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Original Article

Barriers in implementing cancer prevention programme in North Eastern India: A case study from Meghalaya

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***Background & objectives*: India accounts for seven per cent of the global cancer burden, with the highest incidence reported from the northeastern region. To address this burden, the Government of India launched the National Programme for Prevention and Control of Cancer, Diabetes, Cardiovascular Diseases and Stroke (NPCDCS) in 2010, but this programme was implemented in Meghalaya four years after its launch. This paper aims to examine the implementation facilitators and barriers to cancer prevention in Meghalaya within the NPCDCS framework.**

***Methods*: A desk review prior to the interviews enabled selection of relevant stakeholders from the health system. In this qualitative study, fifty-six healthcare professionals and frontline health workers from various tiers of the health system were involved through twenty in-depth interviews (IDIs) with healthcare professionals and four focus group discussions (FGD) with the frontline health workers. Data were transcribed in local language and subsequently in English. A hybrid coding strategy was adopted and a codebook was developed in MS Excel (version 16.6). NVivo-12 software was used to organize the data and codes, facilitating the identification and categorisation of emergent themes in alignment with the research question.**

***Results*: While the programme is intended to provide equal attention to cancer prevention activities, hypertension and diabetes took priority. Barriers included inadequacy in information, education, and communication content on breast and cervical cancers; unavailability of acetic acid for cervical cancer screening; and lack of privacy for cancer screenings. Communication gaps stem from the absence of patient tracking mechanism and programme review meetings at NCD clinics. Training inadequacies affected staff confidence in conducting screenings, while low community awareness compromised the accuracy of data collated for the community-based assessment checklist. Preference for traditional healers further complicated the treatment pathways.**

***Interpretation & conclusions*: Meghalaya's high cancer incidence underscores the urgency to address these gaps for efficient implementation of the cancer activities within NPCDCS framework.**

Key words Cancer - Meghalaya - NCDs - NPCDCS implementation - screening

Cancer is the second leading cause of death, accounting for one in six deaths worldwide[1]. India accounts for seven per cent of the global cancer burden, with the highest incidence reported from its

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northeastern region[2,3]. Despite the high incidence of cancer in the northeast, there are persistent delays in health-seeking behaviour and a concerning lack of awareness among people in this region about the various signs, symptoms and risk factors associated with cancers[4-6].

To address the burden of non-communicable diseases (NCD), the Government of India launched the National Program for Control of Cancer, Diabetes, Cardiovascular Diseases and Stroke (NPCDCS) in 2010[7]. Its implementation is fraught with various challenges, such as low budget allocation, inadequate IEC activities, lack of trained personnel, and irregular supply of medicines and consumables[8-10]. The focus of the NPCDCS programme in Meghalaya has largely been on hypertension and diabetes[11]. The challenges faced by health providers in delivering the cancer-related activities of the NPCDCS have not been explored.

The present study aims to explore the facilitators and barriers in the implementation of cancer-related activities under NPCDCS in Meghalaya. Specifically, we sought to answer the research questions: (*i*) What are the systemic, capability-related, and motivational factors affecting cancer screening activities under NPCDCS? and (*ii*) How do frontline health workers and program administrators perceive and experience challenges in implementing cancer prevention services?

Materials & Methods

The study was conducted in Meghalaya, a hilly tribal State in the northeastern region of India. The State is divided geographically into Khasi, Jaiñtia and the Garo Hills regions[12]. The study was conducted in two districts of two regions in Meghalaya, East Khasi Hills District (EKH) and East Jaiñtia Hills District (EJH), which were purposively selected. The EKH is the largest district, with Shillong, the state capital, located within the district, while EJH is 87 km away from the capital. The study was approved by the university research ethics committee of the Martin Luther Christian University. Necessary permission was also obtained from the Directorate of Health Services (DHS), Government of Meghalaya. A written informed consent was obtained from each participant prior to data collection. The recorder and the laptops were stored in a locked cabinet in the institute, where the electronic data were made available only to the research team for the purpose of research analysis.

Study design and data collection: This study was grounded in the constructivist paradigm, which recognises that knowledge is socially constructed through interaction and interpretation. This paradigm enabled the understanding of subjective experiences of health care providers and frontline health workers in the implementation of the NPCDCS programme. Prior to the qualitative interviews, we conducted a desk review of the NPCDCS operational guidelines and cancer-related reports, along with a stakeholder mapping of the healthcare personnel involved with the implementation of the programme, to identify and recruit the key stakeholders for this study. Based on these activities, participants were selected purposively based on their roles and responsibilities.

Depending on the healthcare personnel's responsibilities, a topic guide was developed and was iteratively adapted for the qualitative interviews [in-depth interview (IDI) and focus group discussion (FGD)]. The topic guide covered questions on health promotion, awareness generation, screening and early detection at the facilities, access to affordable cancer treatment, referrals, follow-ups, rehabilitation, debriefing, and gaps in programme implementation. Fifty six participants were interviewed: including seven NPCDCS programme officers from state and district level, five medical officers, five Staff nurses, one counsellor, and three community health officers (commonly recognized as Mid-Level Healthcare Provider (MLHP) from the two study districts in Meghalaya.

The in-person IDIs were conducted with the stakeholders at their respective offices. Each IDI lasted for about 30-90 min. Additionally, we conducted FGDs with 16 accredited social health activists (ASHAs) and nine auxiliary nurse midwives (ANMs) at the respective community health centers (CHC). Each FGD included 6 to 12 participants. Twenty IDIs and four FGDs were conducted between July to October 2021.

The interviews were conducted by three tribal female researchers from the same ethnic community, who were fluent in the local language and English. Their cultural familiarity helped build rapport with participants. Reflexivity notes were maintained throughout the data collection process, and during the analysis phase, the notes were referred to during discussions to document and reflect on assumptions, reactions, and evolving understanding of the issues.

Data analysis: The recordings of the interviews and FGDs were transcribed first into the local languages and subsequently translated into English by the researchers. To ensure the reliability of the data, another member of the research team, who was not involved in the transcription, reviewed the transcripts by revisiting the in-depth interviews and focus group discussions to ensure the accuracy of the data. A hybrid coding strategy was adopted; the coding began with *a priori* codes informed by the research framework. However, as the research team immersed into the data, new patterns and themes emerged, which prompted the development of new codes through comparison and contrast within each level and between different stakeholders. After anonymizing the codes, the categories were organized into a codebook using MS Excel (version 16.6). At the analytical stage, the categories were organized into broad themes partially aligning to the World Health Organization's (WHO) Health Systems Building Blocks framework[13]. These codes were reviewed by multiple researchers to ensure reliability. NVivo-12 software was used to organize the data and codes, facilitating the identification and categorization of emergent themes in alignment with the research question.

Results

The results of the study highlight the facilitators and barriers associated with the implementation research of the cancer activities of the NPCDCS programme in Meghalaya. The three main themes are capability, intention and health system, which align partially with the WHO's Health System Building Blocks framework. The WHO framework describing the health system building blocks consists of six components: (*i*) service delivery, (*ii*) health workforce, (*iii*) health information systems, (*iv*) access to essential medicines, (*v*) financing, and (*vi*) leadership/governance[14]. In this study, we aligned our findings to two of these six building blocks, mainly to service deliveries, which include availability and accessibility, finance, and affordability. In addition, a brief summary of the initiation of the program in Meghalaya has been included. We anonymized the identities of research participants using broader categories, such as program administrator for program officers, healthcare providers for medical officers, staff nurses and community health officers (CHOs), and frontline health workers for ANM and ASHAs.

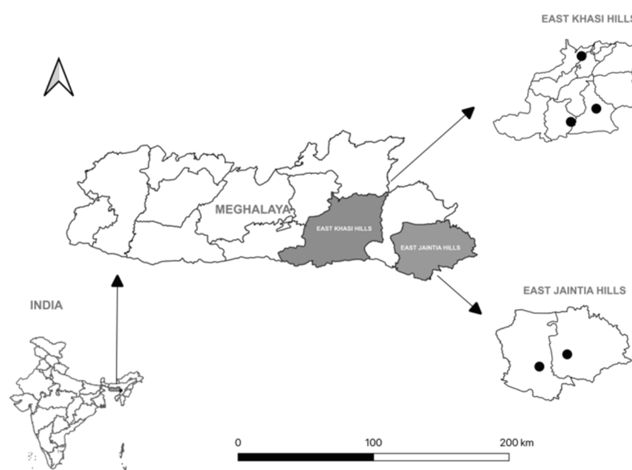

Figure. Map of the study settings. *Source*: Self-generated using QGIS (version 3.34, 'Prizren') for visualization and boundaries were taken from the dataset of the Documentation for the India Village-Level Geospatial Socio-Economic Data Set: 1991, 2001.

Implementation continuum of NPCDCS in Meghalaya: The NPCDCS in Meghalaya was implemented in 2014 with the establishment of the State NCD Cell. Majority programme administrators (2/3) stated that the NPCDCS was implemented initially in the EKH and the West Garo Hills districts. It was eventually expanded to other districts in a phased manner (Figure). At the time of the study, the NPCDCS programme was being implemented in all the districts of Meghalaya. Remaining program administrators (1/3) informed that, while the activities relating to the control and prevention of hypertension, diabetes, and stroke were initiated from 2015-2016, the cancer-related activities of the NPCDCS programme were initiated only in 2018-2019. The COVID-19 pandemic caused further setbacks to the implementation of the cancer component of the programme. It is worth noting that oral cancer screening has been implemented in Meghalaya by another programme, the National Oral Health Program, since 2014-2015.

With cancer, it is only in the year 2018-19 that they started the training for cervical cancer, and besides, the oral cancer screening was conducted only at the PHC level where the medical officer was available (Programme administrator, 002, State).

Health system facilitators and barriers: Themes that are primarily related to the health systems are (*i*) availability, which includes procedural access, provision of services and availability of human resources; (*ii*) affordability in terms of financial

access; and (*iii*) communication in terms of sharing of information effectively.

Availability: Healthcare providers shared that they are mandated, as per NPCDCS guidelines, to conduct population-based cancer screening for oral, breast, and cervical cancers through visual inspection with acetic acid (VIA) at CHC NCD clinics, primary health centre (PHCs) and health and wellness centres (HWCs). All the NCD clinics (CHC) were able to conduct only oral and breast examinations as the acetic acid for VIA was unavailable. The health providers (9/13) at the NCD clinics (CHC) reported that oral cancer screening was regularly conducted by dentists based at these health centres, and such screenings were also conducted in schools and communities since a separate national health program catering to oral health was implemented simultaneously. They also (10/13) mentioned that patients exhibiting signs of tooth pain, tooth decay or oral plaque were referred to CHC for further examination. In communities, the ASHAs and ANMs conduct NCD screenings using the community based assessment checklist (CBAC) form, referring individuals with high-risk scores of four and above to CHC medical officers, who may further refer them to tertiary facilities. In EJH, the frontline health workers informed that public participation in filling the CBAC form was low due to reluctance amongst screened individuals to share personal information (such as substance use), which led to missing data. In particular, women were also hesitant to disclose abnormal vaginal discharge, unlike in the EKH.

Some women refused to disclose their information with us and feel shy to talk about unusual discharges- (Frontline health worker, 004, EJH)

In EJH, health providers continue to emphasise the importance of self-breast examination (SBE) for women in both districts; (4/7) also reported a low acceptance of breast and cervical screening as women were unaware of its importance. This is accentuated as the available IEC content included only the risk factors of oral cancer.

For cancer, the IEC content mainly focused on oral cancer, but we are yet to develop IEC for other cancer screening, especially for breast cancer and cervical cancer.- (Programme administrator, 002, State).

The staffing of the NPCDCS programme in Meghalaya aligns with the national guidelines, but variations exist in human resource appointment patterns across the NCD clinics. Some medical officers (5/6) and a few staff nurses (3/6) indicated task shifting due to them being responsible for managing other health programmes, such as maternal and child health, communicable and non-communicable disease initiatives, besides patient care, and sometimes, these took precedence over cancer prevention activities.

We have to see patients at the NCD clinic. Since we are integrated into the hospital, we have other duties such as OPD, patient rounds, and writing patients' discharge certificates as well. We have to do everything so if we can have more manpower, the programme will be streamed line quite well (Healthcare provider, 001, EKH).

All health providers (13/13) highlighted frequent vacancies in the counsellor positions, which are short-term contracts. Hence, appointed counsellors often left for better opportunities; only one of the six identified NCD clinics had a counsellor during the time of data collection. In all four FGDs, ASHAs and ANMs expressed feeling overwhelmed with activities from different programme at the community level, sometimes leading to neglect of cancer-related tasks.

The lack of privacy for breast and cervical cancer screenings at health camps, as reported by the health providers (9/13), was another barrier to cancer screening. Apprehension and lack of awareness of the importance of cancer screening were other factors that resulted in low screening rates in rural areas as compared to urban areas.

Positive response is more from the urban areas than the rural areas. In the urban areas, when we go to camps in college and survey different government departments, they are much more ready. Even if they do not have any complaints yet, they are willing to come for screening.- (Programme administrator 004, EKH)

Affordability: Healthcare providers reported that another reason for the low uptake of cancer screening is the preference for traditional medicine, as it is commonly used for other ailments and is accessible and affordable in remote areas. They also expressed that people opted for traditional medicine if they felt that the discomfort was caused or related to their cultural beliefs.

Many people still prefer traditional healers. One person whom I know was diagnosed with throat cancer. He was not ready to go to the hospital for treatment. He had always believed

in traditional medicine. After a few months, he passed away.- (Healthcare provider, 001, EKH)

On many occasions, healthcare providers (4/13) stated that patients do not follow through referrals for several reasons, such as high costs associated with undergoing further investigations and out-of-pocket expenditures. They (10/13) also reported that people had fatalistic beliefs that cancer was incurable, which hindered treatment seeking.

Communication: For the operationalization of the NPCDCS, the district programme administrators (4/5) aligned the activities with the national guidelines. Monthly inter-sectoral meetings of NPCDCS involved various departments and were chaired by the district Deputy Commissioner (administrative head of the district). However, formal review meetings at the NCD clinic were not held, prompting healthcare providers to express the need for such meetings to understand roles and progress and improve work quality.

No, we never have review meetings for the NPCDCS programme alone- (Healthare providers- 009, EKH).

Several healthcare providers (6/13) stated that referrals were essential for the confirmation of diagnosis. When a patient has been diagnosed with cancer at the CHC and has been referred to a tertiary hospital, the CHC does not have a systematic system to track the patient's access to treatment in both study districts; the CHC does not know whether the patient has gone to the tertiary hospital for treatment or sought alternative treatments.

As I mentioned before, there are many suspected cancer cases to which we refer to (Shillong) civil hospital (the only state referral hospital for oncology treatment), but patients do not come for follow up. For example, they come to us with difficulty in swallowing, and when they eat, there would be vomiting. This is surely a suspected case of oesophageal cancer, so we refer to the tertiary centre for further management. When they return to the village, they do not return for follow up. This is actually what happens, and we cannot keep track to help them.- (Healthcare provider, 003, EKH)

At EJH, healthcare providers stated that adhering to referrals was even more difficult, as the referral was usually to the only tertiary hospital in Shillong , about 87 km from the district headquarters. This problem was accentuated among patients in both districts who were from low socio-economic backgrounds due to the high costs associated with diagnosis, treatment, transportation, or other out-of-pocket expenditures.

Capability: facilitators and barriers: The capability barriers relate to the knowledge and skills of HPs involved in the NPCDCS programme.

Knowledge and skills to implement effective cancer prevention: The NPCDCS aims to enhance the capacity of HPs through various training programmes, including population-based screening (PBS) for oral, breast, and cervical cancer. The state programme administrators (2/3) reported ongoing training workshops across districts with varying completion rates due to differences in staff uptake capacity. In EKH, many training programmes were conducted for medical officers, NCD staff, CHOs, and ASHAs. In contrast, the initiation of such training in EJH was delayed due to COVID-19, as reported by the HPs (5/7). Despite this, some long-serving FHWs could not recall receiving any cancer-related training in the recent past. In the HWCs, cervical cancer screening was not conducted, as the training for the CHO was yet to be initiated in both districts.

State officials and administrators recognized the inadequacy in training, particularly for cervical cancer screening, compared to oral and breast cancer screening. They mentioned that efforts were underway to increase training frequency in cancer prevention to address the delays caused by the COVID-19 pandemic.

We need to get all the stakeholders to know how to do the screening for cancer, especially VIA. We are still lacking behind with cancer screenin – (Programme administrator, 001, State).

In terms of the knowledge of communities about cancer, the healthcare provider commented that the IEC materials were mostly in English, which was a significant barrier for many people. The materials in the local language had just been received from the NCD cell during the study.

Intention facilitators and barriers: The intention barriers are the provider's motivation and confidence in conducting effective cancer screening. Social influence has a vital role to play in NCD service delivery.

Motivation, belief and influence: With the implementation of NPCDCS, all the State and district programme administrators (8/8) and a large proportion

of healthcare providers (7/13) including frontline health workers reported that since the introduction of the NPCDCS programme, there has been a slowdown of cancer initiatives. Health promotion, screening and sensitization efforts were now mostly focused on hypertension and diabetes; cancer awareness was usually conducted on designated days such as Cancer Day or National Cancer Awareness Week.

... for other problems such as diabetes and hypertension, awareness is frequently conducted, but for cancer, I do not remember someone giving cancer awareness (Frontline health workers-007, EKH).

The healthcare providers (3/13) reported that the community knowledge about cancer was primarily acquired from social networks, such as friends and family members who have experienced the disease. According to the healthcare providers (8/13), people in the community were often reluctant to talk about cancer due to discomfort, which was indicative of perceived stigma. Cancer-induced psychological distress among participants included concern over family, family responsibilities and meeting treatment expenditures. According to healthcare providers, stigma associated with cancer of breast and cervix seems to be common in Meghalaya, in both rural and urban areas as patients commonly use terms such as 'shy' and 'fear' with cancer. Such hesitancy in talking about cancer in the community was also identified as a significant barrier to timely medical consultation. Therefore, the diagnosis is usually kept a secret among close family members and not often disclosed to others.

Yes, stigma is still very prevalent. Till today, we find patients coming to us with very advanced cases of breast cancer, cervical cancer, and oral cancer. They do not want to tell or show themselves to anyone as they have those symptoms, so they feel shy. They do not want to be examined by the doctor or by anyone. Till now, we have patients with breast cancer who come with fungating masses; even those from urban areas. We get patients coming with cervical cancer that has spread to the bladder and the rectum as they were having this stigma–(Healthcare provider, 004, EKH).

Discussion

This study explored the implementation barriers and facilitators that affect the optimal functioning of the cancer-related activities of the NPCSCS programme; cancer being a major cause of morbidity and mortality in Meghalaya[12]. Even though the NPCDCS programme has been evaluated previously[8-11], implementation of the cancer component of the programme has not been comprehensively ascertained. In this study, while the healthcare providers appreciated the intersectoral district-level review meetings, they expressed the need for such meetings at the at the NCD Clinics and HWCs for a better implementation of the programme. Additionally, they highlighted systemic barriers such as the inadequacy of infrastructure, essential materials and consumables, and lack of skilled staff, which affected the cancer screening. These, along-with delay in identification of high-risk patients due to incompleteness of the CBAC forms, preference for traditional healers for cancer treatment, and traditional beliefs and misconceptions, may result in delay in cancer detection and treatment.

The findings of this study resonate with what was earlier reported from Bangladesh, where the lack of basic amenities for cervical cancer screening in public health facilities, coupled with non-availability of operational guidelines, resulted in lower quality of cervical cancer care[15]. Similarly, in underserved areas of Maharashtra, inadequate training of healthcare providers lowered their confidence, resulting in the low uptake of breast and cervical cancer screening[16]. Additionally, the lack of a referral system for high-risk cancer patients in Meghalaya, highlights the need for a comprehensive mechanism to monitor patients through screening, treatment, and follow-up, to monitor disease progression and treatment effectiveness[17]. The use of an appointment register to track HIV patients, negotiation of appointments and a strong community linkage, improved adherence to the antiretroviral therapy in Tanzania[18]. Moreover, familiarizing oneself with the health beliefs of tribal communities and collaborating with traditional health practitioners in cancer care could enhance trust and programme participation, as was reported from a study in Australia where the healthcare professionals' understanding of traditional and complementary medicine helped indigenous patients feel comfortable in disclosing their treatment, promoting a holistic and safer approach to cancer care[19].

This study has several limitations. It was conducted during the COVID-19 pandemic, which may have influenced the health workers to prioritize pandemic control. Moreover, only two of the then eleven districts of Meghalaya were included, thereby limiting its generalizability. Additionally, the lack of an observation method may have overlooked the nuanced behaviours of various stakeholders in cancer care, which could potentially have added more depth to the findings. Nonetheless, this study highlights the programmatic

gaps and implementation challenges in conducting the cancer-related activities of the NPCDCS programme in Meghalaya, where other NCD control activities, such as hypertension and diabetes, have taken priority over cancer prevention, despite the high cancer incidence and mortality.

The efficient implementation of cancer activities within the NPCDCS requires overcoming logistical and infrastructural barriers, besides enhancing awareness and trust among the community members to ensure equitable access to cancer prevention and treatment. Studies have shown that enhancing awareness about cancer and the importance of screening have resulted in increased screening uptake[20] and low misconceptions about cancer[21], leading to reduced stigma. Additionally, involvement of the community members has enhanced the effectiveness of cancer communication in tribal populations[22]. In Meghalaya, community trust and participation can be achieved through the village health council (VHC), which consists of community representatives who work together to improve the health of the tribal communities in Meghalaya[23,24]. The VHCs can serve as a bridge between the healthcare system and the community by helping raise awareness and dispelling misconceptions, improving programme participation, tracking high-risk individuals, encouraging them to seek treatment, and addressing stigma-related issues.

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Conflicts of Interest: None.

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