# **Original Research Article**

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# Community cancer awareness programs: symptom awareness alone doesn't suffice

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#### **ABSTRACT**

**Background:** Although cancer is a global public health problem, maximum impact is on developing economies. In India, socio-cultural factors also operate to add the burden. Aim of the study was to delineate factors causing late presentation of cancers to the point of care.

**Methods:** We gave cancer awareness classes to a village community, preceded by a campaign to attend the classes with the help of a local trustee organisation and primary health center. Data was collected from the attendees using a structured questionnaire prepared to dissect out the awareness about cancer symptoms and concerns about treatment.

**Results:** Only 1.8% of the total population of the area under study attended the classes. Out of the 411 attendees, 323 (78.6%) responded to the questionnaire and of them, 294 (91%) identified the site wise symptoms of cancer clearly and 40 (12.4%) detected their own symptoms warranting cancer screening. Commonest concern was the cost of treatment (40.9%). There were people thinking that cancer is not a life-style disease (3.1%), it is genetic (7.7%), it may be due to fate alone (6.2%), it is contagious (5%), and it cannot be cured (3.7%).

**Conclusions:** Despite high health status indices, literacy rate and high knowledge about cancer symptoms, there are still a lot of superstitions about cancer in Kerala. The most common reason preventing people from approaching health care system with early symptoms of cancer is the fear of cost of treatment. Apart from teaching symptoms of cancer, cancer awareness programs should include familiarisation of various financial aids available for cancer treatment.

Keywords: Community cancer awareness, Cancer survey, Cancer cost

# INTRODUCTION

Cancer is a global public health problem, but the maximum impact is in developing countries like India, owing to its social and economical repercussions. <sup>1,2</sup> In India, more than one million new cases of cancers are diagnosed every year. <sup>2</sup> According to the Indian Council of Medical Research (ICMR), India is likely to have 1.73 million new cases of cancer and 0.88 million deaths due to cancer in the year 2020, with cancers of the breast,

lung, oral cavity and cervix being top in the list.<sup>3</sup> As per Kerala cancer statistics 2014, the crude cancer incidence among males in Kerala was 172 per 100,000 population while that for females was 166.5.<sup>4</sup> There are two established population based cancer registries (PBCR) in Kerala (Thiruvananthapuram and Kollam registries).<sup>5,6</sup> Based on the data from these registries, it is estimated that by the year 2020, 147 new cancer cases will be detected on a day in Kerala, with an annual prevalence of 1,67,307 cases.

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Cancer is essentially a life style disease.<sup>7</sup> Awareness about cancer is certainly important in early detection, prompt treatment and overall prognosis.<sup>8</sup> In India, late presentation of cancer patients to the health care system is very common. For example, majority of breast cancers present in advanced stage.<sup>9</sup> This leads to poor outcome, despite the most aggressive treatment. Lack of awareness and absence of screening are the probable causes for late presentation.<sup>9</sup> Other reasons for late presentation include delay in seeking health advice due to financial and social reasons.

Our institution is a tertiary care government teaching hospital in central Kerala, South India. We cater four districts in central Kerala and as per hospital based cancer registry (HBCR) of our institution, 4000 to 4500 new cases are registered every year. We have taken initiative in conducting cancer awareness classes and early detection camps in the catchment areas of our hospital from the year 2014 onwards. But to our surprise, people approaching us in these camps with symptoms which alarm the need for cancer screening investigations were minimal. The present study was to dissect out the causes for this observation.

#### **METHODS**

The study was designed as a population based cross sectional observational study using a structured questionnaire. After getting approval from Institutional Ethical Committee of Government Medical College Thrissur, the study was done in a rural area, Avinissery Grama Panchayath in Thrissur district of Kerala State, South India, from May 2018 to July 2018. Avinissery primary health center (PHC) and a local trustee organisation (Sri Sathya Sai Seva Organisation) helped us for executing the study in a systematic way. Initially doctors and health staff from PHC and trustee members were given a cancer orientation program in the Department of Radiation Oncology, Government Medical College, Thrissur using power point slides, emphasising the types of common cancers, risk factors for their development, site wise symptoms, prevention and screening methods, treatment modalities, Government initiatives and funds available for cancer control and common concerns of the public regarding cancer.

A structured questionnaire was made with 48 questions to encompass personal details of the respondent (5 questions), self-assessment of site-wise warning symptoms (15 questions), family history and cancer experience (3 questions), life style and risk factor assessment (10 questions), common concerns about cancer (10 questions), feedback and opinion survey (5 questions).

The initial group who had training at our institution was sub divided into three functional groups; each with a doctor, a health staff and two trustee members. The total panchayath region was divided into three areas. The health staff and trustee members of each functional group attended every household under their purview and prompted people to attend cancer awareness class on a particular day in a public area near their residence. Local political party members also helped in the campaign.

On the day of awareness class, the attendees were taught by the doctor in the functional unit using power point slides in regional language. After the class, all attendees were asked to fill up questionnaire survey individually. Attendees from 18 years to 70 years age who consented to participate in the study were included. Rest of the attendees and our health staff were excluded. The response was analysed in our institution and all the respondents with suspected warning symptoms and strong family history of cancer were asked to attend a cancer detection camp in their homeplace. In the camps, these people had a thorough clinical examination and necessary screening investigations.

#### Statistical analysis

The survey recruited people by random probability sampling, stratified by region. Cross sectional life-style and opinion survey was done. The percentage of respondents were analyzed based on the population statistics of the area. Qualitative data was analyzed by descriptive statistics.

#### **RESULTS**

A structured questionnaire was given to the people who attended cancer awareness class (attendees). Out of 411 attendees, 323 answered the questionnaire (respondents). The total population of the Panchayath at the time of the study was estimated to be 22760, which means that only 1.8% population positively took up the preclass campaign conducted by health workers and trustees.

# Demographic and social charactersistics

Among the attendees, 78.6% (323 out of 411) answered the questionnaire. Out of them, 101(31.3%) were males and 222 (68.7%) were females. Regarding the age, 67 (20.7%) were in <40 years age group, 63 (19.5%) in 40-60 years age group and the remaining majority were in the geriatric (>60 years) age group. Majority (138 out of 323, 42.7%) were housewives, 84 (26.0%) had private jobs or self employed, 25 (7.7%) were health care workers, 27 (8.4%) were government employees and 28 (8.7%) were unemployed (Table 1).

# Life style and risk factor assessment

Only 25 (7.7%) respondents had the habit of cultivating and using organic vegetables in home. None of the females had habit of smoking or liquor consumption. Among males, 7 out of 101 (6.9%) were smokers and 21 out of 101 (20.8%) had the habit of liquor consumption. Among females, 32 (14.4%) had estrogen-progesterone

hormone treatment and 16 (7.2%) had thyroid hormone treatment. None of the males had any hormone treatment. Out of 197 females who mentioned the age at 1<sup>st</sup> child birth, 122 (61.9%) had 1<sup>st</sup> child birth before 30 years, 45 (22.8%) had it after 30 years and 30 (15.2%) were nulliparous.

Table 1: Demographic and social characteristics.

Characteristics		Proportion	%
Response rate	Attendees per population campaigned	411/22760	1.8
	Respondents per attendees	323/411	78.6
Sex	Male	101/323	31.3
	female	222/323	68.7
Age	Less than 40 yrs	67/323	20.7
	40 to 60 yrs	63/323	19.5
	More than 60 yrs	193/323	59.7
Occupation	House wives	138/323	42.7
	Self employed	84/323	26
	Health care workers	25/323	7.7
	Govt. Employees	27/323	8.4
	Unemployed	28/323	8.7

### Symptom recall and recognition

The cancer awareness class included site wise description of symptoms with regard to cancer, both early symptoms and late symptoms. Fifteen questions in the questionnaire were aimed at assessing their knowledge on cancer symptoms. Out of the respondents, 294 (91%) understood the site wise symptoms clearly; 40 (12.4%) detected their own symptoms which needed further clinical examination and investigations for cancer screening.

# Cancer history and experience

Only two respondents had past history of cancer, 37 (11.5%) had one family member with history of cancer, 4 (1.2%) had more than one family member with history of cancer and 72 (22.3%) had close rapport with cancer patients, as neighbours or as care givers.

# Common concerns about cancer and its treatment

Ten questions were aimed at understanding the fear of target population regarding cancer and its treatment. Out of the respondents, 132 (40.9%) still thought cancer treatment is costly and not affordable, even though we gave detailed explanation on available government funds and insurance schemes. A few i.e. 25 out of 323 (7.7%)

were under fear of genetic back ground in cancer development whereas 20 (6.2%) thought that cancer emergence is due to fate alone and another 10 (3.1%) thought life-style modification has nothing to do with decreasing the risk of developing cancer. Some people (12 out of 323, 3.7%) thought that cancer cannot be cured and it was surprising that around 5% (16 out of 323) marked cancer to be contagious (Table 2). A good number of people (60 out of 323, 18.6%) opined that proper counselling to the patient and relatives is needed to alleviate fear and queries once cancer is diagnosed.

Table 2: Common concerns about cancer and its treatment.

S. no.	Concerns	Proportion	%
1	Treatment is costly	132 out of 323	40.9
2	Fear of genetic background	25 out of 323	7.7
3	Cancer is due to fate	20 out of 323	6.2
4	Cancer cannot be cured	12 out of 323	3.7
5	Cancer is contagious	16 out of 323	5

#### Feedback

Last five question aimed at feedback to the whole program. Many of the respondents (125 out of 323, 38.7%) thought that the awareness program and questionnaire were adequate. Thirty percent (97 out of 323) gave overall grading as excellent, 44.3% (143 out of 323) as good and 6.5% (21 out of 323) opined that the program needed improvement. However, 62 (19.2%) didn't attempt the questions regarding feedback (Figure 1).

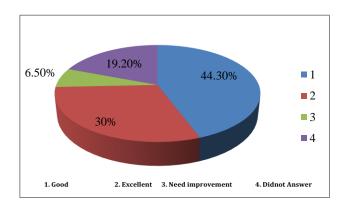


Figure 1: Feedback to cancer awareness program.

#### **DISCUSSION**

Kerala has high literacy rate, educational status and health care indices, all at par with those of developed countries.<sup>10</sup> Despite these facts, it is a common

observation in our center that a lot of cancer patients present at advanced stage of the disease, which is in concordance with data from other parts of the country as well. This really alarms the need for a good gap analysis for detecting the causes of late presentation, which in turn increases the mortality and morbidity from cancer, increases the treatment costs and negatively affect the quality of life. In the present study we have tried to bring out the understanding of community regarding site wise symptoms and common concerns regarding the disease and its treatment, since we thought that dissecting out these factors may help in identifying the causes for late presentation of cancer patients to health care system.

We assembled people from a rural area into three regional centres with the help of a local trustee organisation, health staff of local PHC and local politicians. After giving an initial cancer awareness class, we collected data through a structured individual questionnaire. Around 2% of the total population who attended the classes represented the community, though females, especially house wives, and elderly were over represented. Males and working class were probably under represented since the class was during working hours. Despite widespread publicity and good local support, we were able to mobilize only less than 2% of the population for the cancer awareness class. This suggests that we should resort to other mass education methods and large-scale interventions for better penetration into the community. 11

Around 80% of the attendees filled up the questionnaire and the analysis were done on them. It has been found that 91% understand the site wise symptoms clearly and 12.4% were even able to detect their own alarming symptoms which needed further diagnostic workup. These higher percentages are probably related to the high literacy status and educational standard of the Kerala community. Also these indicate the successfulness of our awareness program in improving the knowledge about cancer, as demonstrated earlier by the Pink Chain Campaign. 12

An important finding in the study was that even after explaining the financial aids in cancer care, with various funds like Rashtriya Swasthya Bhima Yojana, Karunya Benevolent Fund, other central/state government funds and local body funds, 40.9% still had the fear about cost of cancer treatment. This may be one of the reasons why people do not turn up for early diagnosis and treatment, even if they understand redflag symptoms warranting further diagnostic workup. Small percentage of people were over concerned about genetic background in cancer development (7.7%) whereas a similar minority believed that cancer emergence is due to fate alone (6.2%) and there were even people believing that cancer is contagious (5.0%) and cannot be cured (3.7%). All these may again add on to the late presentation of the disease. Another factor which may be important is the cultural taboo about cancer prevailing in our society.<sup>13</sup> This may be contributing to the denial and ultimately to the late presentation.<sup>14</sup> Direct questions regarding this were not there in our questionnaire; however, it should be noted that investigating these points by a questionnaire is very difficult.

The study emphasised the need for much penetrance into the community with regard to cancer screening programs and health and health system awareness. 15 We were able to demonstrate that even though the Government is providing several funds and supports for cancer treatment, the knowledge of the same is not reaching the community, suggesting that sufficient publicity is the need of the hour. Also dissipation of the knowledge about cancer treatment and about the governmental support for the same to the community through public health nurses, ASHA workers and other grass root level health workers may help in tackling the situation.<sup>16</sup> Cancer survivorship programs, good care giver support and cancer rehabilitation programs also may increase the confidence of the general public, helping in throwing away taboos regarding the disease resulting in early detection and treatment. 17,18 A more wider and scientific gap analysis helps in identifying the defects of the present health care activities in early cancer detection and screening. This in turn will help in achieving the ultimate goal of good cancer control and best quality of life in a cost-effective way.

#### **CONCLUSION**

This cross sectional observational study was conducted to investigate the probable factors contributing to the late presentation of various cancers. High literacy rate and other social factors may be behind the high awareness about cancer in our society. Despite this, it is surprising that a very high percentage of the people with cancers present at advanced stage of the disease. Our study suggests that the major reason for this is the fear of cost of treatment. Though we have various governmental and non governmental financial aids, people are still not fully aware of them. Cancer awareness programs to the public should include educating about the importance of early detection of cancer for excellent prognosis and about the financial aids prevailing for its treatment. Future studies should focus whether psychological denial of explicit symptoms also contribute to the late presentation of cancer patients.

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