RESEARCH ARTICLE

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Designing and Implementing a Cancer Screening Program for Underserved Tribal Women in Jharkhand

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Abstract

Background: The status of cancer screening in India is concerning, especially in tribal states like Jharkhand, where the percentage of women who have ever undergone screening for cervical, breast, and oral cancer is 0.5, 0.1, and 0.2 percent, respectively. Adopting the community-led approach, Karkinos Healthcare, a purpose driven oncology platform, conducted a cancer screening program in collaboration with a livelihood-focused NGO in selected districts of Jharkhand. This study aims to describe the program's implementation and assess the program's performance vis a vis provision of care continuum from screening to treatment. **Methods:** The program was designed to provide comprehensive services including cancer awareness, enrolment for specialized cancer insurance for one year to cover the cost of treatment, risk assessment, screening for oral, breast, and cervical cancers, diagnostics to screen positive cases, and treatment to the confirmed cancer cases. **Results:** A total of 16875 women underwent risk assessments, all of whom were invited for screening at community clinics. A total of 5993 women (34.9%) reported at community clinics and 5873 (34.9%), 5843 (34.7%), and 5029 (29.9%) underwent screening for oral, breast, and cervical cancer. 70% of the total HPV-positive cases had high-risk types other than HPV 16 and 18. 22.4% of the total screened women were navigated for advanced diagnostics and treatment among which 6 confirmed cases of cancer were reported. **Conclusion:** While the program design tried to address the implementation challenges like fragmented care, accessibility, and affordability of cancer care services, conversion from screening to treatment was limited.

Keywords: Oral Cancer- Breast Cancer- Cervical Cancer-Tribes

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Introduction

Cancer has become the second and fourth leading cause of death in urban and rural India, respectively, and the estimated 1.15 million new cases in 2018 are predicted to double by 2040 owing to demographic transition [1]. The leading cancers in the country include breast (13.5%), lip and oral cavity (10.3%), cervix uteri (9.4%), lung (5.5%), and colorectum (4.9%) [2].

The cancer screening coverage in India is abysmally low [3]. The percentage of women who have ever undergone screening for cervical, breast, and oral cancer in relatively better-performing states like Tamil Nadu is 9.8, 5.6, and 1.2 percent, respectively as opposed to only 0.5, 0.1, and 0.2 percent in Jharkhand which is predominantly tribal [4]. The crude annual incidence rate of all cancers in Jharkhand increased from 58 per 100,000 in 1990 to 64.3 per 100,000 in 2016[5].

The poor rate of screening in these tribal regions can be attributed to various barriers such as low socioeconomic status, poor social support like lack of health insurance, and cultural beliefs [6], and discouragement from the family members; psychological barriers such as embarrassment and perceived lack of need; and other barriers such as poor availability and accessibility of healthcare facilities [7].

Community-based approaches that involve local community leaders and volunteers have proved to ensure trust and improve the acceptability of screening programs [8]. Prior studies show that women's groups can play a significant role in improving women's knowledge and attitude towards cancer screening and improving their participation in screening programs [9, 10]. 92.8% and 99.8% of the participation rates in cancer screening were achieved in Mysore [9] and Uttar Pradesh [10] respectively

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through a community-based model [9, 10]. Over 5 years, 40,000 women for human papillomavirus (HPV) positivity were screened in Kolkata, successfully demonstrating the role of community health workers in recalling screened-positive women for further diagnosis and treatment [11]. Another door-to-door breast cancer screening program in Kerala identified political support, female volunteers, community engagement, cancer-specific insurance, and teamwork as keys to success [12].

However, barriers such as fear of screening procedures, lack of awareness, and cultural beliefs persist [13]. Successful programs often involve community organizations, but scalability and long-term impact remains a challenge [14]. To improve uptake, there is a need to focus on increasing awareness [13]. Additionally, training and motivating community volunteers can significantly enhance screening coverage and empower them with new skills [15].

Karkinos Healthcare (KH) designed a screening initiative in Jharkhand using a community-led approach in collaboration with a local non-governmental organization (NGO) that has a well-established network of women-led self-help groups, primarily operating as farmer-producer companies (FPCs). Leveraging their existing menstrual health management awareness programs within the community, the collaboration aimed to enhance outreach for cancer screening among the tribal areas. The screening program tailored a comprehensive spectrum of services, encompassing cancer awareness, enrolment in one-year cancer-specific insurance to cover treatment costs, risk assessment, and screenings for oral, breast, and cervical cancers. Additionally, women who screened positive were navigated for advanced diagnostics and treatment. Efforts were made to ensure the accessibility of as many services near the community as possible without compromising quality.

This study aims to study the implementation of a cancer screening program and to assess the program's performance in providing the care continuum from screening to treatment.

Materials and Methods

Project Site

According to census 2011, Jharkhand has a population of 32 million of which about 16 million are female [16]. 28.81% live below the multidimensional poverty index (MPI). Approximately 26.2% of the population belongs to the Indigenous communities of Scheduled Tribes [17].

The program purposively recruited participants from seven blocks across six districts mentioned in Figure 1. All participants enrolled for screening were women who were either enrolled with the FPC or part of the community to which the FPC had access. This was done to have repeated access to the participants at various stages of follow-up.

Although the mandated age group of the participants was between 30 to 65 years [18], later a small section of women (4.8%) less than 30 years were included due to high cases of early-age marriages and initiation of sexual activity at an early stage.

Oral, breast, and cervical screenings were conducted over 18 months between April 2022 to September 2023 in 126 cancer screening camps. 10 treatment clinics were organized for those who screened positive.

Training of health workers

The medical team comprised 4 nurses, 3 dentists, and 1 gynae-oncologist who received a week-long theoretical and practical training for screening of oral, cervical, and breast cancer by a team of oncologists in Kochi, Kerala. Hands-on training for HPV testing was provided in community camps. International Agency for Research on Cancer (IARC) and World Health Organization (WHO) guidelines were followed for oral, breast, and cervical screening.

Training of outreach volunteers

The FPC ran a menstrual hygiene management (MHM) program for its members and maintained a cadre of community volunteers called health coordinators to run awareness activities. The cancer screening program recruited this cadre and trained them to create cancer awareness. Village volunteers were further trained by these health coordinators and were responsible for conducting awareness, and risk assessments through mobile application and mobilization in the community. The health coordinator also assumed a central responsibility in coordinating care navigation and counselling the participants at various stages of treatment. The involvement of FPC resources and personnel not only ensured the effective implementation of the program but also played a vital role in cultivating trust within the community, thereby eliciting positive responses to the program's various initiatives. Figure 2 describes the FPC structure involved in implementation.

A cancer care module covering risk factors for non-communicable diseases (NCDs), signs, and symptoms of common cancers in females was developed. The awareness sessions were conducted at the village level in small batches of 10 to 20 members.

Screening facilities

Screening clinics were organized at government schools, panchayat bhavans, and primary health centres. Treatment clinics were conducted at community health centres, sub-divisional hospitals, and private hospitals. Most sites did not have lighting and the clinical team brought with them battery-operated headlamps for patient examination. Privacy was ensured by covering all doors and windows in non-clinical spaces

Interview and examination

Village volunteers conducted risk assessments on a customized health technology application called Kare Mitra, which ran an artificial intelligence-based questionnaire. The risk category was based on individuals having a positive history of cancer or family history of cancer or any risk factor exposure - tobacco (smoking or smokeless), areca nut, alcohol, or any positive symptoms for specific disease type were categorized as above average risk. Participants irrespective of their risk score underwent screening.

Oral visual examination (OVE), clinical breast

examination (CBE), and assisted human papillomavirus deoxyribonucleic acid (HPV DNA) screening for cervical cancer were done with the help of trained doctors and nurses. The collected cervical cell samples were sent to the Advanced Centre for Cancer Diagnostics and Research (ACCDR) in Kochi and Mumbai.

Screening algorithm, lab investigation, and follow-up

A team of physical and digital support systems called the Command Centre provided information for accessing the diagnostic services and coordinated navigation support between participants, the field, and the medical team. While village volunteers mobilized the participants, the health coordinators with the support of the medical team, played an important role in counselling the participants. Consultation, treatment guidance, and virtual tumour boards were conducted by the specialist team of KH through online consultations. The diagnosis and treatment were carried out at the local partner cancer hospitals. Figure 3 depicts the various steps involved in the program.

A team of 4 nurses, 3 dentists, and 1 gynae-oncologist also conducted preventive treatment clinics for HPV and OVE positives in collaboration with local private and public hospitals with adequate health infrastructure. Colposcopy, cervical biopsies, thermal ablation, and Loop Electrosurgical Excision Procedure (LEEP) were provided for HPV-positive cases as per the lesion characteristics whereas oral punch biopsies were conducted for OVE-positive cases. The collected tissue samples were sent to the ACCDR in Kochi and Mumbai.

Figure 4 depicts the cancer care pathway including screening, diagnostics, and treatment procedures.

Data collection and analysis

A quantitative approach was adopted to evaluate the program's performance. We gathered quantitative data on risk assessments, screening, diagnosis, and treatment from existing data available on an online platform, KH website application. Data analysis was done on SPSS.

Informed consent was obtained from all participants at various stages of the program. During the initial risk assessment stage, participants were briefed on the questionnaire and the importance of the risk score. Informed consent was then obtained before conducting the interview. At the screening stage, participants were informed about the procedures involved in breast, cervical, and oral cancer screenings, and written consent was secured before any examinations were performed. Similarly, written informed consent was obtained before conducting any diagnostic procedures, such as colposcopy, biopsy of suspected lesions, or preventive treatment for HPV-positive patients with cervical dysplasia. These procedures were thoroughly explained to the patients to ensure they fully understood before providing their consent.

Results

Table 1 demonstrates the demographic characteristics of the participants. 57.5% of the participants belonged to the 30-44 age group. 869 (5.1 %) women were smokeless tobacco users. 886 (5.2%) had a history of diabetes, 1262 (7.5%) had a history of hypertension and 53 (0.3%) had a history of cancer.

Table 2 shows the overall participation of women in screening and early detection programs. 16875 women attended awareness sessions and underwent risk assessments among which 14.9, 23.5, and 6.1 percent reported above-average risk for oral, breast, and cervical cancer respectively. Overall 6476 (38.8%) women were above average risk. Irrespective of the risk scores, all of these women were invited for screening at community clinics. A total of 126 community clinics were attended by 5883(34.9%) women and 5873 (34.9%), 5843(34.7%), and 5029 (29.9%) underwent screening for oral, breast, and

Table 1. Demographic Characteristics of the Participants (N = 16,875)

Demographic Variable	Number	Percentage
Age group		
15-29	805	4.8
30-44	9,707	57.5
45-59	5,430	32.2
60 and above	933	5.5
Habits		
H/o breastfeeding	13,559	80.3
Smoking tobacco	351	2.1
Smokeless tobacco	859	5.1
Dual users (both smoking and smokeless)	264	1.6
Insurance cover	6,888	40.8
Disease characteristic		
H/o diabetes	886	5.2
H/o Hypertension	1262	7.5
H/o of cancer	53	0.3

Table 2. Summary of Risk Assessment and Cancer Screening Participation

S.No	Parameters	Frequency	Percentage
1	Oral cancer risk		
	Above average risk	2,513	14.9
	Average risk	14,021	83.1
2	Breast cancer risk		
	Above average risk	3,952	23.5
	Average risk	12,574	74.6
4	Cervical cancer risk		
	Above average risk	1,034	6.1
	Average risk	15,536	92
5	Overall risk		
	Above average risk	6,476	38.8
	Average risk	9,983	59.1
6	Reported for screening	5,883	34.9
7	Oral Cancer Screening	5,873	34.9
8	Breast Cancer Screening	5,843	34.7
9	Cervical Cancer Screening	5,029	29.9

Figure 1. Cancer Screening Intervention Districts in Jharkhand

cervical cancer respectively. Table 3 presents the screening outcomes. Out of the screened individuals, 1207 (20.5%) individuals were screened positive for one of the common cancers. 70% of the total HPV-positive cases (n=484) had high-risk types other than HPV 16 and 18.

Table 4 presents the results of the care continuum through patient navigation and treatment. 271 (22.4%) individuals who screened positive were navigated for advanced diagnosis and treatment. 14.6% of the OVE positive, 41.1% of CBE positive, and 28.3% of HPV positive were navigated. 6 confirmed cancer cases were identified, including two breast cancers, three cervical cancers, and one endometrial cancer.

Discussion

A key aspect of the program was the integration of cancer care and menstrual health management, addressing two stigmatized topics within the tribal community. The active involvement of local community volunteers ensured trust building and encouraged participation among tribal women. Another important aspect was the program's comprehensiveness in design as it encompassed promotion for prevention as well as treatment of cancer following the basic principles of financial protection, health care access, and affordability for the most marginalized communities.

While program design tried to address the challenges

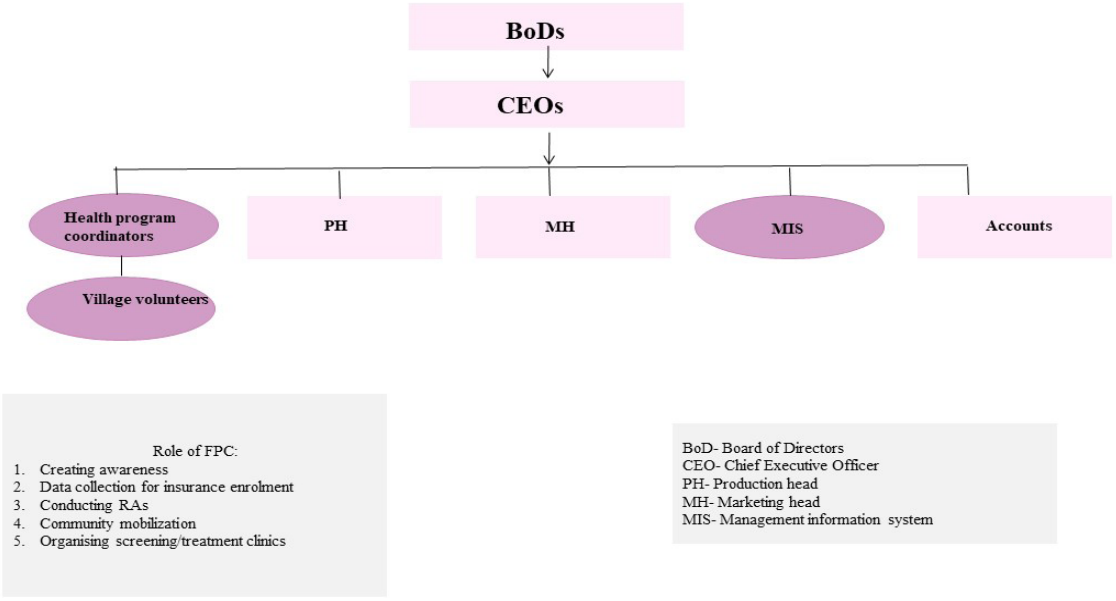

Figure 2. Organizational Structure of the Farmer Producer Companies (FPCs) and Their Roles in the Implementation of the Cancer Screening Program

Table 3. Summary of Cancer Screening Outcomes (N=5,883)

Sn.No.	Screened Positive	Frequency	Percentage
1	Oral Visual Examination (OVE) +	616	10.5
2	Clinical Breast Examination (CBE) +	107	1.9
3	Human Papilloma Virus (HPV) +	484	9.7
3a.*	HPV 16	144	29.7
3b.*	HPV 18	58	11.9
3c.*	Other high-risk HPV	339	70

*3a-c, percentages of HPV types (16, 18 and other high risk HPV) were calculated with total HPV positive (484) as the denominator. The number for types of HPV doesn't add up to 484 as there were many co-infections reported.

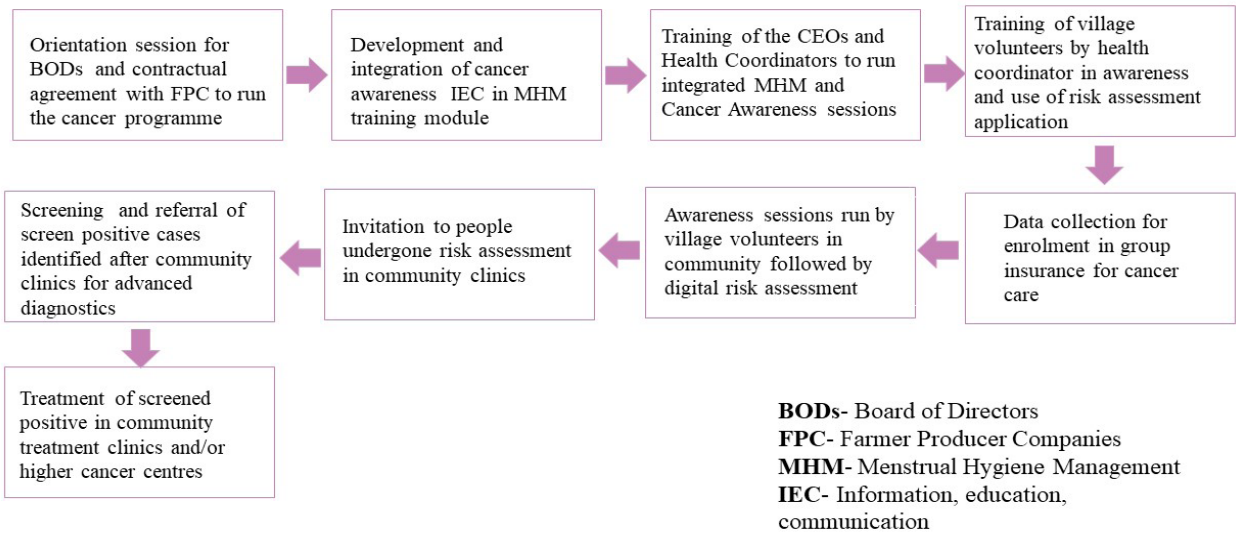

Figure 3. Implementation Process of the Cancer Screening Program

of implementation like fragmented care, accessibility, and affordability of cancer care services, limited conversion from screening to treatment was seen due to structural issues of the healthcare system. Among 16875 women who participated in awareness sessions, and underwent risk assessments, the total footfall for the screening program was 34.9%. Similarly, in Uttar Pradesh where a cancer screening program was organized, the overall acceptance rate of cervical cancer screening was 32%. This could be attributed to various barriers such as low community awareness, language barriers, lack of knowledge about symptoms or disease, and fear that the cervical screening would be painful and result-related anxiety and embarrassment [3].

4.8% (805) of the total screened belonged to the age group of 15-29 years. Over 44% of Indian women aged 20-24 years are reportedly married under the age of 18 [19]. There is a need to lower the age of eligibility for cervical and breast cancer screening in India due to the prevalence of early marriages and pregnancies [20].

Risk assessment is a crucial component of cancer screening [21]. Comprehensive risk assessment can help identify high-risk individuals who may benefit from more intensive screening protocols than those recommended for average-risk populations [22]. However, in our program, we screened individuals regardless of their risk scores,

Table 4. Summary of Screened Positive Women Navigated for Advanced Diagnostics and Treatment (Care Continuum)

Sr.No.	Care Continuum Pathway	OVE (total screened positive =616)	CBE (total screened positive =107)	HPV (total screened positive =484)
1	Screened-positive women navigated for advanced diagnostics and treatment	90 (14.6)	44 (41.1)	137 (28.3)
1a.	Navigated to tertiary centres	67 (74)#	44 (100)#	59 (43)#
1b.	Community diagnostic/ treatment clinics*	23 (26)#	-	78 (57)#
2	Confirmed cancer cases	0 (0)	2 (1.9)	4 (0.8)

The table shows the summary of the screened-positive women who were navigated for advanced diagnostics and treatment to higher centres (1a) and community diagnostic/treatment clinics (1b), and the confirmed cancer cases. # Out of the screened positive women who were navigated for advanced diagnostics and treatment, 26% of the OVE+ and 57% of the HPV+ were navigated to community diagnostic/treatment clinics *Thermal ablation and LEEP procedures were performed

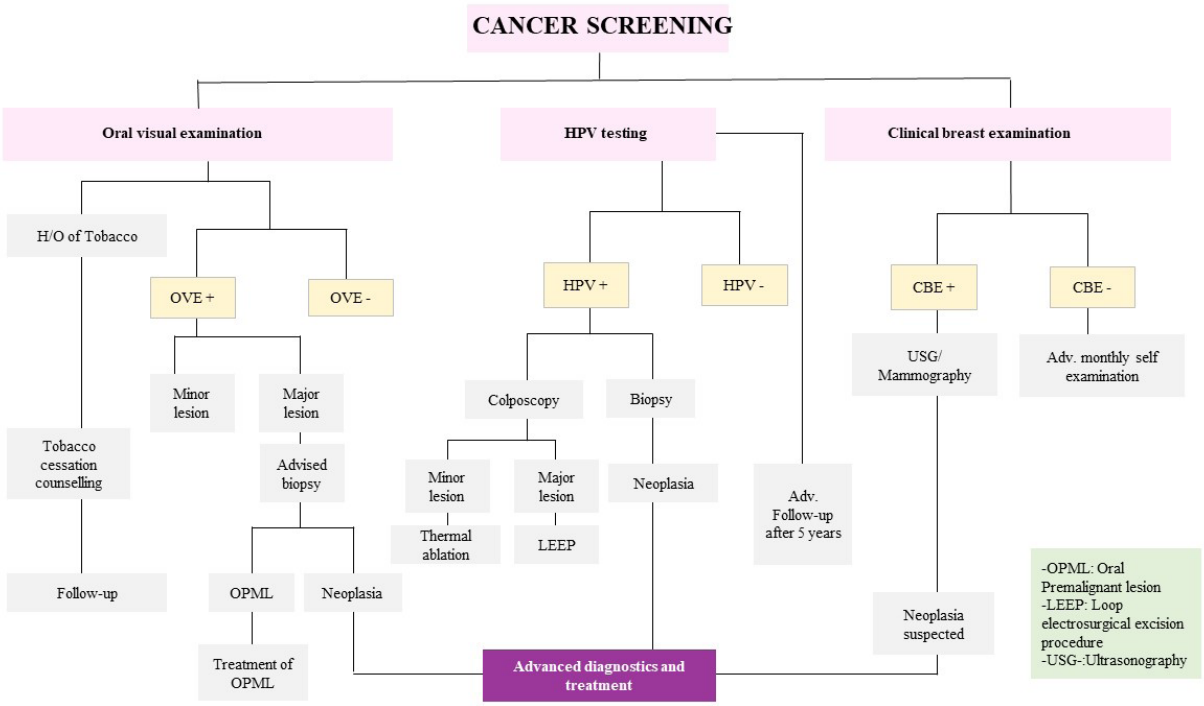

Figure 4. Cancer Care Continuum Pathway: Diagnostic and Treatment Protocol for screened positive cases

recognizing that the risk assessments conducted by local volunteers offered limited advantages due to their inadequate medical training and understanding. Involving trained healthcare professionals, such as nurses and doctors, would enhance the accuracy and effectiveness of risk-based screening. Even so, this approach may face practical challenges, including time constraints and the availability of medical personnel, which could limit its feasibility for large-scale population screenings [21, 23].

The prevalence of oral pre-malignant lesions (OPMLs) among the total population screened (N=5873) was 10.5%. OPMLs are highly prevalent in India, with studies reporting rates ranging from 3.73% to 39.8% [24, 25]. A high incidence of prevalence of OPMLs has been witnessed in Uttar Pradesh, Bihar, and Jharkhand [26].

The prevalence of HPV infection among the total women screened (N=5029) was 9.7%. In a study conducted among 2034 tribal girls in the states of Madhya Pradesh, Jharkhand, and Chattisgarh the overall prevalence of HPV infection was 12.9% [27]. Risk factors such as early age of sexual debut (<15 years), early age pregnancies, increased number of sexual partners, unprotected sex, smoking, and chewing tobacco have been recognized [28]. 70% of the total HPV-positive cases had high-risk types other than HPV 16 and 18 as opposed to a study conducted in central India where HPV 16 was most prevalent [29]. Further studies that focus on identifying high-risk HPV types in the Indian context could significantly improve treatment outcomes and inform more targeted vaccination strategies.

22.4% of total screened positive cases (OVE, CBE, and HPV) were navigated for diagnostics and treatment to higher centres or field clinics. The healthcare team faced numerous challenges such as unwillingness due to lack of health literacy, lack of support from family, fear of loss of day's wages, and fear of diagnostic procedures while navigating screened-positive patients for further treatments. The lack of infrastructure in tertiary hospitals in the state of Jharkhand exacerbated the situation. Hospitals also prescribed extra tests that added to the expenditure and made it difficult to get insurance claims. Similarly, a cancer screening program launched in Uttar Pradesh observed poor follow-up compliance, about 30.1%, owing to lack of time, mode of transport, and illiteracy [10]. High compliance rate to further diagnosis and treatment in cancer screening programs of over 70% in Kolkata [11] and over 60% in Kerala [12] was achieved owing to their long-term impact, involvement of community health workers, primary involvement of a public-funded tertiary cancer centre and involvement of local self-governments [11, 12]. To address such structural barriers community treatment clinics were organized where oral biopsies were performed for individuals with OPMLs and a screen and treat initiative was adopted for HPV-positive women.

The program was designed for rural tribal women and hence generalization of data has to be seen in a specific context. The method of implementation was through the farmer producer companies which had established networks and hence replicating it in other regions would need to consider the local scenario. Challenges were faced in the form of refusals for cervical screening as there was a lot of fear and stigma in the community. It was observed that older women were less receptive to cervical screening, frequently citing reasons such as perceived irrelevance after menopause and the cessation of sexual activity for advanced diagnosis and treatment. Challenges were also faced when there was a need for navigation of the screened positive individuals. A lot of resistance was observed from the husbands of the screened positive women highlighting a need for couple

counselling. Rigorous training for community volunteers was provided throughout the program. Family and patient counselling was given at each step. Incentives in the form of food, clean drinking water, and transport were provided to the screening participants as well as screened-positive individuals throughout their care continuum journey. Another limitation was that the program was only funded for one year which interfered with insurance and any treatment beyond this period required funds mobilization from different sources. This decelerated the progress that was made with the community in terms of trust building, awareness, participation, and compliance to further diagnosis and treatment.

To improve future programs, extending their duration can foster deeper community engagement and enhance outcomes. Comprehensive awareness campaigns and health navigators are essential to address participation barriers. Strengthening tertiary care infrastructure and collaborating with local organizations will further support program success, while participant feedback ensures continuous improvement. Inclusivity of all genders is crucial for raising awareness, alongside empowering women to make informed health decisions. Research should focus on identifying barriers and risk factors in tribal populations to develop improved screening models, ultimately improving the efficiency and effectiveness of cancer care programs.

Author Contribution Statement

Rewati Raman Rahul (RRR), Somika Meet (SM), Hemlata M Tiwari (HT), Kunal Oswal (KO), Neetu Sinha (NS), Amol Gaikwad (AG), Yogesh Jain (YJ), Umesh Rana (UR), R Venkataramanan (RV), R Sankaranarayanan (RS). Conception and design: RRR, SM, KO, AG, RV. Administrative support: UR, RV. Collection and assembly of data: NS, UR, SM. Data analysis and interpretation: RRR, SM, KO. Technical inputs and manuscript review: YJ, RS. Proofreading: YJ, RS, RV. Manuscript writing: All authors. Final approval of manuscript: All authors. Accountable for all aspects of the work: RRR, SM, KO.

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Ethical Declaration

Dr D Y Patil Ethics Committee (Pune) approved the study. Informed consent was obtained from all participants in the study.

Availability of data

Data is available on reasonable request from the corresponding author.

Conflict of Interest

The authors declare no conflict of interest.

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