

Challenges in Population based Cancer Screening in India - A Pilot Study

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Abstract

Introduction: In India Cancer has become a single largest reason of Mortality. Among them Oral, Breast and cervical Cancer are among the top three cancers which are prevalent and screening of these cancers at an early stage can prevent them.

Methodology: Population based cancer screening (PBCS) was conducted in a field practice area of North Bangalore. Out of the 1226 individuals who were surveyed, 856 were eligible to undergo screening. However, out of the only 105 individuals (12.26%) participated in the screening camp. Owing to the large percentage of non-responders, visits were conducted to the village as a post camp activity. A house to house survey was conducted in 5 % of the sample population and reasons for non-participation were sought. Furthermore, in depth interviews of the health workers were conducted to get a further understanding into the behavioural attitude of the participants towards PBCS.

Results: In the surveyed sample of 43 individuals, we found that only 3 had participated in the screening activity. Out of the 40 individuals who did not prefer to participate, we found that 35 of them were aware of screening activity being conducted, while 5 of them did not seem to be aware of the it.

Conclusion: Smart utilizations of resources has to be done to improve the cancer screening which changes with each location and region.

Keywords: Cancer; Population; Screening; Health

Introduction

India is currently one of the nations with highest incidence of Non Communicable Diseases (NCDs) often leading to preventable deaths and Cancer is one of the four major NCDs.

According to the GLOBOCAN project incidence of cancer will rise to over 1.5 million by 2035 from one million as reported in 2012 [1].

Cancer of the breast, cervical and cancer and mouth cancers contribute to about 34% of total cases of cancer in India. Hence these are the conditions which require organized public health interventions on priority in India [2]. Both oral and cervical cancers have long latent periods and manifest as clinically detectable precancerous lesion making it technically feasible to have screening protocols for the same [3].

India boasts of a dedicated National Programme for the Prevention and Control of these NCDs which was started in 2010 and later combined with National Health Mission (NHM) for better reach. The aim of these programs was to enable opportunistic screening and provide the advantage of ‘lead time’ which is helpful when it comes to the prevention of NCDs.

This opportunistic screening is carried out at community health center (CHC) level. Under the NHM, population based screening for NCDs include the three most common cancers i.e. Oral, Breast and Cervical Cancer [4].

Implementation of these population based cancer screening programmes could be met with a number of challenges, such as cost, technical skill and technology to name a few which has been listed in the literature [5]. Public screening programmes are highly dependent on the beneficiary compliance to achieve high effectiveness and efficiency, however it is seen that participation in low inspite of adequate awareness and notifications for the said programs [6]. This paper describes the challenges faced in achieving community participation in a population based cancer screening organized by an NGO in a peri-urban area of Bangalore, India.

Subjects and Methods

The population based cancer screening activity was held in the field practice area of Rajanukunte located in Bangalore North area of Bangalore district, Karnataka. Population based screening as envisaged by the NPCDCS has not yet started in the PHC area. As a pilot, Singanayakanahalli village was chosen for the screening programme. The community leaders, ASHA workers and Anganwadi workers were actively involved in mobilizing the population. House to house visits was conducted by health workers to sensitize the local community regarding the need for screening activities. During the visits pamphlets in local language were distributed, containing information about cervical, breast and oral cancer. At the same time, a high risk survey was conducted to identify individuals at high risk for oral cancers, ie those who used tobacco and alcohol.

All women aged 30 years and above and all individuals who were at high risk for oral cancers were invited to participate in the screening camp. Two camps were conducted in the locality on two different dates. For the convenience of the beneficiaries, camps were held on weekends (Saturday and Sunday). On the day before the screening activity, public announcements were held in the local language regarding the conduct of the camp to further garner population attention to the programme. Oral cancer screening was conducted by visual inspection by dentists and cervical screening was conducted by per speculum examination and PAP smear test. Clinical breast examination was also done. The results from the screening camp are discussed elsewhere. This outreach program was free of cost for all beneficiaries. The ASHA and other Health care workers served as ancillary staff in the screening camp. The population based screening activity had been provided ethical clearance by the institutional review board AJ Institute of Dental Sciences, Mangaluru.

Out of the 1226 individuals who were surveyed, 856 were eligible to undergo screening. However, out of the only 105 individuals (12.26%) participated in the screening camp. Owing to the large percentage of non-responders, visits were conducted to the village as a post-camp activity. A house to house survey was conducted in 5 % of the sample population and reasons for non-participation were sought. Furthermore, in-depth interviews of the health workers were conducted to get a further understanding of the behavioral attitude of the participants towards PBCS (Table 1).

Total number of population	2900
Total number of people surveyed	1226
Total number of females	680
Total number of males	546
Total number of people at high risk	856
Total Number of people screened in camp	105
Total number of Males screened	76
Total number of females screened	29

Table 1

Results

A total of 43(5% of the eligible population) individuals who were residents of the village were surveyed to seek their participation in and reasons for non-participation in the screening camps.

In the surveyed sample of 43 individuals, we found that only 3 had participated in the screening activity.

Out of the 40 individuals who did not prefer to participate, we found that 35 of them were aware of screening activity being conducted, while 5 of them did not seem to be aware of it (Table 2).

	Attended the camp	Did not attend the camp
Knew about the camp	0	35
Did not know of the camp	0	5

Table 2: Descriptive data of people attending the screening.

Among the 35 individuals who knew about the conduct of the camp but did not choose to participate, the reasons for their non-participation is as given in the chart below (Figure 1).

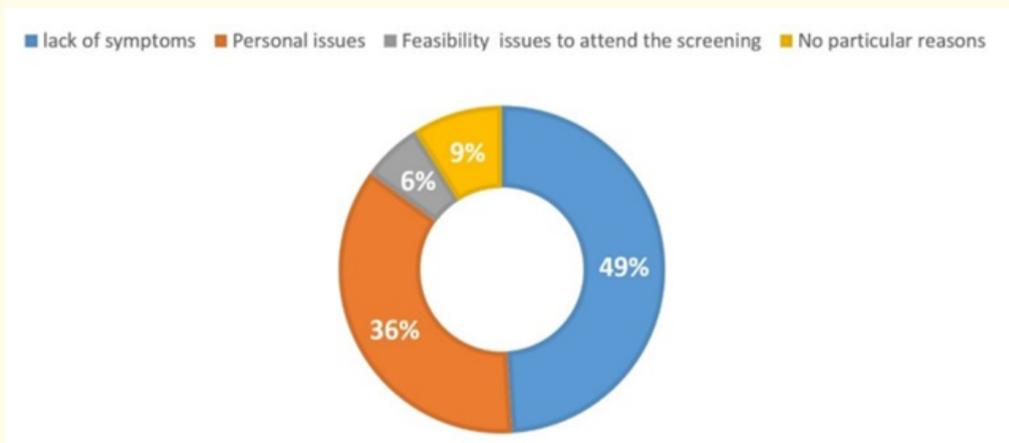


Figure 1: Descriptive data of issues for people not attending screening.

Among the 43 individuals, 38 were females and 5 were males. The literacy rate of these individuals was poor with only 23% of them have completed high school (Figure 2).

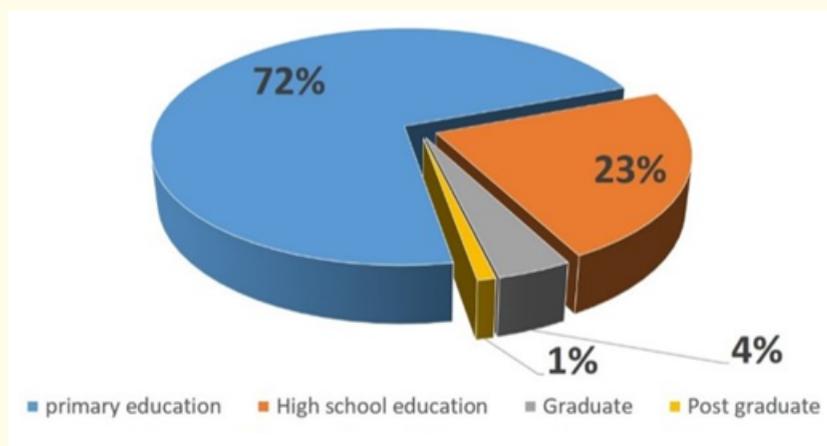


Figure 2: Percentage of literacy in the population.

Discussion

Sociocultural barriers to health and cancer care

There are enormous cultural and social differences that span across India, owing to the diverse history of our region. Generalizations approaches to cancer screening have always been a challenge in India are therefore have never succeeded.

The major socio-cultural factors that affect approaches to cancer screening in India include social taboos which include blind faith in traditional practices, superstitions, the caste system, gender inequality, and the nihilistic attitude of cancer diagnosis (i.e. cancer fatalism). Though common in both rural and urban areas, they seem to be more anchored in the mindset of the rural population. With the advent of Corporate Social Responsibility (CSR), large organizations are providing the means to implement programs in creating awareness regarding the benefits of screening, it still remains a Herculean task to bring forth the mindset that healthcare should largely be 'preventative' and not 'curative'.

In the present study it was found that 36% of the individuals had personal issues for not having attended the screening camp. According to a study conducted by Neal, *et al.* 53% of 500 participants believed that those who suffered from cancer "brought it on themselves" [7].

Myths and certain taboos that prevail in the social ecosystem often prevent individuals from seeking regular health-care checks ups. This tends to lead to neglect and more often than not individuals are in an advanced stage of diagnosis by the time they receive the relevant care. This is especially true for cancer cases. Patients often tend to keep the diagnosis of cancer a secret, even from family and friends, ultimately compromising treatment and outcomes.

The fear principle plays a very important role in cancer diagnosis and prognosis, it can alter human behaviour such that even after a positive cancer diagnosis, individuals tend to maintain normality in their life and accepting recommended care is a challenge for them. This leads to poor follow up behaviour which negatively influences the outcome of the disease. As mentioned earlier two of the most common cancers, breast and cervical affect women, however gender inequality and patriarchal society seen in India leads to further neglect of diseases affecting women. Documented studies present in literature support this view that the health of women and senior citizen are often given less priority men and younger family members [8]. Although incidence of Breast cancer is higher in the western countries than India, their survival rate is better due to early diagnosis. Some registries in UK in fact show that hardly 15% of cases present in their advanced stages [9]. In contrast to this in India the disease is often diagnosed in the advanced stages. Confirming this fact it has been reported by hospital-based registries and surveys done in rural areas that about a half of newly diagnosed breast cancer cases are presented at the latter stages of the disease (Stage III or IV) [10,11]. Studies done in other countries with limited resources also reported that a majority of patients with various cancer diagnoses presented at latter stages of the diseases, inevitably increasing the risk of high mortality [12].

Patient illiteracy, prevalent in rural areas, plays an important role in delay in diagnosis. This is well documented in a study by Sathwara, *et al.* where the literacy rate of women who participated in the program was higher than those who did not [13].

Reiterating the hazards of a patriarchal society it was seen that the woman concerned took the decision not to participate in the screening in only half of the observed cases, this meant that personal and highly important health care decisions are often taken for the women by other member of the family. A common misconception such as "no need for screening as I have no symptoms", "Uncomfortable or fearful of gynaecological examination", "possibility of sterilization" or even fear of the possibility of a cancer diagnosis and equating such diagnosis with certain death, are seen as common reasons for opting out of the screening test. Women overburdened with domestic responsibilities and not being able to take time out for the screening program was another reason given by at least 40% of the non-compliant women [14].

Further highlighting patriarchy as a reason for noncompliance, a community-based study from Karnataka, 2/3 of rural and about 1/3 of urban underprivileged women who participated in the study, said that they needed the consent of their spouse or elder in order to participate in the screening [15]. Social stigma attached to cancer is another reason people opt out of such programs as they believe cancer is incurable and must be kept as a secret from the community at large [16]. This attitude leads to poor adherence to cancer treatment guidelines and recommended follow ups. The key to improvement in participation is the implementation of comprehensive health education programs targeted at high risk populations. A cluster randomized trial followed a pattern where in the medical social workers (MSWs) established communication with opinion leaders in the community. They then administered a baseline survey to identify eligible women. Participants in the intervention group were then personally invited by the MSWs to participate in the screening program. The results showed that the average compliance to three rounds of cancer screening was 71.4% for breast screening and 64.9% for cervical screening.

This finding is similar to participation rates seen in controlled screening studies in developing countries [18] and even with non-controlled screening trials in developed countries [19].

In the above trial, those of older age group, Muslims, having poor literacy or not being able to speak Hindi or Marathi showed non-compliance to screening [17]. Another study in Maharashtra also showed similar findings for non-compliance to cervical cancer screening program [20].

Conclusion

India as a nation has to fight many evils, in addition to poor education, there is the looming threat of myths prevalent in the society and enablers of these myths, who present themselves as godmen or so-called healers. In such a scenario it is easy for vulnerable individuals to get deceived even to get influenced into not following recommended conventional treatment protocols. The present study echoed the findings of various other studies where most of the participants who were non-compliant had poor educational backgrounds. This reiterates the fact that targeted health education, following all its principles is the key to increase compliance rates to such programs.

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