RESEARCH ARTICLE

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Mapping Choice of Healthcare Institutes for Cancer Care: A Study in Northeast India

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Abstract

Objective: To map and identify the sequence of visitation to institutes by patients with common cancers. **Methods:** This paper used a mixed method to follow a descriptive multiple-embedded case study. Participants selected in phase one were 388 by stratified random sampling, and in phase two, by purposive sampling, a semi-structured interview was conducted for 21 participants (15 participants and six key informants-oncologists: radiation - 2, medical - 2, surgical - 1 and gynaecology - 1). Ethical clearances were received from the study institutes. Informed consent was obtained from the participants. **Results:** Sparse research exists on mapping and choices of healthcare settings by cancer patients from northeast India. The main finding comprises a vivid overview of the decisions taken by cancer patients to get their necessary treatment based on all factors mitigating and inhibiting. Up to five hospitals for cancer treatment across the country. Private hospitals were preferred on the first visit by 74 percent (287), followed by the government by 26 percent (101); this, however, changes in subsequent hospital choices, with the latter preferred over the other, which could be due to the long duration of cancer treatment that is directly influenced by the paying capacity of the individual. Visitation was not limited to famous cancer hospitals, but few participants reported accessing herbal medicines, Ayurveda and Homoeopathy. **Conclusion:** Mapping patient choices of cancer institutes by patients from northeast India is essential as the challenges faced are unique to the region. By mapping patient choices of cancer institutes, insights into the preferred healthcare facilities can influence policies to improve the accessibility of cancer facilities. Findings from this study can support improving access to quality healthcare services, promoting cultural sensitivity, enhancing the quality of care, and informing policy planning and resource allocation.

Keywords: Barriers- cancer- cancer care access- northeast India- mapping cancer institutes

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Introduction

Mapping the journey of a patient in cancer care access is sparse. A narrative review from the patient's perspective (Devi et al., 2020; Gaulandi et al, 2019; Joffe et al., 2003) in non-communicable disease presents the current work is concentrated on the high- income countries and limited to low-income countries. However, the existing literature on patient-provider satisfaction and their relationship is a factor that influences decisions to initiate or continue cancer care services in a hospital. Studies in Mexico and the United States of America (Joffe et al., 2003; Jalem, 2020) report that the key to an efficient outcome in patients care services. was, shared decision-making, less waiting time and proper instructions from doctors or nurses on medication enhanced patient satisfaction continue their treatment.

In India, cancer patients take a long and often difficult path to walk the line for their cancer treatment. For instance, research in India (Datta et al., 2022) found that it takes one to nine months from the appearance of cancer symptoms to the first consultation with a doctor. After visiting multiple hospitals, it takes three to twenty- four months to reach a specialist cancer centre. Such a scenario reflects the need to address social determinants to understand the treatment outcomes of an individual's journey for cancer care. India's healthcare sector provides a wide range of care, from globally acclaimed hospitals to facilities that deliver care of unacceptably low quality. Efforts to improve the quality of care are particularly challenged by the need for more reliable data on quality and by technical difficulties in measuring quality (Datta et al., 2022; Mohanan et al., 2016). While several studies in India (Broom and Doron, 2012; Narayana, 2017) illustrate the lack of knowledge or failure to transform this knowledge by the public to practice cancer prevention and treatment, there is a gap in understanding the sequence of visits undertaken by cancer patients. This paper discusses the choice of institutes, sectoral preferences and list of cancer hospitals with a sequence of visitation of the participants seeking cancer care. Mapping the institutes, the study participants accessed in their quest to seek care is described in this

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paper by the sectoral type and facilities available in these institutes. This information could help understand patient behaviours, preferences, and patterns in accessing cancer care. This paper uses visual representation for network mapping by showing the connections between patients and the hospitals they have accessed and visualizing patients' visits to different states.

The aim of the study was to map and identify the sequence of visitation to institutes by patients with common cancers. This information was gathered by triangulation of findings from both the phases with examination of patient medical records and other secondary data.

Materials and Methods

This paper followed a descriptive multiple-embedded case study design (Yin, 2009) with a mixed method approach combining quantitative and qualitative methods. This approach allows the gathering of both in-depth and quantitative data, leading to a more comprehensive understanding of the research problem. Quantitative methods provide a systematic way to collect numerical data and test hypotheses, while qualitative methods offer rich and in-depth insights into the experiences, perceptions, and perspectives of the individuals. Each case was treated as a separate study in itself comprising of five common cancers (oral, lungs, stomach, breast and cervix) which are embedded and the results of each is used to build a comprehensive understanding of the larger phenomenon of cancer care access phenomenon in the study area. The use of multiple cases allows for the examination of a phenomenon from different perspectives, and helps to increase the generalizability of the findings. It also allows for the comparison and triangulation of data across cases, leading to a more robust and thorough understanding of the complex and diverse phenomenon of access to care for common cancers in northeast India.

Integrated theoretical framework

In an array of settings in healthcare, a person pursues a means to solve its health disparities. Amidst the task of sorting out a facility, physician, treatment and financial solutions, it is the ease of the process which is primal for such accomplishment. The need and appropriateness of utilizing or refraining from this avenue compels one to look beyond the enumerations of deficits in infrastructure, or shortage of human resources. An integrated model (Gittel, 2009; Thomas and Penchansky, 1984) was therefore utilized as a guiding reference since not one model is sufficient. The integrated model discussed comprises of, (i) Thomas and Penchansky Theory of Access and (ii) Relational Coordination framework of Jody Hoffer Gittell. Thus, enabling a rich insight to the phenomenon of understanding cancer care access.

Using the report of National Centre for Disease Informatics and Research, 2017 (National Centre for Disease Informatics and Research, 2020) as a guide, the participant selection in phase one followed a stratified random sampling procedure to ensure equal representation from each stratum of common cancer sites of oral, lung, stomach, breast and cervix. The sample size was calculated as $n=N/1+N(e)^2$, where n is the sample size, N is the population size, and e is the level of precision or error limit. With a 95% confidence interval and e of 0.05, the sample size is $n=14,845/1+14,845(0.05)^2$, which equals n as 390. Excluding male breast cancers (<10), the final sample size was 388 (breast-86, cervix- 57, lung-68, oral-96 and stomach-81). In phase two, 21 participants (15 participants and six key informants-oncologists: radiation - 2, medical - 2, surgical - 1 and gynaecology - 1) were selected by purposive sampling for a semi-structured interview. The inclusion criteria for both phases were participants diagnosed with common cancers who had visited hospitals outside their domicile state for any consortium of cancer services and have now returned to their state cancer institute to continue their cancer care. The interaction with the participants and key informants was conducted in the study sites.

Phase one

In phase one, a questionnaire was administered to the participants. The questionnaire comprised of three parts; (i) Socio-demographic information; (ii) Healthcare; and (iii) Cancer care.

Phase two

In phase two, a semi-structured interview was conducted with the key informants and in consultation with them the patients were identified and interviewed. The sampling recruitment stopped on reaching a saturation point when no new themes emerged. All the interviews were conducted face to face, with each interview lasting from around 30 to 50 minutes. With the participant's approval, each interview was recorded along with hand-written notes taken by the researcher. Each transcription was cross-referred with the audio recording and hand-written notes for accuracy.

Study setting and participants

The study was carried out in two cancer institutes in Arunachal Pradesh and Assam in northeast India. Both these states have cancer incidences above the national average (NCDIR, 2020). One out of every four males in the Papumpare district, Arunachal Pradesh and Kamrup urban, Assam and East Khasi Hills district were likely to develop cancer in the age group 0-74 years. In the Papumpare district, Arunachal Pradesh, one in four females had a chance of developing cancer in the age group 0-74 years. A comparison of the registries showed males in northeast India had higher risks, whereas, in females, registries other than the northeast had a higher risk for cancer (NCDIR, 2020). Few registries in Arunachal Pradesh and Assam are among the highest AAR per 1,00,000 population all sites within the country, in Asia and the world.

Data collection and analysis

The data collection was carried out from February 2021 to January 2022. The quantitative data were assessed for an association by chi-square and Kruskal-Wallis H test. The qualitative data were transcribed verbatim following the data codes for emerging themes. Triangulation through cross-case syntheses was done to understand the relationships of the findings.

Results

The results enlist the institute's choices made for cancer services while revealing the perspectives of the patient-provider on the reason and impediment of this journey. Findings from both the phases are discussed by cross-case synthesis and its emerging themes which are (i) sectoral preferences, (ii) entailing outside state visits for cancer care services, and (iii) Facing challenges in accessing care in state cancer institutes.

Table 1. Descriptive Demographic Participant Profile

Profile	Frequency	Percent
Age		
18-39	64	16.5
40-59	208	53.6
60-79	107	27.6
80-89	9	2.3
Education		
Illiterate	98	25.3
Primary	132	34
Secondary	83	21.4
Diploma, graduate & post graduate	73	18.8
Others*	2	0.5
Marital status		
Unmarried †	23	5.9
Married	321	82.7
Divorced	3	0.8
Widowed	33	8.5
Separated	6	1.5
Ethnicity		
ST	123	31.7
SC	14	3.6
OBC	37	9.5
General	213	54.9
Don't know	1	0.3
Size of household		
1-3 members	92	23.7
4-6 members	215	55.4
7-9 members	63	16.2
>10 members	16	4.1
Others ‡	2	0.5
Religion		
Hindu	202	52.1
Christian	62	16
Buddhist	9	2.3
Muslim	76	19.6
Donyi-Polo§	37	9.5
Others ll	2	0.5

*, Monastery education; †,Unmarried comprised of bachelors, spinsters and monks; ‡, Others comprised of monks who lives in the monastery; §, Local animist religion in Arunachal Pradesh; ll, Others comprised of atheist / no religion.

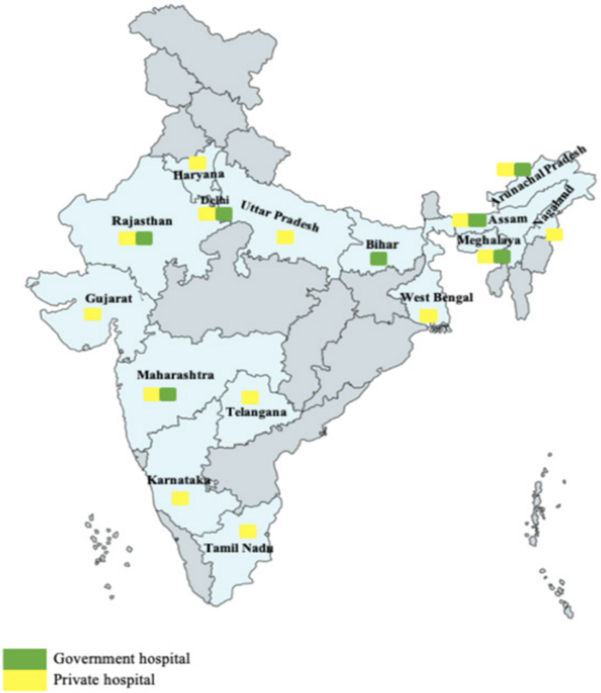

Figure 1. Sector-Wise Hospital Choices for Cancer Care

Participants demographic profile

Participants comprised 57.0 percent (221) women and 43.0 percent (167) from 18 to 89 years, with the median age being 50-59. There was a statistical difference between gender and type of cancer ($X^2(4)=57.7$, p = <0.001). Those who lived in urban areas comprised 66.0 percent, and in rural 34.0 percent (132). The first language was vernacular, as reported by 99 percent (384) of the participants. There was a statistical difference between occupation and type of cancer ($X^2(4)=54.6$, p= <0.001). Health insurance coverage was reported by 59.1 percent (n = 229) by a government scheme. All participants from Arunachal Pradesh have coverage under the Chief Minister Aarogya Arunachal Yojana (CMAAY) for US $6,016.3. In Assam, most participants were covered under Atal Amrit Abhiyan, which gives cashless coverage up to US $2,406.6 per annum. Ayushman Bharat Pradhan Mantri Jan Arogya Yojna gives both states cashless coverage of US $6,016.3. Table 1 includes the descriptive and demographic profiles of participant.

All the participants travelled far and wide from their domicile state in the quest for cancer care. Both public, 26 percent (101) and private, 74 percent (287) hospitals were explored for cancer care. Figure 1 includes the sector wise choices of hospital for cancer care.

Result of the qualitative part of the study

Family decisions were central in deciding visits to cancer institute's outside the state. In a few cases, the travel was because of a doctor's referral for the tertiary cancer centre facing infrastructure shortages. However, the other institute was a comprehensive cancer centre which did not make any referrals. Figure 2 includes the state-wise visitation with district-wise bifurcation for cancer care.

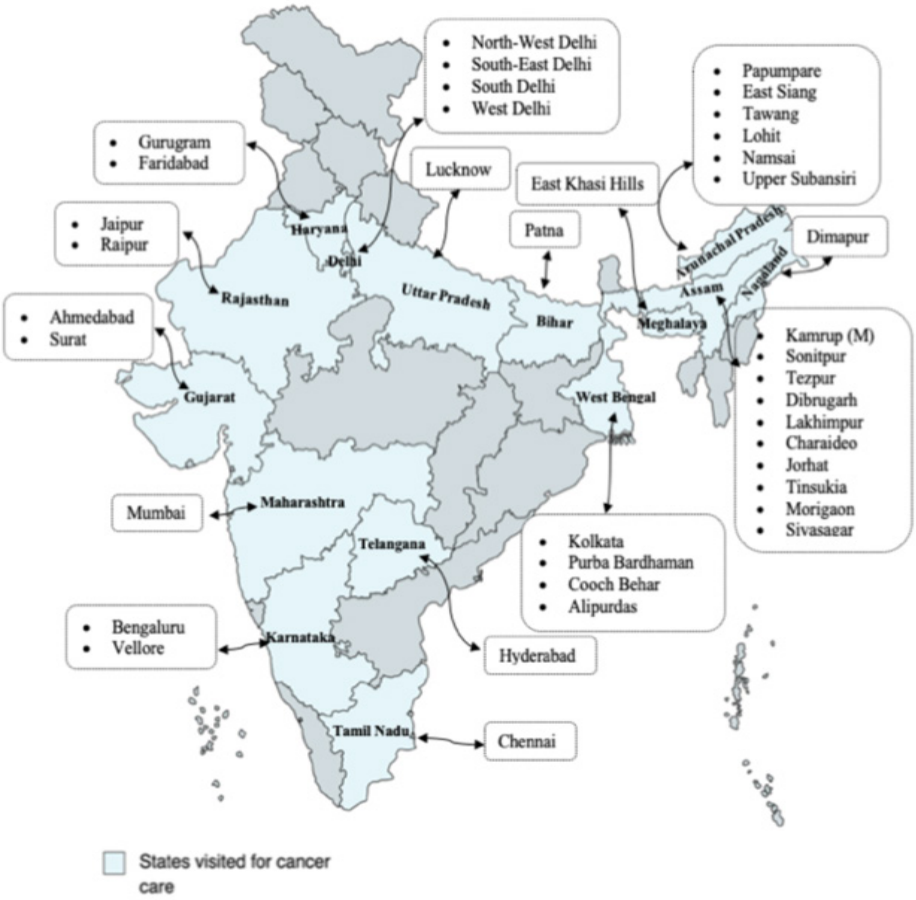

Figure 2. State-Wise Visitation for Cancer Care: District Bifurcation

As echoed by a medical oncologist in service for 15 years:

'Main problem that we face is the lack of investigation facilities in TRIHMS because patients go outside for this purpose. For example, in oral cancers, the operable cases are referred outside because of the non-availability of head &neck oncology surgeons and IMRT or IVRT facilities. Cervical cancer patients are referred for brachytherapy. There is a lack of dedicated ICU and ward for cancer patients. Unavailability of a cardiothoracic surgeon and targeted therapy compels us to refer lung cancer patients'.

Similarly, the likely cause of outside state travel, as explained by a radiation oncologist in service for 16 years as:

'*Lack of awareness of state cancer hospitals. They probably don't know that this can be done in state cancer institute. Secondly, those who go outside the state for treatment could be going due to high waiting times in government cancer institutes. It takes a long time to meet the doctors, to get the investigation, you don't get the appointment easily for biopsy'.*

A 57 years old woman, a home maker with breast cancer from Arunachal Pradesh confirmed this as:

'*I was referred to BBCI for the surgery from NEIGHRIMS, Shillong. I got the surgery done with radiation and chemotherapy. I have stayed in Guwahati*

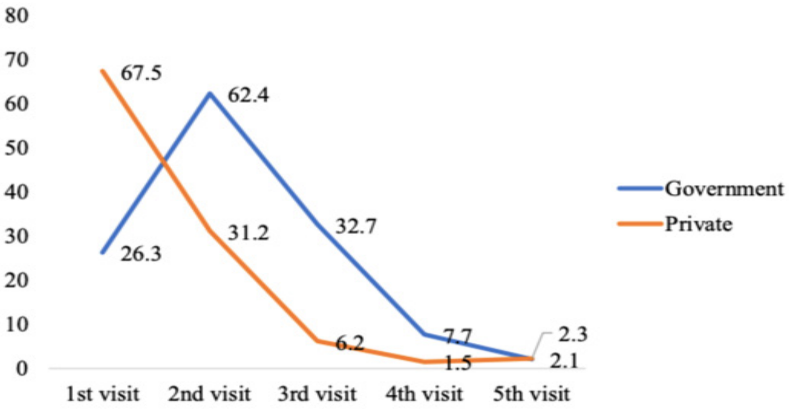

Figure 3. Sequence of Visitation for Cancer Care Access

for one month so far. I have spent around Rs. 5,00,000 (US $6,016.3). Finally, I had a shortage of money and told my doctor. I was surprised when he referred me to our state medical college which has cancer facilities to complete my treatment. I was not aware we have a cancer facility in my state'.

The participants visited at least five different hospitals, with the first visitation in a private hospital, switching to a government hospital on subsequent visits. These preferences from the former to the latter could be due to their return to the domicile state for continuing treatment in a government hospital due to financial constraints and ease of geographical access.

Entailing Outside State Visits For Cancer Care Services

Time is crucial between the first diagnosis and the start of treatment; participants were asked how long it took to get cancer treatment after the first diagnosis. There was variation in the duration of seeking treatment. The time taken for initiating cancer treatment from the first diagnosis ranged from eight to 30 days - 37.9 percent (147), less than seven days – 25.0 (97), two to three months – 24.5 percent (95), more than four months – 12.1 percent (47) and, same day - 0.5 percent (2).

Participants would likely travel to the neighbouring state cancer institute if they lived on the inter-state border; this saved them resources incurred on expenses for cancer treatment. Figure 3 includes sequence of visitation for cancer care access. A 57 years old woman, a homemaker with breast cancer from Arunachal Pradesh, echoed as:

'*I was diagnosed in Assam Medical College, Dibrugarh, where I had gone for consultation. I am from Changlang, and this is the closest big hospital. My diagnosis was confirmed with a biopsy, and I received five cycles of chemotherapy in Dibrugarh'.*

Similarly, a 66 years old man, a retired school teacher with oral cancer from Assam shared:

'I got my consultation and tests done in my state government cancer institute. I was being prepared and scheduled for radiation but I went back home with my family before treatment initiation. A relative of mine who got cured in cancer facility in Arunachal Pradesh suggested we visit it. I told my son to take me there as it was closer for us (approx. 200 km from home) than going to Guwahati (which is 500 km away). Since my treatment started, we have rented a house near the hospital, which is convenient for us'.

The first place for cancer treatment for 41.8 percent (163) was the government hospital of the domicile State. Whereas 37.2 percent (144) preferred the private hospital outside the domicile State as their first choice of cancer care. 13.9 percent (56) availed cancer care in government hospitals outside State. At the same time, 3.4 percent (12) opted for alternative treatment in their domicile State and 0.6 percent for alternative treatment outside State. Herbal medicine was taken as the first choice of treatment by 0.6 percent (23) of the participants. Visitation was not limited to famous cancer hospitals, but few participants reported accessing herbal medicines, Ayurveda and Homoeopathy.

Facing Challenges in Accessing Care in State Cancer Institutes

There was a homogenous difficulty reported by the participants, which were institute specific and a few general hardships. Likewise, the key informants said they, too, faced challenges when providing care to cancer patients. These challenges were cited as treatment delays or loss to follow-up due to financial constraints, lack of awareness of cancer services available in the state, opting for herbal or alternative medicines and infrastructure shortages.

Discussion

The main finding of the study comprises of a vivid overview of the decisions taken by cancer patients to get their necessary treatment based on all factors mitigating and inhibiting. A clear insight into the broader impact of these decisions comes at a cost to the patients, who would have sought a convenient and better alternative to their current choices if given a wider pool of options. Considering the high incidence of cancer in northeast India with increasing travel outside its domicile state, this paper describes the state and district-wise travel, adding to the existing literature to understand the cancer treatment journey of the region. The interaction with the participants brings to light that the visitation to multiple facilities is influenced either by financial status, hospital popularity, distance or testimonials from somebody known. An interpersonal relationship between the patient and the provider is vital to patient satisfaction. In consensus with existing research (Narayana et al., 2017; Chawla et al., 2014; Rozmovits et al., 2004; Greenfield et al., 2014), infrastructural shortages faced by the doctors cause a restrain, forcing the patient to move out of state for cancer care, which aligns with other studies (Brenan et al., 2013; Malhotra et al., 2013). There is a need to emphasize the up-gradation of existing cancer facilities recognizing the constraints faced by the region's participants in accessing its state cancer facilities (News Click, 2018; Bagchi et al., 2022). Hospital preference for private over government is evident in the first visit by the participants in the study. However, contrary to other studies (Azhar et al., 2022; Hossain, 2019; Ngaihte et al., 2019; Ngangbam et al., 2019), in the subsequent choice of hospital, participants lean towards the government, which could be due to the long duration of cancer treatment that is directly influenced by the paying capacity of the individual. The government health insurance scheme (Government of Assam, 2022; Pradhan et al., 2023; Chawla et al., 2014) provide free surgery, chemotherapy and radiation, which helps reduce cost, as revealed in this study. However, substantial research is required to understand these schemes' impact on cancer services in the region. Further research is needed covering all eight states of northeast India to understand the cancer treatment journey within a diverse socio-cultural framework; this will perhaps strengthen policies to reduce the region's morbidity and mortality from cancer. Mapping of choices of cancer institutes by patients from northeast India is essential and this paper identifies findings which can enable existing work to enhance cancer care access as follows:

Access to healthcare

Patients from northeast India often face difficulties in accessing quality healthcare services due to geographical and infrastructural barriers. By mapping patient choices of cancer institutes, healthcare providers and policymakers can gain insights into the preferred healthcare facilities and make efforts to improve the accessibility of these facilities.

Cultural sensitivity

Patients from northeast India have diverse cultural and linguistic backgrounds, which can affect their healthcare choices. Mapping patient choices of cancer institutes can help healthcare providers understand the cultural and linguistic preferences of patients and tailor their services accordingly, thereby promoting better patient-provider communication and satisfaction.

Quality of care

Mapping patient choices of cancer institutes can also provide insights into the quality of care provided by different healthcare facilities. Patients' choices are often based on factors such as reputation, quality of care, and cost-effectiveness, among others. By analysing these factors, healthcare providers and policymakers can identify areas where improvements are needed to enhance the quality of care.

Policy planning

Mapping patient choices of cancer institutes can also inform policy planning and resource allocation. By identifying the most preferred healthcare facilities, policymakers can allocate resources accordingly to ensure that these facilities are adequately equipped and staffed to meet the needs of patients from northeast India.

The study was conducted in cancer institutes in two out of eight states in northeast India, so the findings cannot be generalized to the region. Besides, the selection bias limits only to five common cancers by excluding the other types of cancer. Despite these limitations, the study contributes to mapping the state, district and sectoral bifurcation along with the visitation sequence influencing the choice of the hospital sector, which can strengthen existing policies for patient-provider care and support.

In conclusion, travelling outside the domicile state for cancer care is significant in this paper, adding to the existing literature by delineating state and district-wise visitations. Financial status, geography and testimonials influence the decision on hospital selection. Participants registered in the government health insurance scheme got support for their cancer treatment. Future research examining the impact of these schemes on cancer service beneficiaries will help understand and strengthen the health system delivery in reducing morbidity and mortality due to cancer in the region. Overall, mapping patient choices of cancer institutes by patients from northeast India is essential for improving access to quality healthcare services, promoting cultural sensitivity, enhancing the quality of care, and informing policy planning and resource allocation.

Author Contribution Statement

Kuru Dindi: conceptualization, data collection, methodology, analysis, writing, reviewing and editing.

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Ethical Declaration

Ethical clearances were obtained from the Institutional Review Board of Tata Institute of Social Science (2020-2021-27 dated 18/12/2020), Tomo Riba Institute of Health & Medical Sciences (TRIHMS) (TRIHMS/ethics/01/2019-18 dated 18/12/2020) and Dr B. Borooah Cancer Institute (BBCI) (BBCI-TMC/Misc-01/MEC/289/2021 dated 19/05/2021). Informed consent forms and participation information sheet were given and obtained from the participants in English and Assamese.

Data Availability

The data of this paper's findings are available on request from the corresponding author. The data are not publicly available due to privacy or ethical restrictions.

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