Community Participatory Approach in Cancer Control: "The Kannapuram Model" for Breast Cancer Control in Northern Kerala, India

Abstract

Background: Breast cancer accounts for 26.6% of cancers among Indian women. Lack of awareness and fear lead to late-stage presentations and high mortality. This study aims to describe a novel community participatory model for cancer control in a Grama Panchayat in northern Kerala. **Methods:** The screening program in the Grama Panchayat was preceded by systematically planned, multifaceted, community-level cancer awareness activities, under the leadership of the Local Self Government Institution and technical support from a Comprehensive Cancer Care Center. **Results:** The activities led to a screening participation rate of 96% among women above 30 years, in a breast cancer screening camp organised in the Grama Panchayat. Out of the 203 (6.2%) referred, 135 women (66.5%) underwent further investigations. The detection rate was 0.96 per 1000, all in the early stages. **Conclusion:** Continuous community sensitization about cancer, alleviation of fear and misconceptions, accessible and approachable screening program settings, and an efficient patient navigation system, led by female Local Self Government Institution members, culminated in the successful 'Kannapuram Model', in terms of screening participation and treatment adherence.

Keywords: *Breast cancer, community participation, Kerala, screening*

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Introduction

Breast cancer is leading in incidence and mortality globally among women, accounting for one in six cancer deaths.[1] Advanced stages at diagnosis in most of the transitioning countries in Asia lead to high mortality rates, mainly due to a lack of population-based screening programs.[1,2] Moreover, the widespread misconceptions about the risk factors, symptoms, diagnosis, and treatment among the public, and even healthcare workers, add to the delay in these countries.[3,4] Despite efforts from government and nongovernmental organizations, women's participation in screening programs is not satisfactory, even in developed countries.[5] Lack of awareness about symptoms, treatment facilities as well as financial constraints often lead to late-stage presentation and high mortality in India.[3] Community-based interventions were found effective in disseminating public health information,[6] formulating policies for social change, reducing health disparities,[7] and improving cancer awareness.[4,5,7] In India, well-designed, large-scale community-based cancer control interventions are very few compared to other noncommunicable diseases.[8] Moreover, programs utilizing multidimensional awareness interventions targeting the community, health workers, and other stakeholders are also deficient in the country.[8] This study aims to describe a planned multifaceted and consistent community participatory intervention model for cancer control in a selected Grama Panchayat (GP) in Kerala, India.

Methodology

The study setting is the Kannapuram Grama Panchayat (GP) in northern Kerala which has a total land area of 14.39 square km, 4531 households,[9] and a population of 18,459 (55.5% females) as per the census (2011).[10] A GP is the lowest level of the three-tier Panchayath Raj System and represents a village or group of villages.[11] As part of decentralized development in Kerala, the transfer of power, finance, and expertise to Local Self Government Institutions (LSGIs) encouraged the participation of the local population in planning innovative programs.[12]

Owing to the increasing burden of cancer, the GP decided to plan cancer control

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activities in the area for the next 3 years, utilizing the allocated funds, and seeking expertise from a Comprehensive Cancer Care Centre (CCCC). The main focus was on alleviating public fear about cancer and facilitating early detection and treatment.

A series of events were planned in the GP for the next 3 years in a phased manner.

Phase 1

In the 1st year, sensitizing workshops were conducted to convince all stakeholders (Local Self Government members, staff of the Primary Health Centre, and self-help groups) on the importance of screening, early detection, and lifestyle modification for cancer prevention by doctors from CCCC, and a project for cancer control in the GP was conceived. Committees were formed for program planning and implementation at the grassroots level. A house-to-house survey to understand the general health aspects of the GP and the high-risk subjects who needed cancer screening was conducted by community volunteers using a structured questionnaire in 3800 houses. However, many hesitated to give the right information due to ignorance and fear. This highlighted the importance of reducing fear by creating public awareness, which was feasible only through active community involvement.

Phase 2

During the 2nd year, sustained multifaceted public awareness programs were planned under the guidance of CCCC, in collaboration with other social service organizations, and the health department. Distribution of Information, Education and Communication (IEC) materials, conducting health exhibitions during social, religious, and cultural gatherings for awareness on early detectable cancers, organizing "winners meet" where survivor experiences were utilized to reduce fear about cancer treatment, food fests to promote locally available, pesticide-free, dietary fiber and antioxidant-rich seasonal fruits such as jack fruit and mango, literary competitions for students and public, panel discussions on diet and cancer prevention, and supporting and promoting setting up of kitchen garden were few of them. Awareness campaigns on cancer and tobacco were also conducted in schools with the involvement of the Parent Teacher's Association. Observation of cancer-related days like National Cancer Day in November, World Cancer Day in February, and World No Tobacco Day in May, with various awareness programs and public rallies kept the ongoing activities live.

Phase 3

With the multilayered awareness programs gaining momentum, during the 3rd year, the GP initiated a novel woman-centered project for breast cancer screening. A single-day registration campaign was conducted by the community volunteers visiting 3800 houses. A mega screening camp of 10 days was conducted in the GP with community participation, where healthy women above 30 years without a history of breast cancer were included. The program gained publicity as a women's health empowerment movement, as females took the major lead, all female stakeholders getting screened on the first day and becoming role models. Trained female technicians screened 200–500 women daily, with a handheld, noninvasive medical device with piezoelectric sensors to differentiate varying tissue elasticity, along with Clinical Breast Examination (CBE). Pamphlets and training on breast self-examination methods were given. Women with positive test results were counseled and referred to the CCCC for further tests (mammogram or ultrasound). Referrals were coordinated by a special women's squad, a unique model of patient navigation by the dedicated female members from the GP. They contacted each female to ensure participation, accompanied them, coordinated travel and appointments, and enabled them to undergo investigation with ease. The model was a great success in terms of screening participation and follow-up adherence. Those detected to have breast cancer were treated at CCCC by enrolling in one of the available Government treatment schemes. The details of the screening program are given in Figure 1.

Ethical considerations

The project received ethical clearance from the Institutional Ethics Committee of the CCCC. A gatekeeper's consent from the GP head and individual participant consent were also taken.

Results

Among the invited 3247 women above 30 years, 3118 participated in the breast cancer screening camp (mean age 48.3 ± 10.46). The majority of women were married and 3.6% were unmarried. Further investigations were required for 203 women (6.2%), as per the positivity in the screening test and findings of the CBE. The majority (84%) had no symptoms. Of these, 135 (66.5%) underwent mammography. Out of this, 109 women (80.7%) with BI-RADS (Breast Imaging-Reporting And Data System) 1 or 2 were advised regular screening. Those with BI-RADS 3 (n = 10, 7.4%) were advised 6 monthly follow-ups. All 15 women (11%) with BI-RADS 4 and one with BI-RADS 5 underwent wire-guided biopsy, of which three were confirmed to have early-stage carcinoma (DCIS (Ductal carcinoma in situ), Stage 1A, and Stage 2A, respectively). All have completed treatment and are presently disease-free. Further assessment participation rate either at the CCCC or elsewhere was 66.5% due to continuous intervention and motivation by the volunteers despite having no symptoms. It was noted that 33% of referred women failed to undergo further investigation, posing challenges to the successful completion.

The reasons that were probed by the navigators are categorized and presented in Table 1.

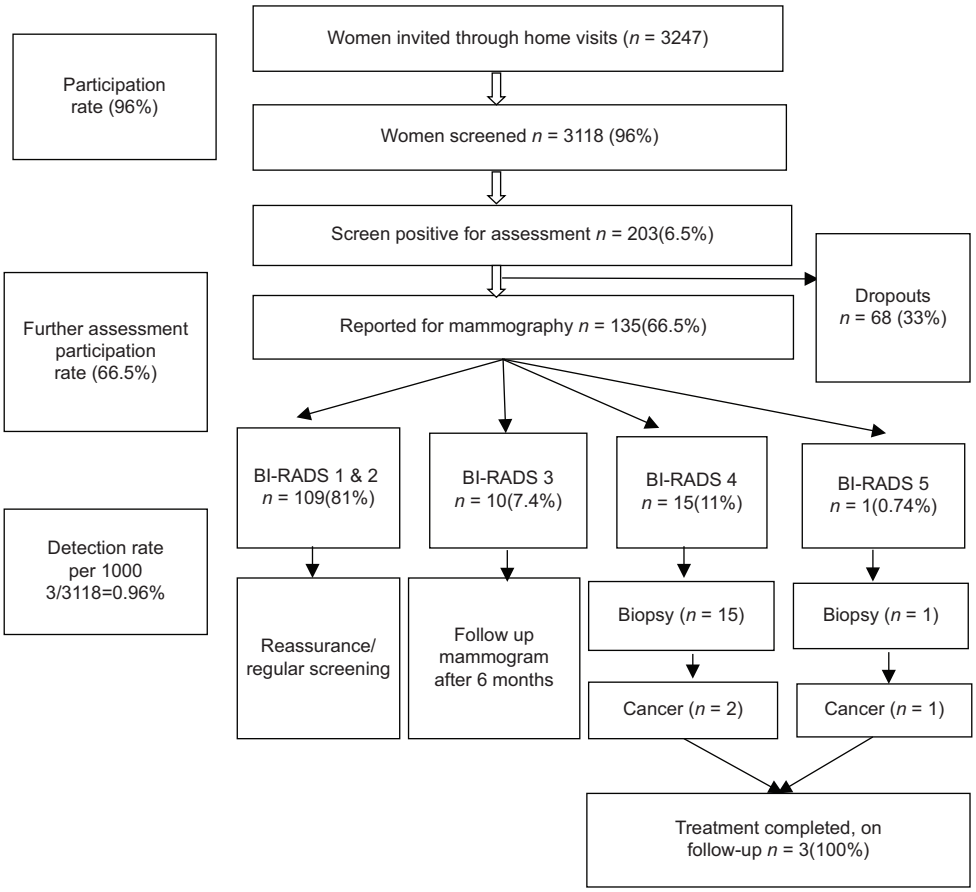

Figure 1: Flow chart showing the outcome of the breast cancer screening program at Kannapuram Panchayat, Kerala, India

Table 1: Reasons given by the women for not undergoing follow-up as reported by navigators (*n*=27)

Factors	Reasons
Health related (*n*=3)	Self-health issues (*n*=1)
	Spouse's health issues (*n*=1)
	Age related health issues (*n*=1)
Family related (*n*=8)	Spouse not interested (*n*=2)
	Children not keen (*n*=1)
	Husband abroad (*n*=1)
	Nobody to accompany (*n*=1)
	Marriage in family (*n*=1)
	Daughter coming from abroad (*n*=1)
	Daughter's delivery (*n*=1)
Fear related (*n*=11)	Fear of disease (*n*=1)
	Fear of diagnosis (*n*=1)
	Not willing for any test (*n*=5)
	Not responding to calls (*n*=4)
Work related	Cannot take time off from work (*n*=1)
Symptom related	Came for mastalgia, no symptoms now, hence not ready for test (*n*=1)
Access related (*n*=3)	Out of station (*n*=1)
	Presently staying far away with daughter (*n*=2)

Discussion

In our study, the prior community participatory efforts and multifaceted awareness interventions have resulted in a high turnover in breast cancer screening camps and adherence to follow-up and treatment. Community interventions such as posters, street plays, group discussions, house visits,[8,13] public education campaigns delivered by broadcasts, workshops, multimedia programs through kiosks, health promotion messages displayed in the workplace, and exercise centers[14] have proved effective in improving awareness in many countries including India and resulted in women being more positive toward medical help-seeking, and admitting that breast cancer diagnosed early is treatable.[5] Health fairs and other community events being used for the dissemination of cancer-related messages[15] were also in confirmation with our study. Such localized approaches, partnerships, and culturally acceptable tailor-made strategies of community-based awareness have proven to improve screening rates even among underserved populations.[16] Our study shows a participation rate of 96% which was also seen in the intervention group in another study from Kerala.[17] In our study, the further assessment participation rate was 66.5%, much higher than the study from southern Kerala (49%),[17] and from Philippines

(35%).[18] Using trained community health volunteers in another study from northern Kerala reported a follow-up similar to ours.[4] The allocation of funds for bearing the cost of tests by the GP dealt with the financial barriers described in other studies.[3] Failure to report to healthcare facilities after detecting a breast lump is a major reason for delayed diagnosis in LMIC.[3] This underlines the efficiency of the patient navigation strategy in our model. In our study, the navigators acted as the bridge between the health system and community, motivated women to attend the camp, provided informational and emotional support, and accompanied them during follow-up managing the complexities of the healthcare system, in confirmation with other studies.[16] In our study, the detection rate was 0.96 per 1000, almost in line with a study from southern Kerala.[17] Although the cutoff age in our study was not keeping with the standard guidelines, this was done, as demanded by the women who received awareness and considering breast cancers being reported at younger ages in our country.[17] All detected cases were in the early stages, as in other studies on breast cancer screening.[4,17]

The 7A framework for barriers to screening access was described as approachability, acceptability, affordability, availability, appropriateness, awareness, angst, and fear.[19] Studies show that women not only feared the test results[4] but also the confabulations in society regarding attending a cancer screening camp.[19] In our study, the continuous awareness campaigns led by female LSGI members, acceptable and cost-free screening methods, well-organized screening camps with female providers, and the geographically accessible camp site , led to increased screening participation. The involvement of the community helped to overcome most of the barriers at large, address the possible mistrust between the health system and the public, and sustain the interventions to achieve the goal.[8] The Global Breast Cancer Initiative of WHO also advocates health promotion and early detection; timely diagnosis; and comprehensive cancer management as the three key pillars for reducing breast cancer mortality.[1] Our model also aligns with achieving these goals. The shortcomings in drafting large-scale community projects owing to the inexperience of local communities,[12] were overcome here by the expert guidance from the CCCC, in scientifically structuring the program. The program was designed in a phased manner, with activities being scaled up in each phase, in terms of variety, frequency, and number; starting with sensitization of stakeholders, mass survey for situation analysis , house-based awareness, and involvement of the public in multifaceted awareness programs which led to deflating the fear about cancer and gaining public trust regarding curability of cancer. This resulted in the successful completion of a breast cancer screening program by the women of the panchayat, in terms of participation, early cancer detection, timely treatment, and good survival.

Conclusion

Acceptable screening methods and continuous community sensitization through awareness programs alleviated apprehensions and improved participation in the screening program. In a country, with an already overburdened health system, a collaborative approach with community engagement is desirable for cancer care. This successful model, in terms of high participation, follow-up, and treatment rate, resulting from community coalition and awareness activities scaled up before the initiation of screening, is now popularized as "The Kannapuram Model," after the name of the GP. Along with the benefits of community mobilization, the model also addressed the emotional, physical, and financial sequelae of the screen positives and ensured their follow-up. Despite all efforts, failure to report was still there, which calls for further research.

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Conflicts of interest

There are no conflicts of interest.

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