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Implementation research on registering cancer cases in primary health centres of Puducherry through community health workers

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***Background & objectives*: Hospital-based cancer registry does not represent the true burden of cancer in the community. Initiating a Primary Health Centre (PHC)-based cancer registry may better estimate population-level data for cancer cases in an area. This study aimed to set up a system for facilitating a PHC-based cancer registry and to assess the registration status of cancer cases in various PHCs of Puducherry. The facilitating and limiting factors while setting up this registry were also assessed.**

***Methods*: A quasi-experimental study with an embedded mixed-method design was conducted in 31 PHCs/Community Health Centres (CHCs) from March 2021 to November 2022. The interventions were implemented in all PHCs/CHCs of Puducherry with the involvement of the State Non-Communicable Diseases (NCD) cell. The line list of cancer cases from the Jawaharlal Institute of Postgraduate Medical Education & Research (JIPMER) Hospital-based cancer registry was shared with all PHCs/CHCs. Sensitization sessions for all Community Health Workers (CHWs) were conducted, and feedback on cancer registration status was given to the State NCD cell. Focus group discussion (FGD)/Key informant interview (KII) was undertaken to understand strengths, challenges, and suggestions. The logic model was used to understand the various indicators while setting up this PHC-based cancer registry.**

***Results*: Over a one-year intervention period, 1270 cancer cases were registered at Puducherry's PHCs/CHCs, 1203 (88%) from the shared list and 67(5%) from other facilities. However, only 53 per cent of the expected living cases were captured in the various PHCs. Major limitations for registration were the COVID-19 pandemic, stigma, inadequate manpower, infrastructure issues, and privacy concerns during screening.**

***Interpretation & conclusions*: It was feasible to set up a PHC-based cancer registry in all PHCs of Puducherry. However, registration of cancer cases was suboptimal, as population-based screening of cancer cases, as recommended in the National Programme for Prevention & Control of Non-Communicable Diseases (NP-NCD) programme, was weak due to the COVID-19 pandemic. Once this is strengthened, the PHC-based cancer registry will better represent the population.**

Key words Cancer - community health workers - implementation research - PHC-based cancer registry - population-based registry - PHC-primary health centres

Cancer is one of the leading causes of morbidity and mortality globally. According to the Global Cancer Observatory (GLOBOCAN) estimates, ~ 19.3 million incident cases of cancer and 10 million cancer-related

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deaths were reported worldwide in 2020[1]. In India, cancer has emerged as a major public health concern. Cancer is one of the leading causes of death in India, accounting for 5.7 per cent of all deaths[2]. In 2020, over 1.3 million new cancer cases were diagnosed, and 0.85 million people died of cancer in India[3].

Cancer registries are vital in the formulation of cancer control programmes and monitoring their effectiveness[4]. The National Cancer Registry Programme (NCRP) was established in 1981 in India to generate data on the magnitude and patterns of cancer through cancer registries[3]. Under NCRP, 36 population-based cancer registries (PBCRs) and 236 hospital-based cancer registries (HBCRs) are functional in India[5]. HBCR is useful in improving the quality of care for cancer patients within hospital settings. However, this will not give the true burden of cancer cases in a community[6]. PBCR captures cancer cases from a defined population. It estimates cancer incidence, its trend, mortality, and cancer burden in the community[7]. In India, the PBCR is unevenly distributed across the country, and only 10 per cent of the Indian population falls under the purview of PBCRs[8]. It is not easy to set up PBCR, as cancer is not declared a notifiable disease in India, and the tracking of cancer cases from various hospitals and laboratories is weak[9,10].

Primary Health Centres (PHCs) can be vital in registering cancer cases from their service area. Presently, PHCs in India do not have records of cancer cases from their service area[8,11]. Creating a PHC-wise cancer registry may act as a surrogate for population-based cancer registries and can give better estimates of an area's cancer burden. Maintaining the registries or database of cancer cases at the PHC level can also help strengthen palliative care and other services.

As per the National Programme for Prevention and Control of Non-Communicable Diseases (NP-NCD) programme, it is recommended to screen the population for common cancers using Community Based Assessment Checklist (CBAC) forms by Community Health Workers (CHWs) during house-to-house visits and refer the suspected cases to higher healthcare facilities for confirmation and management[12,13]. During this population-based screening it is possible to identify already diagnosed cancer and register them in PHC-based cancer registries. Other services like palliative care can also be further strengthened in the process. In this context, this study was undertaken to set up a cancer registry, each in all the PHCs of Puducherry. Furthermore, the status of cancer cases registration in the PHCs following the setting up of the mechanism to register these cases in PHCs was also assessed. The strengths and limitations of setting this mechanism have also been assessed.

Material & Methods

This was an implementational research (quasi-experimental study with an embedded mixed method design) conducted in various PHCs in Puducherry, South India, from March 2021 to November 2022 after obtaining appropriate approvals from the Institutional Ethics Committee of Jawaharlal Institute of Postgraduate Medical Education & Research (JIPMER) and the associated administrative approvals from Puducherry Government Health Services. The study participants included were individuals who were diagnosed with cancer and were residing in Puducherry.

Study setting: Puducherry is one of the eight Union Territories (UT's) of India. The Puducherry district has a population of 9.5 lakhs (Census, 2011)[14], consisting of 4,68,258 males and 4,82,031 females. The literacy rate of the Puducherry district is 85.4 per cent as per the census 2011 with nearly 69.2 per cent of the people living in urban areas. Primary health care services for the public sector were delivered through a network of two Community Health Centres (CHC), 29 PHCs, and 56 Sub-centres (SC).

As per the NP-NCD programme, population-based screening for common cancers needs to be done at the community level for all individuals aged 30 yr and above by the CHWs using CBAC and facilitating confirmation of diagnosis at higher facilities, if needed[13].

There is a Regional Cancer Centre (RCC) at JIPMER, which provides free treatment to individuals in need. It also maintains a HBCR. The study objective was implemented in two phases with this registry as one of its base.

<u>Phase I: Approval of State authorities and baseline assessment:</u> For initiating the cancer registries at PHCs, approval was obtained from the Directorate of Health & Family Welfare Services, Puducherry. In the initial phase, all PHCs/CHCs of Puducherry were approached to see if any records were maintained for the diagnosed cancer cases in their service area.

<u>Phase II: Intervention package phase</u>: The Intervention package included: *(a)* the sensitization of Health Care

Workers on registering cancer cases in PHCs/CHCs across the Puducherry district in coordination with the State NCD cells, *(b)* facilitating population-based screening to identify both newly diagnosed cancer cases as well as previously diagnosed cancer cases from the community, *(c)* sharing the line list of cancer cases of Puducherry from JIPMER HBCR to respective PHCs/CHCs through the State NCD cell, *(d)* facilitating initiatives to include other medical institutions of Puducherry district to capture cancer cases that were diagnosed/treated cases of cancer outside of JIPMER, *(e)* capturing the death date through house visits and by reviewing death register maintained at PHCs, *(f)* quarterly feedback to the State NCD cell regarding the status of registration of cancer cases in various PHCs/CHCs of Puducherry.

Sensitization phase: The investigators, with the help of the State NCD cell, conducted sensitization sessions for Medical Officers (MOs) and CHWs of various PHCs/CHCs of Puducherry regarding the importance of the PHC cancer registry and the procedure of registering cancer cases in PHCs. The sensitization sessions were conducted between March 2021 to July 2021 at various PHCs/CHCs of Puducherry. A register was kept in each PHC/CHC for registering the cancer cases in their area. Lady Health Visitor/Public Health Nurses were expected to facilitate cancer case registration from their service area by involving CHWs [Accredited Social Health Activist (ASHA) and Auxiliary Nurse and Midwife (ANMs)]. Medical Officers were expected to review the progress of their activity at regular intervals.

To facilitate the identification of cancer cases in Puducherry, initially, we made a list of cancer cases in Puducherry by collecting data from the JIPMER HBCR. Data was collected from January 2018 to August 2021. Following this, the data for newly registered cancer cases, during the data collection period, was collected quarterly from the JIPMER HBCR and shared with the State NCD cell. Analysis was done for the line list shared till July 2022. The State NCD cell segregated the data, generated PHC wise list of cancer cases, and shared it with all PHCs to facilitate the registration in respective PHCs.

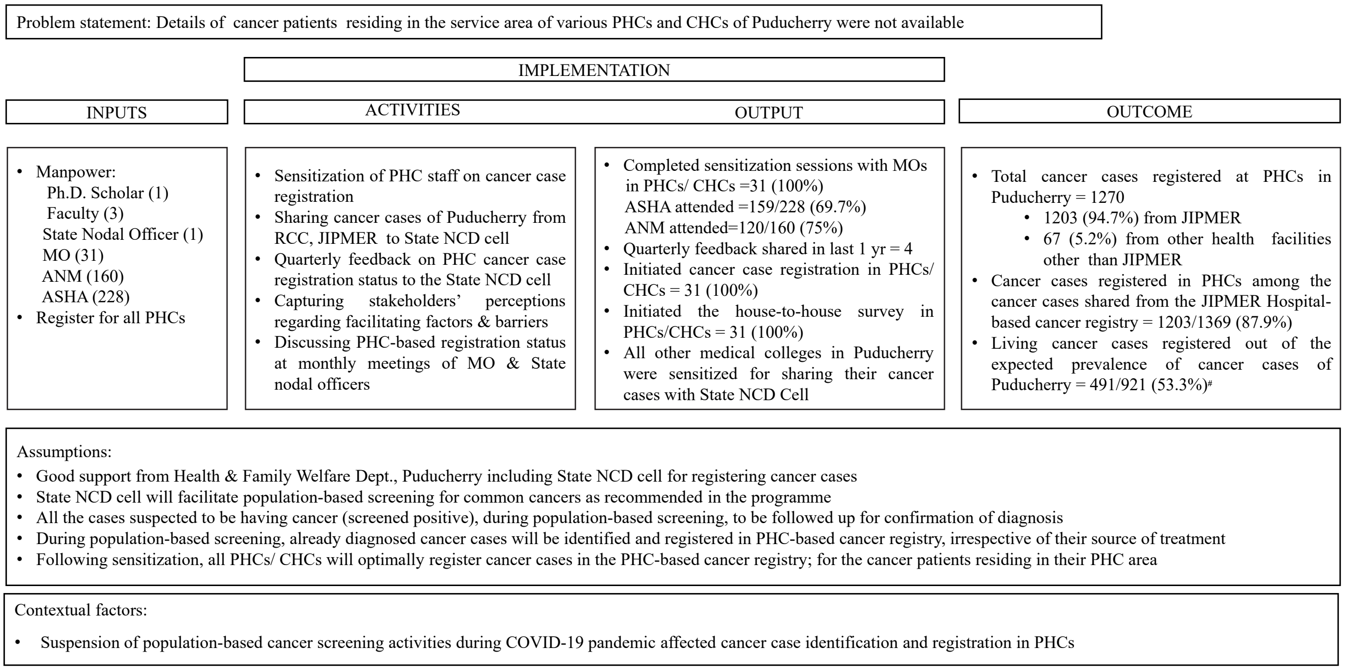
The CHWs, while doing their routine enumeration activities and population-based cancer screening, as recommended in the NP-NCD programme, were sensitized to identify living cancer cases in the community and register them in the PHC-based cancer registry, irrespective of the health care facility where they sought cancer treatment. Individuals found positive on population-based screening were also expected to be facilitated by CHWs for referral, confirmation of their diagnosis status, and registration if found positive for cancer. The registration of cancer cases shared from the JIPMER Hospital-based registry in the PHC-based cancer registry was also facilitated. The shared list of cancer cases from the JIPMER Hospital-based registry included cases diagnosed/registered between January 2018 and July 2022. Following this, the State took initiatives to include other medical institutions of Puducherry district, to capture cancer cases that were diagnosed/treated outside of JIPMER.

The CHWs were expected to verify and record the details of all individuals with cancer, such as their place of stay, date of diagnosis, treatment status, and living status, before registering them in the PHC-based cancer registry. The individual's residence was determined based on the area where they resided during the address verification as done by the CHWs. The individual's cancer diagnosis date was obtained from the individual's medical reports/records (biopsy/microscopic/histopathology/scan reports).

The CHWs also captured the date of death while verifying and confirming the addresses during their field visits and from the death register maintained in the PHCs.

Quarterly feedback to State NCD cell: After the sensitization phase, the investigator visited various PHCs/CHCs every quarter and gave feedback to the State NCD cell regarding the status of cancer registration at various PHCs/CHCs of Puducherry. During these quarterly visits, the investigator captured the cancer cases registered in PHCs from the shared JIPMER HBCR and the confirmed cancer cases receiving treatment at other facilities. The vital status (*i.e.*, alive or deceased) of the registered cancer cases was verified during this period. Additionally, Focus Group Discussions (FGDs) were conducted with CHWs to identify the facilitators and challenges they faced while registering cancer cases at the PHCs.

Qualitative inquiry: The FGDs were conducted among ASHAs and ANMs, and Key informant interview (KIIs) were among State Nodal Officers and MOs. After obtaining their consent, the interviews were audio recorded. Manual thematic analysis was done to identify various themes and codes. The codes were organized into the SCOT (Strength, Challenges, Opportunities, and Threats) framework.



Problem statement: Details of cancer patients residing in the service area of various PHCs and CHCs of Puducherry were not available

IMPLEMENTATION

INPUTS	ACTIVITIES	OUTPUT	OUTCOME
• Manpower: Ph.D. Scholar (1) Faculty (3) State Nodal Officer (1) MO (31) ANM (160) ASHA (228) • Register for all PHCs	• Sensitization of PHC staff on cancer case registration • Sharing cancer cases of Puducherry from RCC, JIPMER to State NCD cell • Quarterly feedback on PHC cancer case registration status to the State NCD cell • Capturing stakeholders' perceptions regarding facilitating factors & barriers • Discussing PHC-based registration status at monthly meetings of MO & State nodal officers	• Completed sensitization sessions with MOs in PHCs/ CHCs =31 (100%) ASHA attended =159/228 (69.7%) ANM attended=120/160 (75%) • Quarterly feedback shared in last 1 yr = 4 • Initiated cancer case registration in PHCs/ CHCs = 31 (100%) • Initiated the house-to-house survey in PHCs/CHCs = 31 (100%) • All other medical colleges in Puducherry were sensitized for sharing their cancer cases with State NCD Cell	• Total cancer cases registered at PHCs in Puducherry = 1270 • 1203 (94.7%) from JIPMER • 67 (5.2%) from other health facilities other than JIPMER • Cancer cases registered in PHCs among the cancer cases shared from the JIPMER Hospital-based cancer registry = 1203/1369 (87.9%) • Living cancer cases registered out of the expected prevalence of cancer cases of Puducherry = 491/921 (53.3%)[#]

Assumptions:

- Good support from Health & Family Welfare Dept., Puducherry including State NCD cell for registering cancer cases
- State NCD cell will facilitate population-based screening for common cancers as recommended in the programme
- All the cases suspected to be having cancer (screened positive), during population-based screening, to be followed up for confirmation of diagnosis
- During population-based screening, already diagnosed cancer cases will be identified and registered in PHC-based cancer registry, irrespective of their source of treatment
- Following sensitization, all PHCs/ CHCs will optimally register cancer cases in the PHC-based cancer registry; for the cancer patients residing in their PHC area

Contextual factors:

- Suspension of population-based cancer screening activities during COVID-19 pandemic affected cancer case identification and registration in PHCs

Fig. 1. Schematic diagram explaining the logic model for registering cancer cases at various PHCs of Puducherry. [#]According to the National representative Household Survey 2014, the prevalence of cancer was estimated to be 97/100000 population. MO, medical officers; ANMs, auxiliary nurse and midwife; PHC, primary health centres; CHC, community health centre; RCC, regional cancer centre; JIPMER, Jawaharlal Institute of Postgraduate Medical Education & Research; NCD, non-communicable diseases.

Statistical analysis: The cancer cases registered in PHCs/CHCs were captured and entered into Microsoft Excel, and analysis was done using IBM SPSS Version 21. The total cancer cases registered in PHCs/CHCs from the shared line list of the JIPMER Hospital-based registry were expressed in frequency and percentages. The expected living cancer cases of PHCs/CHCs per respective population estimate were calculated (Supplementary Material: Box) and summarised as proportions. A schematic diagram depicting the logic model was prepared to evaluate the status of cancer case registration at various PHCs/CHCs of Puducherry (Fig. 1).

Results

In the present study, all the health centres of Puducherry (29 PHCs and 2 CHCs) were included. Around 70 per cent (159/228) of ASHA workers and 75 per cent (120/160) of ANMs participated in the sensitization sessions conducted at PHCs/CHCs in the presence of corresponding MOs of various PHCs/CHCs of Puducherry.

At the baseline, no records of cancer cases were found in any of the PHCs/CHCs. Following the sensitization and in coordination with the State NCD cell, the registration status of cancer cases in various PHCs/CHCs of Puducherry improved.

A total of 1369 cancer cases of Puducherry, registered in the JIPMER Hospital-based Registry were shared with Puducherry's PHCs/CHCs through the State NCD cell. Among the shared list, around 1203 (87.9%) of the cancer cases were registered at various Puducherry's PHCs/CHCs.

After the sensitization phase, 1270 cancer cases were registered at PHCs/CHCs of Puducherry over one year. These cases constituted 1203 cancer cases from the shared line list from the JIPMER HBCR, and an additional 67 cancer cases were identified by CHWs that were not listed in the JIPMER HBCR (Supplementary Table I). Among these cancer cases, 491 (38.6%) were alive, 478 (37.6%) were dead, and 301 (23.7%) were not traceable for confirming their living status, although it was confirmed that they had stayed in the area. Among the cases registered, the most common cancer cases were breast cancer (254, 20.0%), head & neck cancer (240, 18.9%), and cervix cancer (162, 12.7%) (Fig. 2).

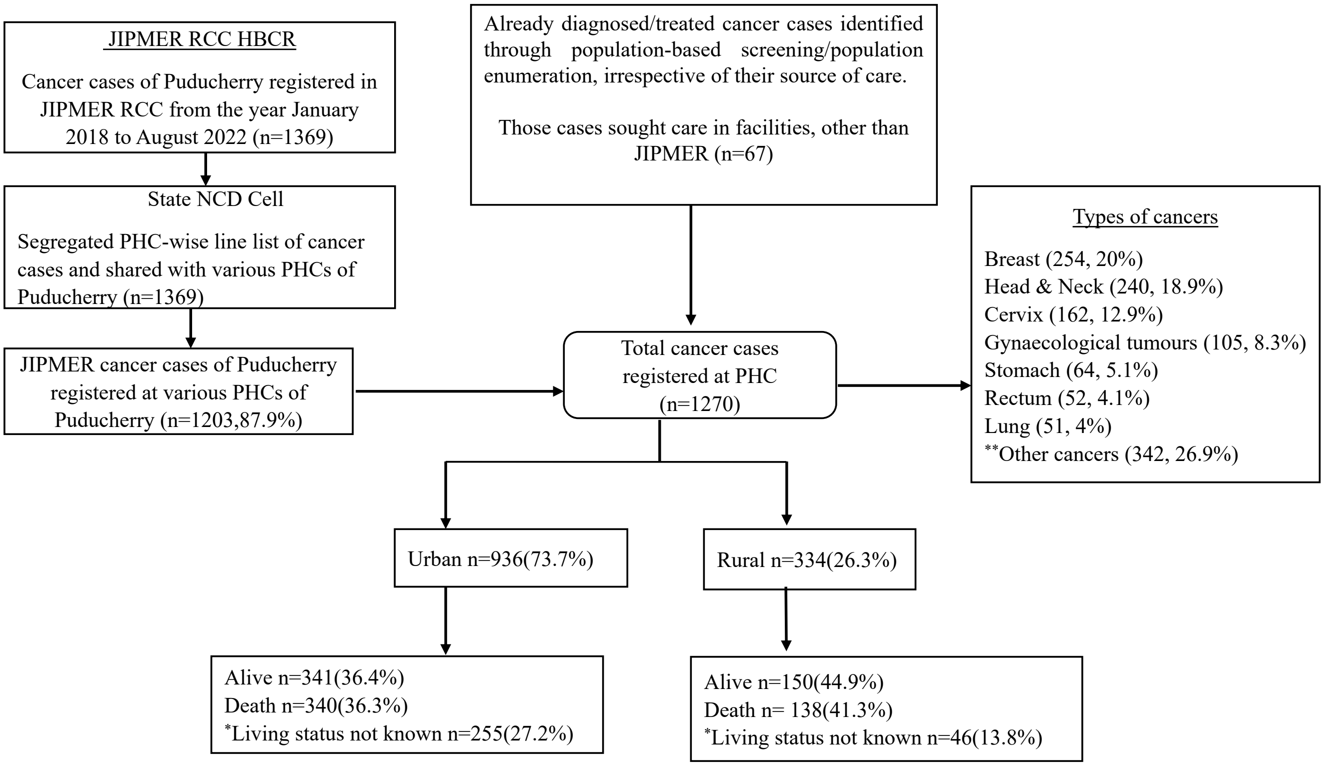


Fig. 2. Distribution of cancer cases registered at various PHCs/CHCs of Puducherry at the end of 12 months following the sensitization at various PHCs/CHCs of Puducherry. *Cancer patients previously resided in that particular area but relocated and were untraceable to confirm their living status; **Other cancers include genitourinary cancers, oesophagus, abdominal tumours, liver, brain, colon, connective tissues, *etc*.

Table I shows the PHCs/CHCs performance based on the proportion of expected living cancer cases registered in various PHCs/CHCs of Puducherry. It was observed that there was an increase in the proportion of PHCs/CHCs that achieved at least >50 per cent of registration status, *i.e.*, from 9.6 per cent (3/31) at the end of the sixth month to 35.4 per cent (11/31) at the end of 12th month.

The proportion of Rural PHCs/CHCs that achieved >50 per cent registration status for expected living cancer cases registered at various PHCs/CHCs of Puducherry increased from 11.7 per cent (2/17) at the end of sixth month to 41.2 per cent (7/17) at the end of the 12th month. Similarly, the proportion of urban PHCs with >50 per cent registration status increased from 7.1 per cent (1/14) at the end of sixth month to 28.5 per cent at the end of the 12th month.

Qualitative results: We conducted 12 FGDs (3 FGDs quarterly) and five KII during the intervention phase

Table I. Proportion of expected living cancer cases registered in various PHCs/CHCs of Puducherry

Registration status (%)	At the end of 6th month			At the end of the 12th month		
	Urban PHC n=14 (%)	Rural PHC n=17 (%)	Total PHC n=31 (%)	Urban PHC n=14 (%)	Rural PHC n=17 (%)	Total PHC n=31 (%)
*Category 1: >75 %	1 (7.1)	0	1(3.2)	2 (14.3)	4 (23.5)	6 (19.3)
Category 2: 50–75%	0	2 (11.8)	2 (6.4)	2 (14.3)	3 (17.6)	5 (16.1)
Category 3: 25–50%	2 (14.3)	4 (23.5)	6 (19.3)	3 (21.4)	7 (41.2)	10 (32.2)
Category 4: <25%	11(78.6)	11 (64.7)	22 (70.9)	7 (50)	3 (17.6)	10 (32.2)

*Category for the % of cancer cases registered at PHC (Supplementary Material: Box)

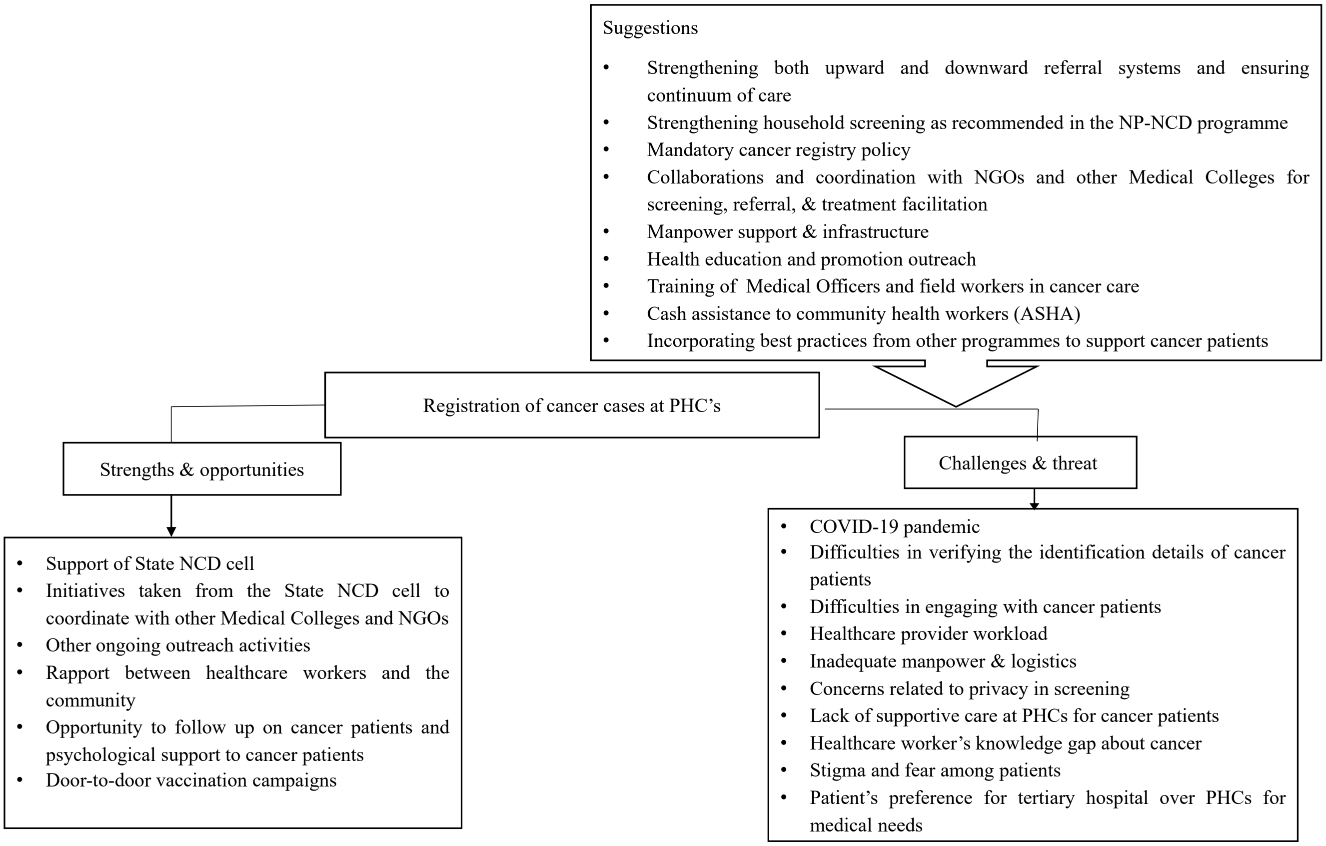


Fig. 3. Conceptual framework of the perception of stakeholders (State Nodal Officers, Medical Officers, Community-based healthcare workers) on registering cancer cases at the primary care level. NP-NCD, National Programme for Prevention and Control of Non-Communicable Diseases; NGOs, non-governmental organizations; ASHA, accredited social health activist.

among 76 CHWs, 4 MOs, and the State Nodal Officer of Puducherry. Half (53.7%, n=43) of the participants were >35 yr. More than half (51.8%, n=42) of the participants had a secondary education. A majority (76.3 per cent, n=61) of the participants who participated in the FGD/KII had <10 yr of experience as health workers.

Figure 3 summarizes the Strengths, Challenges, Opportunities, and Threats of the PHC-based cancer registry and the suggestions. The perception of Stakeholders was summarized in themes, categories, and codes provided in Supplementary Table II.

Strengths and opportunities: Initiatives such as support from the State NCD cells and coordination with other medical colleges, have facilitated the registration of cancer cases at the primary care level.

The outreach activities of CHWs and their rapport with others, such as neighbours and Anganwadi helpers contributed to identifying cancer cases within the service area of PHCs. Additionally, CHWs felt that it provided an opportunity to follow up on cancer cases and provided psychological support to them to cope with the diseased condition.

"We detect cases during the routine field visits survey like NCD case detection visits or by interacting with the people residing in that locality." (ANM from rural PHC with six years of experience)

During door-to-door vaccination campaigns, many individuals with cancer revealed their status to CHWs by inquiring whether it is safe to receive the vaccine for them. This presents an opportunity for CHWs to identify diagnosed cancer cases from the community.

Challenges and threat: The HWs expressed that registering cancer cases at PHCs was challenging during the COVID-19 pandemic, as most CHWs were busy with COVID-19-related activities. As a result, the population-based screening was affected.

Some CHWs faced challenges while locating cancer cases within their service area. This was due to the wrong contact details of the cancer cases in the database.

"People from Tamil Nadu will also come to Puducherry and use their relative's contact details for check-ups and treatments." (ANM from Urban PHC with eight years of experience)

CHWs sometimes faced challenges when inquiring about the cancer status of individuals from family members. This could be due to stigma or the family's fear that the concerned individuals may learn about their cancer status. They felt that stigma and fear about cancer existed in the community, and many individuals were hesitant to disclose their cancer status, fearing that healthcare workers might unintentionally disclose this information in the community.

Health workers reported that some primary healthcare facilities lacked adequate manpower support, infrastructure, and equipment for cancer screening. This has resulted in issues related to privacy for breast and cervical cancer screening in both community and healthcare facilities.

Suggestions from the various stakeholders: The KII, with the State Nodal Officer and MOs, suggested improving the framework. Their priority was strengthening both upward and downward referral mechanisms for cancer patients. They felt this would streamline the continuum of care for affected individuals. They also opined that collaborations with Medical Colleges and NGOs will further strengthen the cancer services. During the conduct of this study the State had taken initiatives to include other medical institutions of the Puducherry district to capture cancer cases that were diagnosed/treated outside of JIPMER.

The stakeholders also suggested the importance of dedicated manpower and infrastructure support for screening and follow up care for cancer cases. To ensure follow up care both the MOs and field staff need to be trained in counselling for cancer as well as palliative care.

It was proposed that incentives for ASHA workers will help facilitate follow up care for individuals with cancer. Incorporating best practices, such as providing financial and nutritional assistance to affected and abandoned individuals, in similar lines to that of the TB programme, will strengthen the support for cancer patients in their respective service areas. For further strengthening the registration, inter-district and inter-State exchange of information for cancer cases will be helpful, as is being done for TB cases in the National Tuberculosis Elimination Programme (NTEP).

The logic model in Figure 1 outlines the inputs, activities, outputs, and outcomes for implementing a PHC-based cancer registry in various PHCs/CHCs of Puducherry. The inputs and activities include coordinating with the State NCD Cell, sharing a line list of cancer cases from the JIPMER Hospital-based registry, and sensitization sessions for HWs. The outcome shows that the present system with registered 1270 cancer cases across PHCs/CHCs of Puducherry. Of these, 88 per cent were from the shared line list of the JIPMER Hospital-based registry, while five per cent were from other healthcare facilities. However, only 53 per cent of expected living cancer cases could be captured in the PHC-based cancer registry at the end of the study.

Discussion

This study assessed the cancer registration status in PHCs/CHCs following the implementation of a PHC-based cancer registry in the Puducherry district. It also explored the strengths and challenges of setting up a PHC-based cancer registry.

As the NP-NCD programme recommends, the frontline health workers (ASHA/ANM) should visit houses and screen the population for common cancers using the CBAC[12,13,15]. Individuals found positive for CBAC for early signs of oral, cervical, and breast cancers need to be referred to appropriate higher healthcare facilities for further management. Along with this activity, if the CHWs also identify the previously diagnosed cancer cases from the community, then this will facilitate capturing all cancer cases residing in a PHC area. Once all the cancer cases from corresponding PHCs are registered in a PHC-based cancer registry, it can become a good surrogate for a population-based cancer registry.

Home visits by the health workers in this study enabled them to verify the details of cancer cases, such as their address, date of diagnosis, treatment, and date of death. This was expected to decrease the chances of duplicate registration of cancer cases in the PHC-based cancer registry.

A line list of 1369 cancer cases from the JIPMER HBCR was shared with the State NCD cell such that these cases were registered in the respective PHC-based cancer registry, and a mechanism was put in place to capture cancer cases being treated in other health care facilities. Monitoring was done to see both indicators, *i.e.*, the proportion of cancer cases registered from the line list shared by the JIPMER HBCR and the proportion of cancer cases registered out of estimated cancer cases expected from Puducherry.

Out of the 1369 cancer cases shared from the JIPMER HBCR, around 88 per cent (n=1203) of cancer cases were successfully registered in the corresponding PHCs of Puducherry. The CHWs identified an additional 67 cancer cases (5.2%) during their field visit, seeking cancer care from hospitals other than JIPMER. In the process, 1270 cancer cases were registered in various PHCs/CHCs of the Puducherry district over one year. Among these registered cancer cases, 491 (38.6%) cases were alive and 478 (37.6%) were dead. Their living status couldn't be confirmed for 301 (23.7%) individuals who were not available in the area.

The number of living cancer cases expected to be registered in the PHC-based registry over one year was ~921. This was based on the National Representative Household survey estimates in India[16] (Supplementary Material: Box). However, only 491 living cancer cases were registered over one year, indicating that the present study could register only 53 per cent of the expected prevalent cases in the PHC-based cancer registry. Among these 491 cases, 424 sought treatment from JIPMER, and 67 sought care from other health facilities. Thus, only 67 (13%) out of the expected 497 cases were registered from health facilities other than JIPMER. This reflects that the PHC-based registry mainly failed to capture cases from those seeking care from facilities other than JIPMER. The proportion of cancer cases registered in PHCs/CHCs was more representative of those shared by the JIPMER Hospital-based registry rather than the population of the Puducherry district. Although the number of cases registered from other facilities was small, the only positive thing was that a mechanism had been put in place to capture cases from other facilities, which is expected to improve with time.

The major limiting factor for sub-optimal registration of cancer cases from health facilities other than JIPMER was that the routine population-based screening for common cancers at the community level, as recommended by the NP-NCD programme, was suspended due to the COVID-19 pandemic[17,18]. COVID-19-related activities such as contact tracing, following up on COVID-19 cases, and vaccination drives were a priority at that time. This observation was also represented in the logic model as one of the external factors that hindered the registration activities in various PHCs/CHCs. In the scenario where house-to-house screening was possible, more cancer cases who were seeking treatment from other healthcare facilities could have been detected from the community. This could have increased the registration of cancer cases in PHCs/CHCs, and the PHC-based registry would have been more representative of cancer estimates in the population.

The strength of this study was the use of a logic model to understand the input, activities, output, and outcome components for registering cancer cases in various PHCs/CHCs of Puducherry district. The study demonstrated that it was feasible to set up a PHC-based registry, but this registry needs further streamlining to improve the registration of cancer cases from Puducherry among those who were not availing services from JIPMER. The State NCD cell was also supportive of initiating a PHC-based cancer registry in all PHCs/CHCs of Puducherry. Looking at the merits of this mechanism, the State NCD cell has taken initiatives to link this with other Medical Colleges in Puducherry district, so that the cancer cases from Puducherry being treated in these institutions are also registered. The FGDs results show that the rapport between healthcare workers and the community during field visits facilitated in identifying and verifying the cancer patients' addresses and helped in confirming their living status at their respective PHCs. These interactions created a platform for streamlining follow ups of cancer cases from PHCs and provided an opportunity for providing essential psychological support for individuals with cancer. Even though the COVID-19 hindered the cancer screening activities of PHCs, few CHWs used the door-to-door COVID-19 vaccination initiative as an opportunity to identify and register cancer cases in the PHC-based cancer registry. These findings also highlighted some of the positive outcomes associated with CHW engagement and efforts in registering cancer cases in a few PHCs of Puducherry.

One of the major challenges in cancer case registration was the workload of the CHWs due to multiple field activities under various National Health

Programmes. These findings align with previous studies conducted in Rajasthan, which also reported that ASHAs were overburdened with multiple responsibilities, ultimately affecting their performance in field activities[19-21]. Other reported challenges include inadequate infrastructure in PHCs for cancer screening and inadequate supply of materials or logistics at the health centres for various screening-related activities. A similar observation was made during the evaluation of the National Programme conducted in Rajasthan[21]. The Health workers revealed that some individuals are not willing to disclose their disease status because of the stigma attached to the disease[22]. This stigma can serve as a barrier to cancer screening and early diagnosis, as observed in studies from India, the United States and Australia[23-25]. The MOs and CHWs acknowledged that they needed training in various aspects of cancer, like palliative care and counselling cancer patients, to give them optimal care at PHCs and at home during their field visits. Therefore, frequent training and continuous support are necessary to ensure follow up care of cancer cases[26].

To improve cancer registration in PHCs, efforts should be made to strengthen the house-to-house screening activities[19]. This includes strengthening the workforce, improving the infrastructure for ensuring privacy for early cancer screening and training for health workers in counselling and follow up care, especially for palliative care. Looking ahead, the State can also integrate the existing NCD app and Health Management Information System (HMIS) for capturing cancer cases from the PHC service area once the population-based screening is strengthened. Additionally, the State can further streamline the involvement of various pathology laboratories and other diagnostic centres in identifying cancer cases and link them to the PHC-based cancer registration.

Our study had certain limitations. The vital status of cancer cases was not verified with the death registers maintained by the Registrar of Births and Deaths, municipal corporations, or the State Department of Statistics. Instead, the CHWs relied on the death register maintained at PHC and information gathered during house visits to capture the death date of cancer patients. Another limitation was that the pathology (histology/cytology/haematology) laboratories and other diagnostic centres in the private sector were not contacted to capture cancer cases. However, the State is continually taking steps to streamline activities in this direction. There was an underreporting of cancer cases in the PHC-based cancer registry as community-based screening for cancer had scope for further improvement.

Overall, the study demonstrates that despite these constraints this approach is feasible to establish a PHC-based cancer registry in all PHCs/CHCs of Puducherry district. Moreover, COVID-19 related delays are exceptions, and this should not impact registering cancer cases in PHC-based cancer registry in the long run. Although the present PHC-based cancer registry was more representative of cancer cases from the JIPMER Hospital-based registry, it has the potential to be representative of a population-based cancer registry in the future once the population-based screening and involvement of other sectors for cancer registration, including the private sector, are strengthened. Focus should be given to strengthening community and opportunistic cancer screening activities, improving health workforce capacity, upgrading infrastructure, providing training for HWs, enhancing referral systems, and ensuring continuity of care in primary care settings. These can pave the way for more representation of cancer cases in the PHC-based registry and make it a good surrogate for a population-based cancer registry.

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