News feature

An Accredited Social Health Activist and her supervisor visit a family in Mawphlang village during an awareness campaign.

INDIA'S SOCIAL HEALTH ACTIVISTS ARE TACKLING CANCER IN RURAL COMMUNITIES

They focus on primary health and disease prevention through behavioral change, while building trust with the local community. **By Meenakshi J.**

It is noon and Darilin Blah is visiting a cancer patient at Mawphlang village, part of the East Khasi Hills district in India's northeastern state of Meghalaya. Darilin is a 48-year-old Accredited Social Health Activist, one of more than 6,000 in the state. Social health activists play a crucial role in providing primary health care services to local communities, acting as an interface between the community and public health system.

Darilin is draped in traditional Khasi *jainsem*, a traditional two-piece garment draped over a blouse and skirt. But it has been raining incessantly for 2 days owing to Cyclone Sitrang, which makes it difficult for Darilin to venture out of her home.

Darilin, like many others in Mawphlang village, belongs to the Khasi tribe, one of the earliest ethnic groups to settle the Indian subcontinent. The Khasi are architects of the living root bridges crafted from fig trees and
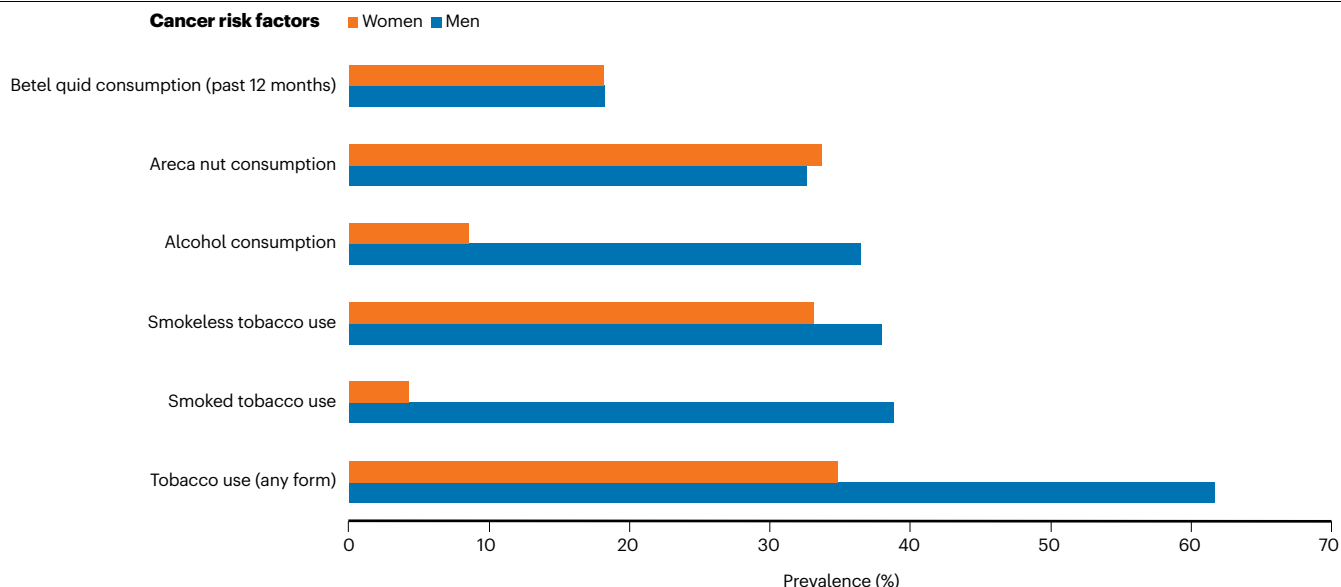
Fig. 1 | Cancer risk factors.

guardians of the biodiverse 'sacred groves' of the East Khasi Hills. The Khasi tribe inhabits the mountainous eastern terrain of Meghalaya and parts of the adjoining state of Assam.

Cancer stigma

Darilin walks to the far end of Mawphlang, to a compact dwelling painted in shades of blue and brown. Lying on a cot is a frail 50-year-old man, K (who preferred not to be named), who greets Darilin upon seeing her. The patient quickly pulls a blanket to his chin for comfort from the sudden chills he has been experiencing and requests that the doors and windows be shut.

The patient is a father of eight children, and like Darilin from the Khasi tribe, and he was diagnosed with stage IV carcinoma of the esophagus in September 2022. The diagnosis was made at the Mawphlang Community Health Centre, which caters to 96 villages in and around Mawphlang, when he complained of throat pain and difficulty in swallowing. Among his risk factors for cancer was his addiction to chewing tobacco and areca nut, known locally as duma and kwai. This diagnosis led the medical officer at the community health center to refer the patient to an oncologist in Shillong, the capital of Meghalaya, located 26 km from his village.

K's family know of his cancer diagnosis, as do Darilin and the chief doctor at the community health center. But they have not told anyone else. "My father is concerned that we would be an outcast for the villagers, if they get to know of his cancer," says one of K's daughters, "so, he hardly goes out during the day."

There is widespread misinformation and lack of awareness among local people about cancer, says supervisor Hindriland Hynniewta, and so the community health center has been conducting awareness campaigns. However, many residents miss the meetings, says Darilin, as the men are away at work and children are at school.

Hundreds of languages

Social health activists are paid a small stipend to support the health needs of communities across India. They provide maternal care, polio immunizations for children, and communicable disease prevention and control, including for tuberculosis, as well as health promotion around nutrition, sanitation and healthy living.

Every village in India has an accredited social health activist, who is selected from the same village or community and speaks the local language. This is essential in a country of 1.3 billion with many hundreds of languages and thousands of dialects. The local connection is crucial—social health activists often know the family medical history of every member in the community and have a bond of trust with each of them.

Social health activists like Darilin continued their work during the COVID-19 pandemic, providing uninterrupted delivery of health services to the community, as well as helping health centers to screen for SARS-CoV-2 and raise awareness about COVID-19. This service was recognized at the 75th World Health Assembly in May 2022, when the Accredited

Social Health Activist program was given a Global Health Leaders Award from the World Health Organization for outstanding contribution toward protecting and promoting health.

Pandemic data

Almost 1.3 million new patients are diagnosed with cancer each year in India, with India's cancer cases and deaths both increasing, according to the Global Burden of Diseases Study 2019.

The East Khasi Hills district has the highest incidence of cancer, especially esophageal cancer, in the state of Meghalaya. This puts the local indigenous tribes such as the Khasi, who constitute 86% of the state's population, at risk of diminishing. This high incidence is in part due to the ubiquitous consumption of tobacco: 59.8% of men and 34.2% of women consume tobacco either in smoked form and/or in a smokeless form like duma.

The COVID-19 pandemic had a disastrous impact on cancer care, but also saw India gather indispensable public health data. The pandemic allowed the state to analyze the entire health sector, including cancer care and treatments, in more depth than ever before, says Sampath Kumar, Principal Secretary of Health and Family Welfare for the government of Meghalaya. This enabled evidence-based formulation of health policies, especially around the prevention of disease.

"We realized that as of now the whole health sector is modeled on curative lines," he says, "so we designed a 3D model, with focus on

prevention and enabling, apart from strengthening the curative aspects."

The Indian Council of Medical Research (ICMR) and National Centre for Disease Informatics and Research (NCDIR) have now collected fresh data on the incidence, mortality and clinical details of cancer in the country. They found that in 2021, non-communicable diseases accounted for 58.8% of total deaths in northeast India, with cancer responsible for 9.5% of deaths.

A supplementary study concluded that Meghalaya is emerging as the 'cancer capital of India', owing to a variety of causes including widespread tobacco usage, excessive alcohol consumption, lack of access to clean fuel and a scarcity of tertiary cancer care facilities.

Many patients are not diagnosed because of a lack of screening and tools for early detection, says Ravi Kannan, surgical oncologist and director of Assam's Cachar Cancer Hospital & Research Center. The actual number of cancer cases is therefore likely to be even higher.

"Most patients in the northeastern states are in advanced stages of cancer, due to lack of awareness and early detection," says Kannan. "The onus to rectify this lies with the government machinery."

Kannan believes that a shift in socioeconomic demography and lifestyle are the main causes of cancer in northeastern states like Meghalaya – with usage of tobacco, alcohol and fermented areca nut and consumption of smoked and fermented food being widespread, including among children (Fig. 1).

Sampath agrees and describes a program from the Meghalaya government to create widespread awareness of substance abuse and tobacco consumption, especially amongst children, through collaborations with over 10,000 schools in the state. There is a key role for local welfare societies such as the Synjuk Mawphlang Society, a non-government, nonprofit charitable organization led by Tambor Lyngdoh, and the heads of various traditional village councils.

Lyngdoh visits villages with his team of volunteers and community health workers. They educate tribal communities on health issues, including family planning and the dangers of tobacco consumption. They also learn about the conservation of sacred forests, which can be a source of employment, and the importance of teaching vocational skills to women and young people.

Kannan provides cancer treatment for free or at subsidized prices through the Cachar Cancer and Research Hospital on the outskirts of Silchar, in the Barak valley of neighboring Assam state. Most of his patients are daily wage workers and agricultural laborers, including those who work in the tea gardens.

Village health councils

The Meghalaya government is implementing Village Health Councils, with 50% women elected to them, by leveraging existing village councils in the state – 7,000 have been established since March 2022. The inclusion of women in these councils was considered essential for community participation and to fix behavioral problems like tobacco consumption among children.

Both men and women need to be involved, says Sampath. Multigravida status, or multiparity, in which a woman has more than five pregnancies, is quite common in Meghalaya and is correlated with a higher risk for cervical cancer.

"To create an awareness about the risk posed by multiparity, the participation of the male member is extremely important, when counselling the female partner," says Sampath.

Kannan believes that health-seeking and health-adopting behaviors will happen only with improved economic conditions. Many cancer patients delay medical intervention because of financial burdens, although a new government health insurance scheme, Pradhan Mantri Jan Arogya Yojana (PM-JAY), is changing this for the better, he says. Such schemes offer financial support when cancer is detected, but do not usually include funding for prevention, such as early detection and screening.

Indeed, the costs of universal cancer screening would be prohibitively high in a highly populated country like India, believes Kannan. Instead, he believes that the government should focus on identification of the early signs of cancer by social health activists, which would be relatively inexpensive.

There is hope that the government, non-governmental organizations and the social health activists can work hand in hand – with community participation.

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