Original Article

Community engaged breast cancer screening program in Kannur District, Kerala, India: A ray of hope for early diagnosis and treatment

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Abstract

INTRODUCTION: Community based programs can assist in early detection and improved survival of breast cancer.

AIMS: To assess the feasibility and explore challenges of a district-wide door-to-door breast cancer screening program "ASWAS" conducted in Kannur district, Kerala, India from 2011 to 2014.

METHODS: Aggregate data from survey records were collected in terms of the population screened, referred, diagnosed, and treated. Case records of breast cancer patients who were identified were reviewed and updated. In-depth interviews were conducted with program stakeholders. The contents of the interview were organized into a strength, weakness, opportunity and threat (SWOT) matrix to describe the screening program.

RESULTS: A total of 1,049,410 eligible women above 30 years residing in 81 panchayats were visited door-to-door by 8,200 community volunteers; of them, 93% were screened using a symptom-risk factor checklist. Of those referred with symptoms (n = 5353), 81% attended the cancer camp. In total, 23 breast cancer cases were confirmed. 14 (61%) were in early stages, treated, and are disease free at 3-year follow-up. Those in the advanced stage and old age had poor outcomes. SWOT analysis identified political support, female volunteers, community engagement, dedicated fund for treatment, and teamwork as strengths. Weaknesses included poor healthcare access, maintaining volunteer motivation, and issues around sustainability.

CONCLUSION: Community participation with the engagement of the health system and local self-government are required for implementing a comprehensive cancer screening strategy. Breast-cancer screening program using local volunteers for early detection is feasible in low-income settings, thereby improving survival.

Key Words: Breast cancer screening, community-based screening Kerala, early diagnosis

Introduction

Globally, breast cancer incidence is rising since 1990s, more so in developing countries.[1] In 2013, it was the leading cause of cancer incidence in 161 countries, the most common cause of cancer mortality, and disability-adjusted life years in 2015.[2]

In India, it has replaced cervical cancer as the leading cause of mortality among women[3] with 144, 937 new cases in 2012.[4] This is likely to continue because of the changes in child bearing and dietary habits.[5] In India, majority seek treatment at advanced stages leading to poor survival rates.[6,7] Breast cancer projection for 2020 goes up to 1, 797, 900 posing a challenge to the Indian health system.[8]

Early detection remains an important strategy in low- and middle-income countries (LMICs) for improved survival and simple cost-effective treatment.[9,10] In India, a breast lump is often ignored due to lack of awareness.[11] Some seek treatment from traditional healers,[12] others have constraints such as poor access, expensive health care, gender-related social barriers, and stigma around symptoms.[11] Screening using trained volunteers was found useful in detecting more early-stage cancers than in the control groups.[12] In poor access regions, more cases can be detected in community-based camps.[9] Operational guidelines for prevention, screening, and control of breast cancer in comprehensive primary health care (PHC) have been formulated as part of the National Program for Prevention and Control of Cancer, Diabetes, CVD and Stroke (NPCDCS).[13] Although isolated screening programs are conducted, large scale implementation is yet to take place.[14]

A community-based comprehensive district-wide cancer screening program "ASWAS" was initiated in Kannur, Kerala, India jointly by the District Panchayat (DP), District Health Service (DHS) and a state government-owned Tertiary Cancer Centre (TCC) from 2011 to 2014. The present study was conducted to assess the feasibility and programmatic challenges of this program.

Methods

Study design

This was an explanatory mixed methods study with a concurrent QUAN-QUAL design: quantitative component involving retrospective analysis of existing records of "ASWAS" project and a qualitative component involving in-depth interviews (IDIs) with key stakeholders.

Study setting

Kerala is a state in South India with the highest human development index (0.79), literacy rate (93.9%), and life expectancy (77 years).[15] It is among the states with the lowest infant mortality rate and highest sex ratio.[15]

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Since 1996, there is a decentralized health planning and devolvement of finances to local self-governments (LSGs), which has empowered them to formulate and finance health strategies relevant to their local context. Kannur district, with an area of 2,961 sq.km and population of 2, 525, 003[15] has nine municipalities and one municipal corporation in the urban area; 11 block panchayats and 81 gram panchayats (GP) in the rural area.

The ASWAS project

The LSG at district level i.e., the "District Panchayat" funded this screening program in collaboration with the TCC and the DHS.

TCC is a 200 bedded cancer center with departments such as medical oncology, radiation oncology, surgical oncology, and preventive oncology. This is an autonomous center under the government of Kerala, equipped with all modern modalities of cancer diagnosis and treatment. Every year it caters to 70, 000 cancer patients. DHS is headed by the district medical officer and assisted by medical officers (MO), health workers in community health centers/ PHC/sub-centers.

An initial district level sensitization and planning workshop was convened involving the Presidents of GP and MO. This was followed by a training of trainers by TCC for all MOs and health supervisors under the DHS regarding the methodology of screening for oral, breast, and cervical cancers at the household level using volunteers. The current paper deals with aspects regarding screening for breast cancer.

At the GP level, 100 to 150 female volunteers were recruited to cover 15, 000 to 20, 000 households. They were trained in two to three sessions about breast cancer and its symptoms. They were also trained about using a symptom checklist for identifying suspected cases of breast cancer. The checklist for screening breast cancer included symptom details such as a lump in the breast or axilla, nipple discharge, retracted nipple, changes in skin, and questions regarding high-risk factors such as family history of breast cancer, unmarried status, and nulliparity.

The volunteers went door-to-door, interviewed women above 30 years, and recorded their symptoms in the checklist. If any of these symptoms were found to be present, the volunteers would refer them to a camp on a specified date for further check-up. If a house was locked, a repeat visit was made within a week. The eligible were given referral slip to attend a community camp organized by the GP and attended by MOs from the TCC [Figure 1].

In the camp, clinical breast examination, fine needle aspiration cytology (FNAC), and nipple discharge cytology were done. Those with suspicion of cancer and those requiring mammogram (family history of breast cancer/lump requiring further evaluation) were referred to TCC where confirmation of diagnosis, treatment, and follow-up were provided. The cost for screening, investigations, treatment, and follow-up were from the planned fund of the DP [Figure 1].

Study population

Quantitative component: Women >30 years in Kannur district eligible for screening under ASWAS project.

Qualitative component: Stakeholders of ASWAS project-District President, District health standing committee member, medical officer, health workers, and community level volunteers [Figure 2].

Data collection

Quantitative data

Aggregate data from project records were collected in terms of the total population screened, referred, diagnosed, and treated. Socio-demographic and clinical variables of the detected cancer cases, their treatment/follow-up status were extracted from case records at TCC. The variables include age, education, marital, socio-economic and childbearing status, family history of breast cancer, stage at diagnosis, modality of treatment, outcome, and current follow-up status.

Qualitative data

IDIs were conducted with the project stakeholders to identify the strengths and challenges of the program. Purposive sampling was employed to select the respondents. The following respondents were interviewed after obtaining written informed consent: DP (n = 1), health standing committee member (n = 1), ward member (n = 1), project officers from district panchayath (n = 2), medical officer (n = 2), health workers, which included health inspectors (n = 5), junior public health nurse (n = 2), and (ASHA) accredited social health activist (n = 2). Interviews were conducted for 10 to 15 min at a convenient time and place using a topic guide.

Data analysis

Quantitative

Aggregate data from the survey records, socio-demographic and clinical profile of the detected cases were summarized using proportions.

Qualitative

The primary investigator noted down the proceedings of the interviews, which were transcribed and translated. Descriptive content analysis of the transcripts was done by two investigators (NAP, SP), and sub-themes generated were organized into a matrix of strengths, weakness, opportunities, and threats (SWOT) analysis. Any discrepancy was resolved following discussion with the third investigator (JPT).

Ethical consideration

Ethics approval was obtained from Institutional Review Board, Ethics Committee of TCC, Thalassery, Kerala, and The Ethics Advisory Group of The International Union against Tuberculosis and Lung Disease (The Union), Paris, France. Informed consent was obtained from each stakeholder prior to the interview.

Results

Of the 1,049,410 eligible women in the district, 978,771 (93.3%) were screened. Among those screened, 5,353 (0.55%) were referred to camp, of whom 4,326 (80.8%) attended. All underwent clinical examination, and

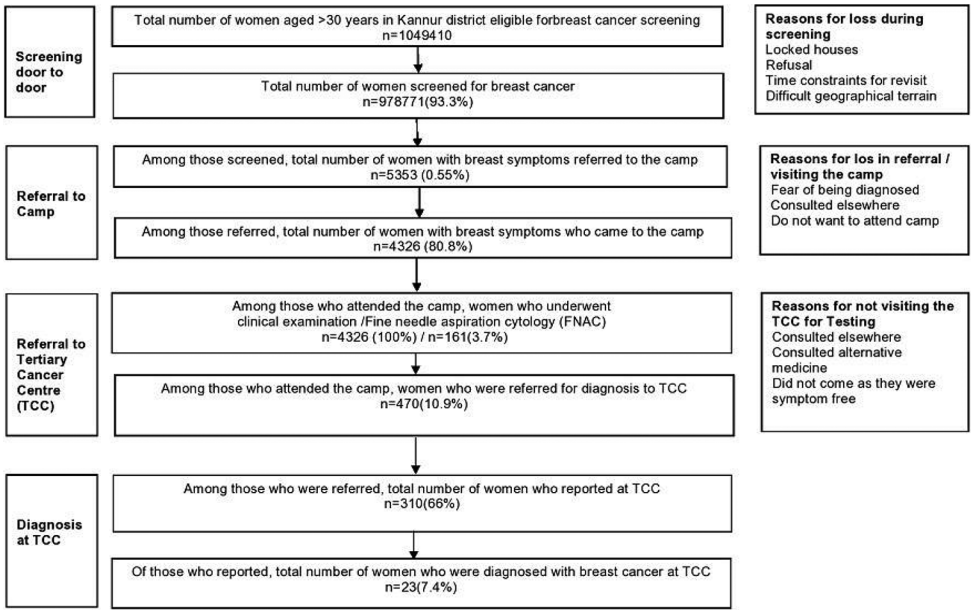

Figure 1: Flow of events and impact of breast cancer screening program "ASWAS" in Kannur district, Kerala state, India from 2011 to 2014

FNAC was done in 161 (3.7%). From them, 470 (10.9%) were referred to TCC, 310 (66%) reported. In total, 23 (7.4%) were diagnosed to have breast cancer. Among them, 13 (56%) belonged to the age group 45–64 years, 20 (87%) were married, and 21 (91%) presented with breast lump [Table 1]. The proportion of early stage cases (stages 1 and 2) was 61% (n = 14), and locally, advanced cases (stages 3 and 4) were 39% (n = 09).

Outcome of stage 4 cases was poor (out of three cases, two cases were referred for palliative care and one discontinued treatment after surgery). All six patients in stage 3 took treatment and are disease free on follow-up.

Of those detected in early stages (14), 10 cases were below 70 years and four were above 70 years. Of those below 70 years, all except one underwent treatment and are disease free on follow-up. All four early-stage cases above 70 years refused treatment and are lost to follow-up [Table 2].

Qualitative data explored the SWOT.

Strengths of the program

a. Political commitment and decentralized planning
   Effectively engaged political commitment was crucial in mobilizing the resources and support needed to coordinate and implement the program. The role of LSGs at district, block, and village level was instrumental in decentralized planning
b. Simple symptom-based questionnaire at the household level
   A simple questionnaire was developed for screening so that the volunteers could be trained and utilized for household screening
c. The presence of lady volunteers helped women disclose their health issues freely. The program was perceived as a women empowerment program with women as volunteers and beneficiaries
   "Women's health is of high priority to our Panchayat. I perceive this cancer screening project as an opportunity to empower women to take charge of their own health" (LSG representative)
d. Dedicated funds were earmarked for diagnosis, treatment, and follow-up of cancer patients at the TCC
e. The program was perceived as an awareness generation activity in the community and to remove associated stigma. *"When one gets cancer, one does not like others to know about it. The stigma related to cancer can be removed only by awareness creation through programs like ASWAS"* (LSG representative).

Weaknesses of the program

a. Poor access to cancer care services was a major barrier. The non-availability of decentralized mammography services caused overload of patients at the TCC
b. Patients detected at early stages were very reluctant to visit TCC
   "It was difficult to bring patients detected at early stages to TCC for treatment as most of them were healthy and had no or minimal symptoms when diagnosed" (TCC stakeholder)
c. Fear/apprehension about investigation results prevented women from attending camps
d. Volunteer motivation was another challenge as remuneration was minimal
e. Being a one-time activity, sustainability and integration into the routine health system is a major constraint.

Opportunities

a. The program led to increased awareness about cancer and screening because of its high visibility and community engagement
b. Several cases were detected at early stages, which otherwise would have been missed.

Threats

a. Non-beneficiaries also attended the camp for free check-up, which was difficult to manage
b. Volunteers demanded more remuneration, which was a challenge because of financial constraints
c. Fear/apprehension about results prevented people from attending camp

Table 1: Socio-demographic and clinical characteristics of breast cancer patients identified through breast cancer screening program "ASWAS "in Kannur district, Kerala state, India from year 2011 to 2014 (*n*=23)

Characteristics	*n*	%
Age group		
30-44 years	03	13
>44-64 years	13	56
>64 years	07	31
Educational status		
Illiterate	04	17
Up to primary education	10	44
Up to higher secondary	04	17
Graduate and above	03	13
Unknown	02	09
Socio-economic status		
Below Poverty Line	08	35
Above Poverty Line	05	22
Unknown	10	43
Marital status		
Married	20	87
Unmarried	03	13
Family history of breast cancer		
Yes	0	0
No	23	100
Reason for attending screening camp		
Lump in breast	21	91
Changes in skin/ulcer	02	09
Nipple discharge	02	09
Lump in axilla	01	04
Cancer stage at diagnosis		
Stage 0	01	04
Stage I	04	17
Stage II	09	39
Stage III	06	26
Stage IV	03	13
Current disease status		
Disease free	15	65
Recurrence	01	04
Not known	07	31

d. TCC was the only referral center, causing patient overload at the facility.

Discussion

The study demonstrated the feasibility of a community engaged model of a population-based cancer control program. The program yielded 23 confirmed breast cancer cases. Most of early-stage cases are disease free on follow-up. Those in late stages were either lost to follow-up or had recurrence. This emphasizes the urgency of early detection at a stage and age when amenable and acceptable to treatment. The program could capture more than 93% of the eligible women in the defined population, which speaks of success of the strategy in terms of its execution. The study also identified SWOT of the screening program, which will give guidance in the planning of routine cancer screening activities under the National program.

In LMIC settings where screening programs are virtually non-existent,[16] and socio-cultural barriers are high, majority of cases reach health system at advanced stages compared to their western counterparts.[11] In a study in India, in four hospitals, only 5% presented in stage 1.[7] As per Hospital Based Cancer Registry in TCC, only 4% presented in stage 1.[17] In this study, 22% (5/23) were detected at stage 1 or below; thus, strengthening the evidence that cancer screening strategy yields cases at early stages amenable to effective treatment and better survival.

The age cut-off for screening women for breast cancer needs further deliberations. In this study, screening for breast cancer was done from 30 years onwards, although there is little evidence as per the national guidelines to support breast screening from such an early age, unless there is a known family history of BRCA mutations. This is likely to unnecessarily burden the public health system because of over diagnosis and treatment. However, this screening program by the LSG (DP) was not only meant to identify cases of breast cancer but also utilize this opportunity to spread awareness on breast cancer in the community, promote women empowerment for health care, and remove stigma associated with breast cancer and its symptoms. This was stated by the project stakeholders during the interviews. Therefore, the age cut-off was lowered to 30 years.

The involvement of trained community female volunteers facilitated screening, attendance at camps, and helped in overcoming resistance to seek medical help for breast symptoms. The program was perceived as "a women empowerment program" by the DP whose planned fund was utilized for women's welfare.[18]

The household level screening of women was from breast symptoms and high-risk history alone. This approach was simple; large number of volunteers (approximately 9000) from heterogeneous background could be trained using a cascade training approach. Acceptability was more in the context, where females were busy with household chores and hesitant to examination by a volunteer. However, volunteers have been trained in clinical breast examination for other similar community-based programs.[12] But, this requires prolonged training and motivation.[19]

The main strengths of the program were political commitment, decentralized planning, and strategy of door-to-door screening through female volunteers. The study depicts an innovative model explaining the process of engaging the community and the LSG for the implementation of a cancer screening program [Figure 2]. There was no external financial support needed as the program was funded by DP.

In our study, a large number of volunteers were mobilized from every Panchayat for carrying out screening. Experience from Sudan also demonstrated the role of volunteers in the success of the program.[12] Programs with intensive field activities will need the continued involvement and commitment of volunteers. Although higher incentives might boost the morale of the workers and draw more support, participation in such activities also improves their goodwill in society.

Table 2: Profile of patients detected from breast cancer screening program "ASWAS "in Kannur district, Kerala state, India from year 2011 to 2014

Stage and patient	Number of cases	Age	Date of diagnosis	Treatment	Disease status	Present status as on October 2016
Stage 0	1					
1		34	25/06/2013	Surgery	Disease free	On follow up
Stage 1A	3					
1		68	21/01/2014	Surgery	Disease free	On follow up
2		40	06/01/2014	Surgery+Tamoxifen	Disease free	On follow up
3		45	04/03/2014	Surgery+CT*+RT** +Tamoxifen	Disease free	On follow up
Stage 1B	1					
1				Surgery+CT+RT	Disease free	On follow up
Stage 2A	3					
1		85	10/03/2014	Surgery	Not known	Not known
2		71	14/03/2014	nil	Not known	Not known
3		62	24/02/2014	Surgery+CT+RT+Tamoxifen	Disease free	On follow up
Stage 2B	6					
1		58	07/02/2014	Surgery+CT+RT	Disease free	On follow up
2		46	02/12/2013	Surgery+CT+RT	Disease free	On follow up
3		83	21/03/2014	nil	Not known	Not known
4		54	25/11/2013	Surgery+CT+RT	Disease free	On follow up
5		62	23/12/2013	nil	Not known	Not known
6		90	27/11/2013	nil	Not known	Not known
Stage 3A	5					
1		51	24/12/2013	Surgery+CT+RT	Disease free	On follow up
2		68	23/12/2013	Surgery+CT+RT	Disease free	On follow up
3		63	10/12/2013	Surgery+CT+RT	Disease free	On follow up
4		63	26/12/2013	Surgery+CT+RT+letrozole	Disease free	On follow up
5		45	06/12/2013	Surgery+CT+RT+Tamoxifen	Disease free	On follow up
Stage 3B	1					
1		61	25/11/2013	Surgery+CT+RT	Disease free	On follow up
Stage 4	3					
1		74	18/12/2013	Surgery	Not known	Not known
2		60	15/03/2013	Palliative treatment	Not known	Not known
3		43	30/11/2013	Surgery+CT+RT	Recurrence	Referred for supportive care

*CT - Chemotherapy; **RT - Radiotherapy

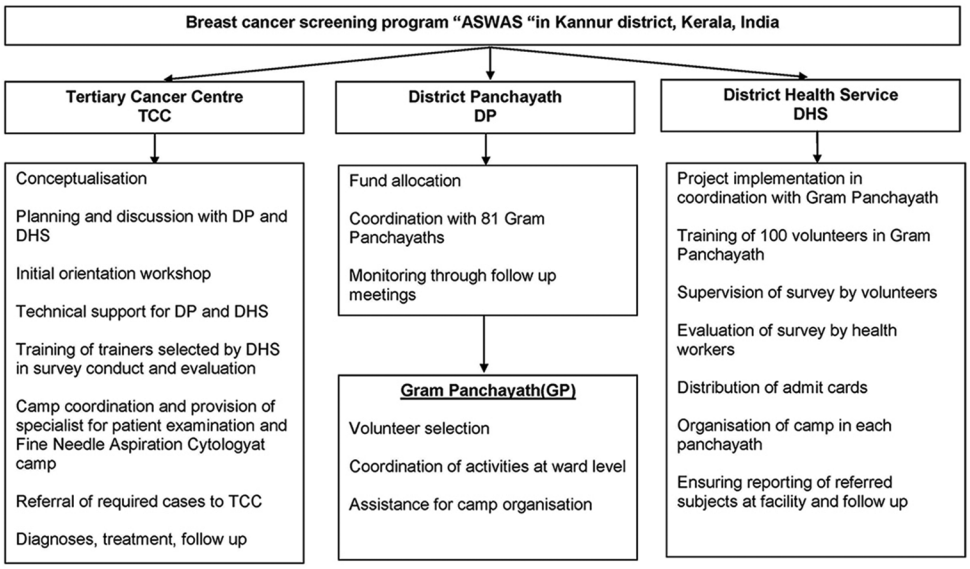

Figure 2: Implementation strategy of the breast cancer screening program "ASWAS" in Kannur district, Kerala state, India from 2011 to 2014

Approximately, 20% did not turn up for the camps because of fear or inhibition. This points to need for counseling and assurance from the volunteers who need be trained on these issues. The current strategy was difficult to implement in tribal areas where access to camps was difficult. One-third (33%) referred for investigation to TCC also did not attend because of distance/fear of diagnosis or because they did not consider their symptoms significant enough

to visit a cancer center. The associated "stigma of cancer" mentioned by a stakeholder may also be a barrier for early detection. The use of this one time mass screening program is limited, if facilities for follow-up are not decentralized for women self-reporting with breast lumps. Hence, widespread awareness creation should be complimented along with strengthening of the system for follow-up, diagnosis, and treatment. The incorporation of cancer screening in the NPCDCS in India is expected to ensure early detection and a continuum of care for those screened for breast cancer at the primary care level.[13]

Conclusion

The implementation of a breast-cancer screening program using local volunteers is feasible in low-income settings. It leads to the detection of cancer at early stages thereby improving survival and productive years of life. However, the effectiveness of this screening program could not be studied due to the lack of a comparison arm.

After this one time activity, sustainability is a key concern. This can be tackled by clearly defining roles of each stakeholder and efficient planning of resources. LSG has to ensure continuous financial assistance for screening and treatment support to diagnosed women. DHS could utilize the trained community volunteers to screen breast cancer routinely at PHCs to aid early diagnosis. State health service may implement decentralized mammography services at designated facility in every district to minimize the patient's overload at TCC. Thus, a comprehensive package of health awareness, local screening strategy, and decentralized diagnostic and treatment facilities with political commitment will increase awareness and self-reporting lending greater impact to breast cancer screening programs. Other states may embrace this screening strategy engaging women community volunteers with the support of LSG. However, more studies are required to establish the effectiveness of the screening program.

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Nil.

Conflicts of interest

There are no conflicts of interest.

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