them led to the participants not only attending the IEC camps but also avail screening services.

"I was ashamed at first, but my husband said that you should go and get the check-up" (FGD1, 4)

Easy accessibility and affordability of services: Ease of accessibility of the screening services also played a role in the women's attitude towards availing them. It was told by the participants that the free-of-cost, easy to access screening camps meant that they could get tested without having to forego the day's work, and therefore risk losing the day's earning. Locally available screening services also meant that they could save time and money by not having to travel to higher centres.

"If these check-ups happen in the garden, it is easy for us to go and get tested. We don't have to travel so much." (FGD 2,7)

DISCUSSION

It has been suggested that the knowledge of cancer or 'cancer literacy' is the primary determinant of screening behaviour in women in both the developed and developing countries [18,19]. It has therefore been argued that the way cervical cancer education programmes increase screening behaviour among women is by increasing the knowledge about the disease and the screening process [14]. Furthermore, in low-resource settings, increasing the accessibility of the screening programs have been suggested as an additional measure that leads to increased effectiveness in the early detection of cervical cancer among women [20,21].

However, field level experience of NGOs in conducting screening camps showed that even after sensitising the women about the disease and making services available at their doorsteps, screening services were not being utilised by all women [10]. The current study provided some insight to the causes of this behaviour and to the factors that might potentially mitigate some of these barriers to cervical cancer screening.

When the lack of knowledge regarding cervical cancer and screening as well as the lack of availability and accessibility of screening services are taken care of, it was seen that socio-cultural factors become the primary barriers to screening. Lack of support from neighbours and friends led women to be much less inclined to visit the IEC or screening camps. Furthermore, the lack of support

and active discouragement from older family members especially husbands also played a major role in serving as barriers towards screening behaviour. This phenomenon is not exclusive to the tribal communities of Darjeeling, as similar observations have been made in studies on the topic elsewhere [Table/Fig-2] [13,22,23].

Authors	Year	Study population and methodology	Findings
Devarapalli P et al., [22]	2018	Systematic review: Health sciences electronic databases like MEDLINE, PubMed, Cochrane library, and Google Scholar were searched for studies published until August 2017. Keywords used for the search were ("cervical cancer screening"), ("barriers"), AND ("LMIC"). Articles were reviewed and data were extracted.	"Lack of information about Cervical cancer and its treatment" (Barrier of lack of knowledge and Awareness); "Embracement or shy" (Psychological barrier); "Lack of time" (Structural barrier); and "Lack of family support" (Socio-cultural and religious barrier) were the most commonly reported among all 22 barriers.
Ngugi CW et al., [13]	2012	50 in-depth interviews from 50 women from the general population in Thika, Kenya.	The majority of the married women mentioned husbands and partners as barriers. The majority of the women reported that their partners would not accompany them to collect the results and hence, they had to rely on friends for emotional support.
Darj E et al., [23]	2019	72 women in the age range of 25-60 years, most were farmers' wives and worked in households and in the fields, 7 Focus Group Discussion (FGDs), each FGD had 8-12 participants in Nepal.	Family acceptance and support was perceived as essential for them to act and to accept cervical cancer screening services.

[Table/Fig-2]: Summary of studies looking into lack of family support as a potential barrier to women towards cervical cancer screening [13,22,23].

The effects of social support or their lack thereof is very pronounced among the tribal population. In these close-knit communities, each member of the community shares a strong bond with other members through their indigenous languages and socio-cultural practices particular to them. Therefore, women are more inclined to trust advice from their social peers than outsiders regarding adoption of new knowledge/behaviour [24].

In the tribal communities, where men are the primary decision makers as well as head of the family, the absence of support as well as active discouragement from their husbands can severely demotivate women from availing care. On the other side, as it was observed in the present study, as well as in tribal communities of Nepal, the active encouragement by their husbands and peers can lead to previously unwilling women availing screening services [23]. Therefore, as a mitigation strategy, it can be ensured that the IEC camps not only focus on the target population of women but the entire community and emphasise on the importance of social support in cervical cancer screening behaviour.

In the study population, in addition to being in charge of the household work, a large section of the women is employed in the tea gardens in various capacities. Thus, in absence of familial support, the burden of responsibility on these women becomes high enough to lead to severe lack of time for them to visit and avail cervical screening. Burden of responsibility and associated lack of time as a barrier to screening behaviour has also been reported in a study from Iran [25].

The effects of this barrier get further amplified when there is a lack of felt need for screening among the participants. It was seen that even without social support or available time some participants attended the IEC and screening camps (FGD1, 3). Women who felt apparently healthy, didn't feel the need to get themselves screened, even after being informed about the disease. Similarly, those who thought that cervical cancer was a disease of the old surmised that they did not need to get screened as they had time until they reach the age where the disease started becoming a problem to them (FGD 6). Therefore, whether there is a felt need among the participants was seen to either amplify or diminish the effects of the other major barriers. Mitigating this lack of felt need can be done by intensifying the IEC materials to include information about the 'apparently healthy' states where the symptoms might not be present, but the pathological process has already begun, which might be misunderstood by women as being healthy [26]. Similar steps also need to be taken to mitigate the heredity fallacy held by the women. Addressing the fear of the women regarding results of the test need to be done at the community level so as to ensure that there is no discrimination towards the person.

The present study is unique in its attempt in identifying the qualitative evaluation of the specific barriers and facilitators in cervical cancer screening after both informing the women about the screening methods as well as conducting camps to ensure accessibility and availability of the services. The principal strength of the present study was the usage of a qualitative methodology to obtain the perspectives of tribal women regarding cervical cancer screening.

Limitation(s)

Although the women interviewed in FGDs spoke clearly, openly and in vivid details about the barriers and facilitators that they felt affected them but using a focused group discussion design might have prevented the shyest of the participants from attending or speaking about their issues. An in-depth interview method might have been more suitable to bring out the more intimate details from the participants.

CONCLUSION(S)

The current study provided insights to the potential barriers among tribal women, living in tea gardens of Darjeeling district regarding their behaviour towards cervical cancer screening, when knowledge regarding the same and availability of the services were not issues. It was seen that the main barriers towards tribal women opting for cervical screening were the lack of social support, burden of responsibility, and the lack of felt need. These barriers can be overcome, by positive community and social motivation, increased knowledge and ease of accessibility.

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ANNEXURE 1

Looking Beyond Knowledge and Accessibility; Barriers for not Availing Cervical Screening Services among Tribal Women in Tea Gardens of Darjeeling, West Bengal

Warm up questions

1. How long have you been living in the tea garden? How many family members do you have.
2. Have you heard of cervical cancer? Do you know anyone who has/had been diagnosed with it? What do you feel about the disease?

Essential questions

3. Did you face any difficulty coming to the screening today?
4. What adjustments did make in your daily schedule to attend the screening services?
5. What prompted you to get screened?
6. How did your family react to your coming for screening?
7. What are your opinions on the necessity of getting screened for cervical cancer even without the presence of any symptoms?

Closing questions

8. How has the experience of screening been for you?

   Has the experience here been different than the hospitals you visit for treatment?