



# The Conundrum of the Cancer Burden and Disparity in Cancer Care Delivery in Northeast India, with Special Reference to Nagaland

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## Introduction

Cancer is a leading contributor to mortality worldwide with approximately nine million deaths in 2020.<sup>1</sup> India accounted for an estimated 7% of cancer cases worldwide with common cancer sites in the breast (14%), lip, oral cavity (10%), and the cervix uteri (9%).<sup>2</sup> Further, the highest estimated mortality rates were due to cancers of the lip, oral cavity (13%), lung (11%), and esophagus (8%).<sup>2</sup>

India has a diverse sociocultural population with unique habits and dietary practices; the incidence of cancers varies geographically due to the interplay of the genetic determinants and environmental factors.<sup>3</sup> The Northeast (NE) region<sup>i</sup> lies on the Eastern border of India and is inhabited by indigenous communities distinctive by a complexed transition zone of cultural, ethnic, religious, and linguistic diversity.<sup>4</sup> Further, these populations share their genomic pool with the southeastern region of China where nasopharyngeal carcinoma (NPC) is common. Comparatively, the incidence of NPC is higher in the NE region than in the rest of country.<sup>5</sup> Furthermore, there are higher incidences of specific types of cancer, such as the departure in the leading cancer site among males from the NE region to the rest of India (ROI).<sup>6</sup> Cancer of the esophagus is the common cancer site in the NE region compared to lip and oral cancer in ROI.<sup>6</sup>

Given the high incidence of cancer in the NE region with distinct clinical presentation compared to the rest of the county, this article highlights issues on cancer burden and the disparity in the cancer care delivery, and discusses ways to address the same.

## Cancer Burden in Northeast India

The NE region is the cancer hub of India, with the highest incidence of adult cancers of the upper aerodigestive tract<sup>ii</sup> (UADT) among both sexes worldwide.<sup>7–9</sup> The highest cancer incidence from the NE region is from Kamrup Urban District in Assam, with the cancer of the esophagus being the most common among both the sexes (28.1% in males vs. 39.3% in females).<sup>7,9</sup> The major contributors to UADT are related to the consumption of tobacco—oral or smoking—alcohol, food habits such as consumption of betel quid, smoked meat, low intake of fruits, infection with Epstein–Barr virus, and poorly ventilated houses.<sup>7–9</sup> Reporting on tobacco consumption among the patients diagnosed with UADT, Kataki et al highlighted that 82% of the patients had tobacco habits, with male patients consuming more than female patients (88.1 vs. 63.2%).<sup>8</sup> To put things in perspective, the median age for esophageal cancer among males is 56 years in the NE region compared to 62 years in the ROI.<sup>6</sup> Similarly, the onset of breast cancer is earlier among females from the NE (47 years) than in the ROI (54 years) due to genetic predisposition and high prevalence of triple-negative breast cancer.<sup>6,10</sup>

Apart from cancers of the UADT, the unique sociocultural elements of the NE region also contribute to site-specific cancers. The cancer of the cervix was the leading cancer site for females in Nagaland, Mizoram, Arunachal Pradesh, and Tripura.<sup>9</sup> Despite the known risk factor of infection with HPV-16<sup>iii</sup> and HPV-18 for the cancer of the cervix, it is implied that the causal factor is multifaceted given the resource-constrained setting to receive timely medical care. The state of Arunachal Pradesh had the highest alcohol

<sup>i</sup> Northeast region of India includes the state of Arunachal Pradesh, Assam, Manipur, Meghalaya, Mizoram, Nagaland, Sikkim, and Tripura. Further, the name is also interchangeably used as Northeast or NE or NE region throughout the article.

<sup>ii</sup> Cancers of the upper aerodigestive tract include the lip, tongue, mouth, pharynx, larynx, and the esophagus.

<sup>iii</sup> HPV is an acronym for human papilloma virus.

consumption in the country, leading to the most number of liver cancer cases in the NE region.<sup>9</sup> The cancers of the stomach were found to be highest in the state of Mizoram and attributed to cultural food habits such as the consumption of smoked meat and fish, fermented pork fat, and the use of alkali in food.<sup>9</sup> Similarly, given the geographical location of Assam with the presence of waterbodies (e.g., Brahmaputra), the incidence of cancer of the gall bladder was the highest in the NE region. These were attributed to the presence of cadmium, iron, and lead in the local waterbodies, pesticides, and adulterants in mustard cooking oil.<sup>9</sup>

### Systemic and Infrastructural Challenges to Cancer Care in Northeast India

On a systemic level, Ngaihte et al reported that the NE states have inadequate hospitals to cater to the region's high incidence of cancer patients.<sup>11</sup> They highlighted that the number of cancer-treating hospitals in a given state did not equate to seeking treatment in the same. Similarly, the lack of trained medical professionals and services drove patients diagnosed with cancer to seek medical treatment out of state. For instance, the states of Arunachal Pradesh, Manipur, Sikkim, and Tripura have only one cancer-treating hospital, each with very few radiotherapy facilities.<sup>12</sup> It was estimated that 5% and 42% of the patients from Sikkim and Nagaland seek treatment from within the NE region, respectively. Further, 95% of the patients from Sikkim avail treatment from outside the NE region as compared to 58% from Nagaland.<sup>6</sup> The ramification of poor infrastructures is such that there are delayed diagnosis and treatment, early mortality from treatable cancers, and out-of-pocket expenditure (OOPE).<sup>6,9,13</sup>

### The Burden of Out-of-Pocket Expenditure in Cancer Treatment

Given the poor infrastructure, patients have to avail out-of-state treatment, resulting in expensive OOPE. In India, the mean monthly OOPE in the year 2017 to 2018, for patients diagnosed with cancer, was Rs 6,549 and Rs 8,811 for inpatient and outpatient care, respectively.<sup>13</sup> The NE region had the highest monthly OOPE in inpatient care at Rs 11,105, followed by South India at Rs 9,834. Further, the healthcare burden was highest for patients opting for private hospitals (58%) to public hospitals (63%), with patients from the South and NE regions reporting the highest from outpatient visits.<sup>13</sup> This expenditure weighs heavily on the families too. For an individual diagnosed with cancer, a family's financial support plays an important role in the continuity of cancer care. For instance, most of the patients had to depend on their earnings and savings to pay for health services. Additionally, to pay for the inpatient care, the patients and their family had to borrow from others or sell their possessions.<sup>13</sup>

With the roll-out of the world's largest comprehensive national health insurance scheme (Ayushman Bharat—Pradhan Mantri Jan Arogya Yojana) in 2018 for the disadvantaged socioeconomic population of the country, accessibility to

healthcare services is made available. This health insurance scheme covers secondary and tertiary care hospitalization at Rs 5 lakhs per family per year in empaneled private and public healthcare services.<sup>14</sup> Presently, cancer schemes such as the Chief Minister's Free Cancer Chemotherapy Scheme by the state government of Arunachal Pradesh provide its residents with free consultation and medicines worth Rs 10 lakhs per patient in a year. The Government of Tripura provides a pension scheme for cancer patients of Rs 600 per month. As part of the Assam Arogya Nidhi, the Assam government covers cancer treatment, such as chemotherapy and radiation, for families below the poverty line by providing financial assistance up to Rs 1.5 lakhs.<sup>15–17</sup> However, other NE states need to step up and allocate funds for cancer treatment to lessen the financial burden. Further, patients with health insurance also face challenges when the high cost of cancer care exceeds the limit the insurance provider gives.<sup>13</sup> Additionally, besides the medical expenses of the patient, the primary family caregivers also have untold nonmedical expenditures related to travel, food, and accommodation, which are not covered by health insurance plan and incurred more if the treatment is availed out of town. Parallel to the fund allocation, there is a need to focus on early prevention and screening interventions as cancers with high incidence and mortality, such as the oral, cervix uteri, and the breast, are preventable through early detection.<sup>18</sup>

### Early Prevention and Screening Interventions to Reduce the Cancer Burden

Low health literacy is associated with limited awareness about cancer screening, the lack of desire for screening, difficulty in understanding screening guidelines, perceived barriers in accessing and navigating the healthcare system, and difficulty in treatment decision-making.<sup>19,20</sup> A study from the NE region reported that despite the high incidence of tobacco-related cancer, almost half (41%) of the participants were unaware of oral, mouth, or tongue cancer. Further, awareness of cancer screening was also low (34%).<sup>18</sup>

The National Family Health Survey (NFHS-5; 2019–2020) found that Assam, Nagaland, and Tripura had the lowest cervical examination within the NE region.<sup>21</sup> For breast examination, attendance was lowest in Sikkim, Nagaland, and Arunachal Pradesh.<sup>21,22</sup> Assam, Nagaland, and Meghalaya recorded the lowest for oral cavity examination among females.<sup>21</sup> For females, screening attendance was better in urban areas. However, for oral cavity examination among males, uptake was better in rural areas, with Tripura and Nagaland reporting the lowest attendance.<sup>21</sup> On a national level, Mizoram ranked third in cervical and breast examinations, while Sikkim was placed second for oral cavity examination.<sup>21</sup>

Given the dearth of studies reporting from the NE region in understanding uptake and barriers to screening behaviors, studies from other parts of the country show that Indian women were reluctant and disappointed to participate in cervical screening as they had no symptoms but had expected treatment for other health-related issues for which

they were experiencing symptoms.<sup>23,24</sup> Consequently, it is possible that negative or unmet expectations may result in dissuading women from participating in future screening programs or follow-ups. Likewise, higher rates of loss to follow-up have been found when diagnostic follow-up with colposcopy or biopsies was not given on the same visit.<sup>25,26</sup> Therefore, a “screen and treat” at the same visit proposal was made to minimize delays and loss to follow-up. These findings suggest that it is important to consider individual experiences, knowledge, expectations, and cultural differences in cancer screenings.

Cultural adaptation to awareness campaigns and interventions on tobacco control, alcohol abuse, and risks of certain ethnic food habits should be implemented through media, counseling, and local support.<sup>9,23</sup> Given the significant investments in financial resources, workforce, and substantial work to organize and sustain screening camps and programs to improve health services, a need to involve a variety of stakeholders (e.g., family members, social scientists, public and private healthcare partnerships) becomes imperative for the successful implementation of screening programs and health campaigns.

### Role of Family in Cancer Care

Given the high incidence of cancer in the NE region, the family's role is pivotal in supporting its family member diagnosed with cancer. It is observed that the participation of the primary family caregiver(s) in the consultation helps improve communication with the physician(s), adhere to the treatment regimen, and yield improved health outcomes.<sup>27</sup> Further, the involvement of the primary family caregiver(s) in the cancer trajectory acts as a gatekeeper in safeguarding prognosis and treatment-related information based on the response by the patient.<sup>27</sup> Apart from medical-related support, the family plays an important role by providing financial assistance and addressing the psychosocial concerns of the patient. For instance, Imchen highlighted the emotional support of the family as a contributing factor to resilience in the patient which resulted in adherence to the treatment regimen.<sup>28</sup> Given the collectivist nature of the society, the family and the community serve as a buffer for the patient to fall back to and collectively share the pain and hold space when transitioning from treatment to palliative care.

### Navigating Healthcare Services in Nagaland—A Special Reference

Among the NE states, Nagaland is observed to be one of the highest per capita burden of cancer.<sup>6</sup> The cancer of the nasopharynx is reported to be the highest in the country.<sup>9</sup> This is attributed to the presence of a genetic risk possibly hinted toward the southeastern region of China, widespread consumption of tobacco, food habit that includes smoked meat and fish, and poorly ventilated house.<sup>5,9</sup> Despite the high cancer incidence in the state, the public health infrastructure is underdeveloped. This includes a lack of trained workforce and a lack of tertiary healthcare facilities, such as

an absence of a medical college (the only state in India), a state cancer institute, and a regional cancer center. Further, there is only one radiotherapy facility in the six cancer-treating hospitals and the absence of a positron emission tomography scan in the entire state.<sup>6</sup>

Consequently, there is a general sense of mistrust in the general public when it comes to availing public healthcare services, with preference given to private healthcare services, especially for tertiary healthcare. Most tertiary healthcare services are availed out of the state, posing practical challenges.<sup>29</sup> While some cases are referrals made by the physician to other hospitals out of the state, most individuals have to navigate the healthcare systems by themselves. Such individuals and their families often have to rely on word of mouth from family, friends, and relatives to choose the physician and the hospital.

Furthermore, Imchen reported that the OOPE by the patients during their treatment surpassed their annual household income.<sup>28</sup> A patient with an annual household income of Rs 70,000 spent Rs 5,00,000 in their treatment expenses.<sup>28</sup> This complex pathway to accessing health services led to delayed diagnosis and expensive treatment processes with poor health outcomes.

Responding to the dire need for appropriate healthcare, on August 2018, the Government of Nagaland signed a Memorandum of Understanding with Tata Trusts to implement a program for providing a comprehensive tertiary cancer care center in the state capital.<sup>30</sup> The main agenda is making cancer care in the public health system more accessible and affordable.

### Way Forward to Address the Cancer Burden and Disparity in Cancer Care Delivery

#### Hub and Spoke Model

Given the pooling of healthcare services in places of commercial and political importance, there is a polarization of accessibility to healthcare with the marginalized and low-income groups being affected the most. Further, the country's scattered geography and multicultural population poses a challenge in implementing quality health systems. Therefore, there is a proposal to adopt a hub and spoke model in healthcare.<sup>31</sup> This model is based on a centralized hub that hosts tertiary healthcare services. On the other hand, the spokes oversee the primary and secondary healthcare services. In this manner, resource allocation is optimized while minimizing cost, a key feature that is important for low- and middle-income countries.

#### Patient Navigation

To address the growing concern of unequal cancer burden in the country, Tata Memorial Center, a premier cancer center in India, in collaboration with the Tata Institute of Social Sciences, developed a full-time, 1-year Post Graduate Diploma in Patient Navigation (KEVAT).<sup>32</sup> It seeks to implement a similar template in the resource-constraint Indian health system scenario by providing a structured form of access and care for the patients in their cancer trajectory. A first of its

kind in the country, KEVAT was launched in the year 2018. The patient navigation program attempts to create a workforce to help the patients diagnosed with cancer and survivors to access care, navigate the complex health systems, consult with the team of physicians, treatment, rehabilitation, insurance, and palliative care.<sup>32</sup> Further, the patient navigators help to create a buffer to the ever-growing load on the healthcare professionals.

### Physician Assistants

Similar to the patient navigators, the role of physician assistants merit attention to diffuse some of the responsibilities of the medical care professionals.<sup>33</sup> Physician assistants work closely and physicians supervise it. They are responsible for holding numerous duties in various disciplines in the healthcare system. The physician assistants hold limited license to practice and can examine patients, order diagnostic tests to carry out, interpret test results, provide medical information, and prescribe medications.<sup>33</sup> Given the nature of their role, physician assistants have immense scope to provide cost-effective and pragmatic solutions to our fragile healthcare system.

There is also a need to scale up patient navigation and physician assistant programs nationwide to tackle short-staffed medical care professionals and improve care and delivery of health. Specifically, to create a sustainable, long-term accessibility to cancer care in the state of Nagaland, there is an imperative need to set up a medical college to put the basic health systems in place, without which the operation will not be successful.

Furthermore, the implementation of e-health in disseminating health awareness can be an added advantage. Given the psychological distress involved in cancer diagnosis, it is pertinent that social workers, counselors, and health psychologists provide services in the cancer care continuum. This would enhance the triadic communication (patient, primary caregivers, and physician(s)) for effective adherence to treatment regimen and agency over medical decision-making. Additionally, given the unique multicultural setting of the country, a culturally and socially appropriate approach should be incorporated into the programs to focus on inclusivity and equitable access to cancer care.

#### Note

The manuscript, "The conundrum of the cancer burden and disparity in cancer care delivery in NE India, with special reference to Nagaland," has been read and approved by the author (Matsungshila Pongener) that the requirements for authorship have been met, and that the author believes that the manuscript represents honest work.

#### Authors' Contributions

Matsungshila Pongener contributed to the concept, intellectual content, literature search, manuscript preparation, manuscript editing, and manuscript review.

#### Conflict of Interest

None declared.

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