

## **Patient-Provider Relationship in Cancer Care: Insights from a Study in two North-Eastern States of India**

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In the journey to cancer treatment, the doctor-patient relationship is pivotal in strengthening oncology service delivery which is sparingly understood in the study area. In this paper we examine the doctor-patient relationship in cancer care in two states of northeast India. A descriptive multiple-embedded case study approach was followed using mixed methods for breast, cervix, lung, oral and stomach cancers- an integrated framework was a guided referee. In phase one, 388 participants were selected by stratified random sampling and 21 semi-structured interviews in phase two, comprising of patients and oncologists. Cancer patients described their feeling of non-involvement in their treatment due to the condescending behaviour of a few nursing staff with the lack of doctor's visits in day-care chemotherapy centres were described as discouraging. While, the request for non-disclosure of diagnosis to the patient by their relatives and the preference for alternative cancer treatment was a challenge for doctors. Incorporating locally relevant activities such as lotteries has supported patient outreach for cancer care. Relational communication between doctor-patient while acknowledging the psychosocial aspects of cancer patients and incorporating them as a mandatory part of the medical and nursing curriculum will enhance the cancer treatment journey.

**Keywords:** Cancer access, Cancer policy, Cancer health system, Doctor-patient relationship, Northeast India

### **Introduction**

Globally, the rise of cancer incidence is homogenous, burdening its health systems and population. The global scenario of cancer in both sexes is worrying. In males, the cancer incidence is 9.5 million cases, with corresponding mortality of 5.4 million (IARC, 2018). While in females, cancer incidences are 8.6 million cases and mortality at 4.2 million cases worldwide. Changing demographic and risk factors have led to observations that cancer is the first or second leading cause of premature deaths in the age group of 30-69 (IARC, 2020). As per IARC, 2020, 8.2 million new cancer

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and 5.2 million cancer deaths were estimated for South, East and South-East Asia, with China accounting for 52 per cent of new cancer cases and 55 per cent of cancer deaths. In females, the most common cancer in Asia is breast, oral, more common in India and Sri Lanka, lung, colorectum, cervix, stomach, liver and thyroid. The rising incidence of breast cancer around the globe and in several countries in Asia – India, Japan, Thailand and Turkey (IARC, 2020) is attributed to changes in the age of menarche, late first childbirth and low parity. While in men, the common cancers are of the lung, colorectum, stomach, liver, oesophagus and prostate, with stomach and liver cancer being the leading cause of death in men. Declining cancer in high-income countries is considered a result of interventions of prevention, early detection, timely treatment, and ease of access to primary care. However, due to resource constraints, countries continue to face poorer cancer detection and survival outcomes due to the associated barriers.

An estimate (Mallath et al., 2014) of India's cancer epidemiology projects an increase from slightly over a million new cases in 2012 to more than 1.7 million by 2035. These projections indicate that the absolute number of cancer deaths will also rise from about 680 000 to 1.2 million in the same period (Mallath et al., 2014). The most common cancers (incidence and mortality) in India (WHO, 2020) are breast (14.0 per cent and 11.1 per cent), lip-oral cavity (10.4 per cent and 9.3 per cent), cervix-uteri (8.4 per cent and 7.7 per cent), lung (5.9 per cent and 8.1 per cent), stomach (5 per cent and 6.6 per cent) and colorectum (4.9 per cent and 5.5 per cent).

A comparison across cancer registries in the NCDIR, 2020 recorded per one lakh population for all sites of cancer combined were highest in Aizawl district in Mizoram (269.4) among males and Papumpare district in Arunachal Pradesh (219.8). While the lowest cancer incidence, male (39.5) and female (49.4), for all cancer sites, were for the districts of Osmanabad and Beed in Maharashtra. An estimate (Mallath et al., 2014) of India's cancer epidemiology projects an increase from slightly over a million new cases in 2012 to more than 1.7 million by 2035. These projections indicate that the absolute number of cancer deaths will also rise from about 680 000 to 1.2 million in the same period (Mallath et al., 2014). The Global Burden of Disease Study conducted from 1990-2016 suggests a variation in cancer burden in India. The cancer epidemiology of India is heterogeneous in its spread and varies across the country, with risk factors unique to each region. The northeastern states are quickly pacing up to become India's leading region for cancer by having a higher distant metastasis and a low survival rate. India relies on its cancer registries to understand the trends and burdens in the country (NCDIR, 2020). Out of the 28 Population Based Cancer Registries and 58 Hospital Based Cancer Registries, there are 12 registries in the eight states of northeast India. These registries are located in urban areas, and the reports could be an underestimation considering the rural concentration of the population. Notifying cancer is the first step for provider and user action but not enforced in India. However, cancer has been made a notifiable disease vide administrative order in four out of eight states in the region, viz. Arunachal Pradesh, Assam, Manipur and Tripura (NCDIR, 2017). Such steps are essential in building resilience in emphasising population coverage to provide means for efficient measures

of interventions for cancer. Existing studies in northeast India focus on clinical research with limited studies (Ngaihte, Z, & Kaushik, 2019; NCDIR, 2020; Soumya, 2022; Datta SS et al., 2022) on understanding the relationship between doctor and patient in the journey to cancer care.

Recognising the rise of cancer incidence in India, the importance of the doctor-patient relationship will significantly impact treatment adherence and, thereby, the cancer epidemiology in the country (WHO, 2022; IARC, 2020 & Selvaraj, S., Karan, A. K., Srivastava, S. et al., 2022). While the availability of data on cancer has improved considerably, research on understanding the doctor-patient relationship in oncology is sparse but upcoming, particularly in developing nations. A systematic review (Selvaraj et al., 2022; Mallath K.M. et al., 2014) covering the period from 1997 to 2021 identifies the failure to address social inequalities and weaknesses in the country's public health system to deliver preventive services. In contrast, India has a passive approach towards cancer screening, although the inclination for breast and cervical cancer screening is more evident than for other sites. The metropolitan cities and urban areas witness a full range of cancer screening while the effort is sporadic as rurality marks the place. From a policy and regulatory perspective, this has enormous implications for translating these findings into individual and population health intervention. Screening for cancers is central to preventing and controlling cancers, but its inequity persists globally. Even when free-of-cost cancer screening is available, acceptance remains low in the high-risk groups (IARC, 2020; Gravitt, P.E. et al., 2010). Existing studies highlight cancer risks and access to facilities has a social and spatial context which could affect how services are accessed. Rural areas experience primary care gaps exacerbated by insurance issues, further limiting access to cancer screening. An analysis of a five-year breast cancer registry in Illinois, USA (McCafferty, S. (2011) showed an increased risk of breast cancer in urban areas. This study examined breast cancer trends in a multi-level model classification of rural-urban place contexts. While for African Americans, the findings were reversed with increasing incidence for those living outside Chicago, suggesting a distinct set of health risks and place experiences that inhibit breast cancer detection, including language barriers and access to primary care doctors in the first place. Cancer interventions in India comprise national programs, policies for administering cancer services and schemes that cater to the needs of cancer patients at the national, state and institutional levels. The public and private sectors provide the country's cancer services. The public sector caters its services through Regional Cancer Centres (RCC), State Cancer Centres (SCC), Tertiary Care Cancer Centres (TCCC) and Comprehensive Cancer Centres (CCC).

In 2010, the National Programme for Prevention and Control of Cancer, Diabetes, Cardiovascular Diseases and Stroke (NPCDCS) was launched, integrating the prevention and control of all Non-Communicable Diseases (NCDs). Under the NPCDCS, several screening camps are conducted for Diabetes, Hypertension and common cancers such as the oral, breast, and cervix. However, the cancer screening program is not uniform across states. Even the available free screening programs need to be more utilised due to a lack of awareness, social misconceptions and urban

coverage. In addition, there is a dearth of research on the screening programs done by private enterprises or on the opportunistic oral cancer screening by dentists (Subash A. et al., 2022, Sahu D. P. et al., 2020; Mohan P. et al., 2020). Studies in India on cervical cancer screening (Chawla B. et al., 2021, Sahu, D. P. et al., 2020; Mohan P. et al., 2020) have found amongst healthcare professionals, the knowledge and attitude toward cervical cancer screening were optimum, but the uptake of its practice was low. There is poor detection and screening of other common cancers in India. Barriers faced by a cancer patient propels the impediments faced by the primary care provider to ensure interventions. Emphasising the importance of cancer screening can only be realised when primary care providers are equipped to diagnose and detect cancers in their routine practice. Such as found in a study on the screening for lung cancers in the United Kingdom (Schiffelbein, J. E., et al., 2020), where a lack of knowledge and gap in clinical guidelines for lung cancer screening did impact access to cancer care. The provider barriers are necessary for ensuring interventions are guidelines followed by the primary care provider to the patients availing these services. Understanding how cancer risks vary socially and spatially is critically essential in planning and improving the locations of cancer screening and prevention (McCafferty, S., 2011). These weaknesses have limited India's ability to protect its citizens from the key causes of cancer and treat the disease in a timely and successful way when it occurs (Selvaraj et al. et al., 2022; Mallath et al., 2014).

Although, the establishment of the National Cancer Grid (NCG) has transformed how care in cancer is accessed in India by using digital platforms for expert opinions and reducing time lags in treatment or patient travel. The NCG is amongst the most significant cancer networks in the world, formed with the primary mandate of working towards uniform standards of patient care across India by adopting evidence-based cancer prevention, screening and management guidelines, which are implementable across the country (NCG - Working Group, 2019). NCG aims to create uniform standards of patient care in the oncology continuum of care and facilitate collaborative basic, translational and clinical research in cancer. NCG today has over 270 hospitals across India, networking with cancer centres, research institutes, patient groups and charitable institutions nationwide (Department of Atomic Energy, 2022). Digitalisation has brought expertise in oncology via the NCG to reduce patient costs in time, travel, logistics and treatment. Since the RCC, SCIs and TCCCs are a part of the NCG, consultation and expert opinion are taken up through the NCG, thereby increasing the efficiency of the institutes in providing cancer services while reducing patient lag and treatment adherence. However, the full potential of the convergence of the NCG network is yet to be realised in the country.

Converging all the NCDs into one national program could not be the best strategic approach in its control. Delineating each NCD with dedicated surveillance, research, training, and an evidence-based action plan to counter it would enhance the current program, which is slacking in these areas. Enforcement of cancer screening by adequately training health professionals would support cancer detection and identification, which currently the country is lagging. The NCG network should expand the upscaling for strengthening the health system's approach for trained healthcare professionals in efficient cancer services. This network has enhanced how doctor-

patient interaction takes place to enhance the country's cancer care experience.

Existing literature (Marchand, K. et al., 2020; Moor, J. S. De, 2016) suggests that acknowledging the perspective of patient experience by the physician is directly associated with patient satisfaction and treatment adherence. The loss in transition for a cancer patient from active treatment to post-treatment for prolonged survival is crucial (Weaver & Jacobsen, 2018). In such a situation, hand-holding and effective patient-provider interaction is vital for effective action in follow-ups and survival outcomes. Interactions with the cancer patient will give a view on the aspects of anxiety faced and dealt with in the care spectrum. Gomez-Cano, M. et al., 2020; McCafferty, S., 2011 reports the strongest predictors of overall satisfaction of cancer patients were the experience of care administration and care coordination in their studies. Another qualitative assessment of understanding the cancer centre catchment area in the United Kingdom by Reyes C. et al., 2020, found that electronic records and surveillance did not capture inequalities among a diverse population. This assessment concluded that there is an opportunity to unify stakeholders on a joint roadmap, where activities are prioritised and resources shared to target modifiable factors and advocate for needed programs and funding.

Several studies showed that provider accountability is enhanced when consumers gain greater access to information (Akhlaq, A., Mckinstry, B., & Muhammad, K. Bin., 2016). However, the experience of availing of cancer care services is a composite of interaction, consent or willingness to walk on the long journey to complete cancer treatment. A cross-sectional study (Ansmann, L., Kowalski, C., Ernstmann, N., & Pfaff, H., 2012) found that breast cancer patients perceived themselves as receiving less support from the physician when there were problems within the hospitals' care organisation, independent of patient characteristics. The quality of patient-physician communication depends on the patient or physician and the hospital organisation (Berlan D and Shiffman J., 2012). Existing literature (Ansmann, L., Kowalski, C., Ernstmann, N., & Pfaff, H., 2012; Berlan D and Shiffman J., 2012; Olaisen, R. H., Schluchter, M. D., Flocke, S. A., et al., 2020; Marchand, K., Foreman, J., MacDonald, S., et al., 2020) suggests acknowledging the perspective of patient experience by the physician is directly associated with patient satisfaction and treatment adherence.

This paper is based on a broader study conducted in Arunachal Pradesh and Assam, focusing on access to cancer care. These two States share high cancer incidence and cross-refers patients amongst one another or more. These States have prominent trends for common oral, lung, breast, gastric and cervix-uteri cancers. The National Cancer Registry Programme, 2020 reports leading cancer in Arunachal Pradesh for males, is stomach cancer, and in females, it is cervix-uteri cancer. Similarly, the prominent cancers are Assam cancer oesophagus in males and cervix-uteri cancer in females. This paper attempts to contribute to the existing literature in understanding the doctor-patient dynamics in oncology, particularly emphasising its access to five common cancers in two Indian states. The perspectives offered by the cancer patients and doctors in the study area additionally provide empirical evidence to address and support treatment transition experienced during the entire journey of cancer therapeutics. Further, the findings empower cancer patients even as their voices echo through this paper. These experiences allow the doctors, nurses and other healthcare

personnel to understand patient narratives, providing a path to support them. These findings offer resilience in building competencies of oncology healthcare professionals and the overall policies for cancer care in northeast India for patient-centric cancer services. A comprehensive strategic plan for cancer prevention and control may convene from these results to build a need assessment to create a targeted intervention to reduce inequities in and within the region.

### **Method**

This paper followed a descriptive multi-embedded case study design integrating quantitative and qualitative methods to understand the frequency of phenomena grounded in the participants' experience. We used stratified random sampling in phase one of the study keeping the National Centre for Disease Informatics and Research report, 2017 as a reference for participant selection using the formula  $n = N / (1 + N(e)^2)$ . Where,  $n$  is the sample size,  $N$  is the population size, and  $e$  is the precision or error limit. With a 95% confidence interval and  $e$  of 0.05, the sample size is  $n = 14845 / (1 + 14845(0.05)^2) = 390$ . Excluding male breast cancers since it was less than 20. The final sample size was 388 (cervix cancer 57, lung cancer 68, stomach cancer 81, breast cancer 86 and oral cancer 96). In phase two, 21 semi-structured interviews were conducted by purposive sampling of 15 cancer patients, three each from the five cancer sites; along with six key informant interviews with oncologists: medical – 2, radiation – 2, surgical – 1 and gynaecology – 1). A written informed consent was taken from all the participants and were provided with a copy of the consent form and participant information sheet in English or Assamese. An integrated framework, Figure 1, provided a path to understand the patient and provider perspectives in determinants of behavioural and relational coordination within and across the patient, providers and inter-intra organizations (Penchansky JWT and R., 984; Betancourt JR, Green AR, Carrillo JE, et al., 2003). Although the cycle displayed in Figure 1 corresponds to the action orientation and outcome of it but the two boxes above the cycle indicates a singular perspective from the lens of the patient and provider on the mechanism, impediments and mitigation to cancer care access. The utilisation of this integrated framework will contribute in adding a new perspective to investigate, identify, describe and understand the phenomenon of cancer care access.

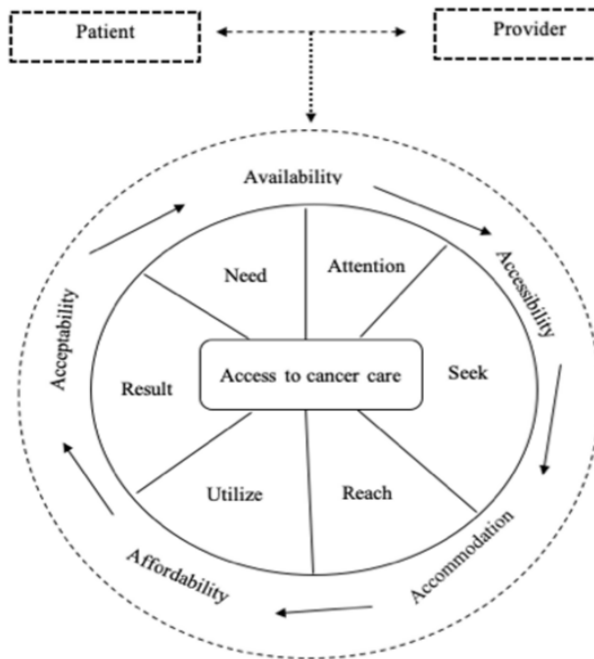
### **Ethical consideration**

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).

### **Data collection and analysis**

Data collection was carried out during February 2021 to January 2022, and participants were interacted with, at the premises of the selected hospitals. For the quantitative data analysis, both univariate distributions and bivariate associations, chi-square test, correlation coefficient and variance analysis were utilised to examine relationships

Figure 1: Integrated framework to understand access to care for common cancers



Source: Integrated framework from two models (i) Thomas & Penchansky Access Theory and (ii) Relational Coordination Model

of determinants or contradictions in the study. Qualitative data were transcribed verbatim and was analysed using the data codes for emerging themes. Coding was done by going through each paragraph and compared with the predefined codes. New codes were added, leading to a final list of codes. The memos were constantly referred for cross-checking if points were left out. The emerging themes were arranged according to a designated heading and sub-headings. In stage three, a cross-case synthesis of individual cases was done by triangulation of findings from both the phases, secondary data and field observations. In triangulation, equal priority with the same weightage was considered for both quantitative and qualitative data. The theoretical framework guided conclusions in the context of the study objectives and research questions. A data display in stage four presented the results and recommendations in conjunction with the study hypotheses and research queries. The style to illustrate the findings are diagrammatic description, tabulation and narration of the flow of events and the direction it entails.

## Results

### Socio-demographic and economic characteristics of the participants

The mean age group of the participants is 40.8 years ranging from 18 to 89 years, 57.0 per cent were females, and 43.0 per cent were males. Participants domicile of Assam were 73.5 per cent and 26.5 per cent from Arunachal Pradesh. More than four

fifth were married participants (82.7 per cent). Overall the place of residence was urban for 66.0 per cent and 34.0 belonged to rural areas. A state-wise bifurcation however, presented the location primarily as rural, Arunachal Pradesh (71.8 per cent) and Assam (63.9 per cent). The report of Census of India, 2011, presents an inference on the rising urbanization of these two states as 14.1 per cent in Assam and 22.9 per cent in Arunachal Pradesh. The median annual income was less than Rs 5,00,000 with only 0.8 per cent reporting an annual income above Rs 25,00,000. Employed participants comprised 42.3 per cent, 10.6 per cent were unemployed, and others were 47.2 per cent (retired, pensioners, homemakers, farmers and monks).

Participants covered by government health insurance comprised 59.1 per cent, with an association between the domicile state of participants and health insurance coverage ( $p = .000$ ). The participants from Arunachal Pradesh were primarily covered under the Chief Minister Aarogya Arunachal Yojana (CMAAY) for Rs 5,00,000 while those from Assam were covered under Atal Amrit Abhiyan for Rs 2,00,000. In both states, 2.8 per cent were covered under the Ayushman Bharat Pradhan Mantri Jan Arogya Yojna, giving cashless coverage of Rs 5,00,000.

The themes emerged are discussed in the subsequent section, integrating information from quantitative and qualitative phases.

### Theme 1: doctor-patient interactions.

Participants felt fostering relational discussion would enhance their treatment journey. A chi-square test of association between the type of cancer and level of satisfaction with the care provided by the doctors was significant at ( $p = .000$ ), Table 1. Participants reported this satisfaction as good by 20.9 per cent (oral cancer), 20.6 per cent (breast cancer), 19.6 per cent (stomach cancer), 13.4 per cent (cervical cancer) and 11.9 per cent (lung cancer). This observed association could be due to the fact that several participants reported that they were handheld right from the start. Another reason could be the comfort experienced by the participants availing cancer treatment in their domicile state after returning back from visiting several other cancer hospitals outside state. They accoladed their appreciation for their treating doctor and the hospital staff. The comfort of availing treatment in a familiar environment in the domicile state could have been influenced due to cost-effectiveness, distance, and family support closer to home.

Table 1: Participants' level of satisfaction with the doctors in the current hospital

State	Good		Average		Poor		Don't know		Total	
	N	%	N	%	N	%	N	%	N	%
Arunachal Pradesh	69	17.8	27	7.0	5	1.3	2	0.5	103	26.5
Assam	264	68.0	19	4.9	1	0.3	1	0.3	285	73.5
Total	333	85.8	46	11.9	6	1.5	3	0.8	388	100.0

However, a few felt left out in the overall treatment process, for instance, a 65 years old male from Assam, a farmer undergoing treatment for oral cancer shared that:



I do not think we are shared enough information on what treatment is given. Even if we ask the doctors and nurses, none of them take our queries seriously. So, I have stopped asking, what can I say, they know best.

As voiced by a 32 years old male police officer who is receiving treatment for stomach cancer:

I want the doctors to take rounds and visit us when we are taking chemotherapy in the day-care. It will give us confidence and the opportunity to interact should we have queries”.

Key informants despite their best efforts often found it challenging in delivery of cancer care, as shared by a radiation oncologist in service for three years:

We identify and ensure who is the primary giver of the patient. We counsel them on the plan of treatment. Sometimes, we give our phone numbers so they can contact us. Nevertheless, the situation gets difficult when dealing with relatives who do not wish to disclose the diagnosis to their patients.

Agreeing that patients should be made comfortable when availing services in the hospital during their treatment, a surgical oncologist, in service for three years, said:

My patients access me through WhatsApp. I have my database for the surgical patients and their clinical records. So, I know which patients require what. The main thing is that the patient should not hesitate to approach the doctor. We have to remove the hesitation.

Communication with the patient, especially when the same language is not spoken, becomes a hurdle for both providers and beneficiaries. A radiation oncologist in service for 15 years echoed her opinion as:

Cancer patients from the whole northeast India visit us, sometimes language becomes an issue. For example, those patients visiting from Tripura, Mizoram and Meghalaya have language barrier since not all can speak languages other than their local dialect.

Some participants found that their interactions when availing of cancer services were unsettling and often confusing. This is in addition to the long waiting time, high out-of-pocket expenditure and rude behaviour of hospital staff. Such experiences made participants uncomfortable and embarrassed, especially when lack of infrastructure was also an issue. The absence of an in-patient cancer ward in one of the study hospitals often compels the doctors to admit them to the general ward of the institute. A 35 years old male with recurrent stomach cancer, who took voluntary retirement from police services due to his cancer treatment, shared his disappointment as:

The nurses in the general ward in the main building are very rude, and they do not even know how to administer the chemo to me. One of the nurses said I should be ashamed of arguing with her as I am taking free treatment from the government. I cried that night. I am discouraged and do not have hope for a cure since I have been undergoing treatment for five years. It would have been better if there was an in-patient ward in the cancer centre as I would feel safer under the care of the staff of the cancer department.

A 35-year-old homemaker undergoing treatment for breast cancer recounting her experience, said:

The hospital is excellent, but sometimes we do not receive cooperation and guidance from the staff. Many of our queries at the nursing station are met with silence. So, we don't know what to do in such a situation.

Several participants described availing government health insurance scheme, CMAAY was not easy, as described by a 32 years old homemaker, a woman with oral cancer:

We were told to fill an online registration, but my condition was serious, so I did not want to waste time. So, we paid up-front instead of wasting time to avail CMAAY services in the referral hospital.

Few participants reported experiencing a non-involvement in their treatment journey by feeling out of place with no doctor visitation in the chemotherapy day-care. Similarly, participants reported the condescending behaviour of a few nursing staff as discouraging and emotionally disturbing. Despite the mixed responses, Table 2 illustrates that the overall hospital services were good according to the participants. Further, a Kruskal – Wallis test which is a nonparametric test done in this paper to determine whether there is an effect on continuing cancer treatment in the current hospital by the participants. The results indicate significant difference for those taking treatment for pain relief ( $p = .000$ ) and those availing follow-up services ( $p = .000$ ), possibly due to the comfort established with their treating doctor and participants' financial status and location.

Table 2: Participants' level of satisfaction for overall hospital service

Participant's level of satisfaction	Frequency	Percent
Good	335	86.3
Average	45	11.6
Poor	5	1.3
Don't Know	3	0.8
Total	388	100.0

**Theme 2: paths to support.** Interventions by the cancer institutes have helped in identifying the gaps and thus to take care of service areas not addressed earlier.

In one of the study institutes, facilitation of services is provided by patient navigators, a concept delivered through professionals who have undergone the Patient Navigation Program offered by Tata Memorial Centre, Mumbai (Tata Memorial Centre, 2018). The patient navigators are placed in strategic locations such as the patient registration centre and OPD to counsel and provide supportive guidance for administration and services. Likewise, in the other study hospital, in addition to CMAAY, further assistance is provided under the Chief Minister Free Chemotherapy Scheme (CMFCS). The CMFCS provides cashless coverage up to Rs 10,00,000 per annum per patient annually for chemotherapy, radiation therapy, protein supplements and consumables.

Participants were asked what recommendation would they give for strengthening

the doctor-patient relationship. Participants with oral, stomach and cervical cancer especially thought that it would be helpful if a preparatory guideline was given by the hospital on the management at home following receipt of chemotherapy. It was voiced by the participants that these management guidelines will enable them to take care of themselves and be prepared in countering the effects of chemotherapy. There were participants who reported that their interactions in the hospital especially with staffs other than doctors were un-pleasant and at times rude which discouraged several participants to engage further in communication such as getting clarity on availing government health insurance when they were referred by doctors to the empanelled hospital. All the participants agreed a guest house in the cancer institute would give them respite. Infrastructure lacked in one out of the two institutes, which the participants suggested could be fixed since they did not want to be referred to hospitals outside state. The suggestions comprised of availability of diagnostic tests such as PET scan, oncology surgeons, oncology nurses, in-patient ward for cancer patient, a lift, shifting of the chemotherapy and day-care in the ground floor. Table 3 presents a summary of the suggestions mentioned by the participants on enquiring their opinion regarding it.

Table 3: Participants’ suggestions to enhance cancer patient treatment journey – by type of cancer

Type of cancer	Guest house for accommodation	Post chemotherapy management at home	Polite interactions and clarity of availing services	Infrastructure availability*
Oral cancer	✓	✓	✓	✓
Lung cancer	✓	×	×	✓
Stomach cancer	✓	✓	✓	×
Breast cancer	✓	×	×	✓
Cervix cancer	✓	✓	×	✓

\* *diagnostic tests, oncology surgeons, oncology nurses, in-patient ward for cancer, lift, toilet and day-care chemotherapy in ground floor*

✓ *Available*

× *Not available*

On interacting with the key informants, it was found that the institutes extended outreach programs for cancer awareness by organising routine screening and health check-up camps. Initiatives in one institute also included patient welfare activities such as psychological counselling, monthly music program, yoga, prayer meeting, sightseeing, magic shows, indoor games, meditation and toy banks. Additionally, the lottery is one of the popular events in the study area, frequently organised during festivals, Figure 2. Tapping this popularity, besides the routine community outreach program by the department, the cancer institutes utilised a unique approach by organising lottery draws to generate awareness of the cancer services available in the state. Locally relevant initiatives were incorporated into these outreach programs, such as organising a lottery for generating cancer care awareness; this was a creative and interactive way to raise awareness about the importance of cancer care and support. Organising a cancer awareness lottery could raise awareness about cancer care and

support and funds for cancer research and treatment. Civil society partnership with one of the cancer institutes was also seen as these lottery draws were organised to raise funds to purchase an ambulance to transport cancer patients within and outside the state. For example, the lottery organised in one of the institutes was priced at Rs. 20 with fifteen prizes to be won, including a television set, kitchen appliances and sports equipment. This lottery was organised during the festival of Diwali, along with a cricket match at the cancer institute. The lottery draw was hosted in the institute’s playground in the presence of the hospital staff, general public, patients and their attendants. Some patients even volunteered to pick the lottery draw, while a few won prizes, which bought smiles and cheers in the vicinity.

In the other institute, the lottery draw was an initiative of an NGO as a community event in collaboration with the cancer institute. People could purchase tickets for a chance to win a prize. The proceeds from ticket sales were used to support cancer treatment by purchasing an ambulance to transport cancer patients within and outside the state. The prizes ranged from Rs. 5,00,000 to Rs 10,000, with the consolation prize of Android mobile phones to be won by the winners. All the key informants said such initiatives resonated among the locals and bought awareness of the state's available cancer facilities. Besides, these lotteries provide an opportunity for generating awareness about the availability of cancer services in the state, enabling efficient and enhanced utilisation of its services.

Figure 2: Lottery tickets for raising awareness about State Cancer Institutes



Source: Adapted from State Lottery Tickets

**Discussion**

The study findings suggest that although the participants were satisfied with the overall service of the hospital and the doctors, those who voiced feeling left out in their treatment journey were homogenous. This observation is similar to the findings of existing work (Ansmann, L., Kowalski, C., Ernstmann, N., & Pfaff, H., 2012; Berlan D and Shiffman J., 2012). Experiences that cannot be undermined, such as unpleasant behaviour of the hospital staff ranging from rudeness, silence or condescending remarks, often leading to psychological unrest in the participants, are highlighted in previous studies. The existing studies (Richards T., 2014; Doherty C., Stavropoulou C., Saunders M.N.K., et al., 2017) found that the reasonable doctor, and the reasonable patient standards may diverge: patients may be concerned more about the functional consequences of their treatment, while doctors may be more inclined to focus on the relative risks of treatment options. Although, the behaviour mentioned above could be due to the overburden of work on the doctor and hospital staff, including the failure to make psychosocial training central in the practice of medicine.

The lack of active participation was described as facing unpleasant behaviour of hospital staff in the form of condescending remarks, rudeness, and even queries met with silence resulting in hesitation to have open communication with the doctors and hospital staff. Participants further reasoned they were continuing the treatment in the study area hospital for pain relief and follow-up services, possibly due to the comfort established with their treating doctor and participant's financial status and location. A constant challenge reported by the doctors was the request from the participant's relatives to maintain diagnostic secrecy, thus hampering open discussions for informed cancer treatment. Answers to patients' perspectives on their cancer treatment or their psychosocial needs being addressed are unclear in oncology (Arora. N.K., 2009). For example, a study (Agle Dahl K.M., Gulbrandsen P. R. F. and Å. W., 2011) in a 300 bedded hospital in Norway found that the main failing of the patient-doctor encounters is not a lack of courteous manners but the moral offence patients experience when existential concerns are ignored. Several studies showed that provider accountability is enhanced when consumers gain greater access to information (Olaisen, R. H., Schluchter, M. D., Flocke, S. A., et al., 2020; Marchand, K., Foreman, J., MacDonald, S., et al., 2020; Akhlaq, A., McKinstry, B., & Muhammad, K. B., 2016; Ansmann, L., Kowalski, C., Ernstmann, N., et al., 2012) of cancer care services is a composite of interaction, consent or willingness to walk on the long journey to complete cancer treatment. Hesitation to communicate with hospital staff, lack of clarity in availing government health insurance in referral hospitals, or infrastructure shortage are findings of this paper which is in consensus with the work of Mathews, M., Buehler, S., & West, R. 2009; Magnezi R., Bergman L.C., & Urowitz S. 2015; Berger, D., 2014; Broom A. and Doron A., 2012; Snyder, J., Crooks, V. A. & Johnston, R., 2012). However, in the present study, a few reported continuing their treatment in the current hospital for pain relief and follow-up services, possibly due to the comfort established with their treating doctor and participant's financial status and location.

In cancer care access, the doctor-patient relationship is significant because cancer can be a complex and overwhelming experience for the patient. Patients often have

many questions and concerns, and they need to be able to rely on their doctor for precise, accurate, and compassionate information. Imbibing the doctor-patient relationship through open communication and collaboration with volunteering organisations and individuals provides a platform of flexibility that the health systems lack, and incorporating locally relevant outreach programs and schemes will have beneficial repercussions.

Further, requests by relatives for non-disclosure of the diagnosis to the patient were a challenge for the doctors in the efficient delivery of cancer care. Non-disclosure is associated with deference and the unquestioning authority of the medical expert. Thus, while these clinicians critique family preference for non-disclosure, such interpersonal dynamics must also be seen as embedded in asymmetrical power relations characterizing the Indian biomedical encounter (Magnezi R., Bergman L.C., & Urowitz S., 2015). Replicating the model of the patient navigator program in all the cancer hospitals will further bring support and ease of accessing services by the patients. A framework formulated from the paper's findings could be utilized to build actionable steps for the professionals, nursing and medical students.

The doctor-patient relationship is a crucial aspect of cancer care access and plays a significant role in the overall well-being and health of the patient. A strong and trusting relationship between the doctor and the patient can lead to better health outcomes, improved adherence to treatment plans, and increased patient satisfaction. Innovations cultured in the study area to make cancer services efficient such as the patient navigators (Tata Memorial Centre, 2018), open an opportunity for its replication to other cancer institutes in the country. Similarly, implementing locally relevant community outreach programs, such as practices of lottery organisations, provides a platform to increase awareness of the availability of services in the state cancer institute. Thus, encouraging patients to avail treatment in their domicile state and reducing their financial burden. Further, the existing schemes for cancer, both government and non-government, have provided respite to those participants who are economically challenged. The services provided by organisations volunteering at the study institutes additionally support the ease of accessing cancer care by the patients, thereby improving the overall health systems.

A good doctor-patient relationship also helps build trust, which is essential when making important treatment decisions. However, access to quality cancer care can be challenging for many patients, especially those who live in underserved communities or who face financial, cultural, or linguistic barriers. In these cases, it is even more critical for the doctor to establish a solid and supportive relationship with the patient and to be sensitive to their unique needs and concerns. Ultimately, the doctor-patient relationship in cancer care access is about partnership, communication, and compassion. When the doctor and the patient work together as a team, it can help to ensure that the patient receives the best possible care and has the best possible outcomes.

### **Limitations**

This paper could not assess the perspectives of the nursing and other staff of the cancer institutes to understand their experiences with the patients for service delivery

as the findings presented in this paper were part of a broader study in the region. Besides, the impact of innovations such as patient navigation and outreach programs could not be assessed.

### **Conclusion**

The study findings contribute to the existing literature in identifying patient experiences to support the cancer institutes in deliverance and best interest in cancer care. Mandatory inclusion of psychosocial aspects in the curriculum for oncology in the medical and nursing schools will enable establishing an environment where patients can voice their concerns without hesitation, making it an experience of partnership. Building the capacity of doctors and nurses in psychosocial management of oncology patients would bring clarity on anticipating nuances of patient reluctance and equip the service providers to bring mitigation for inclusion in the treatment protocol. Aiding the existing patient-management system in cancer institutes by replicating patient care models such as the patient navigator program could further support and strengthen the doctor-patient relationship and act as a redressal system.

### **Practice implications**

The paper reports modalities to understand and identify the relationship between doctor and patient in the cancer journey, which can help strengthen health systems in oncology service delivery.

The study findings contribute to the existing literature in identifying patient experiences to support the best interest in cancer care. This paper emphasis the urgency in making an inclusion in the curriculum for oncology in the medical and nursing schools will enable establishing an environment where patients can voice their concerns without hesitation, making it an experience of partnership. Building the capacity of doctors and nurses in psychosocial management of oncology patients would bring clarity on anticipating nuances of patient reluctance and equip the service providers to bring mitigation for inclusion in the treatment protocol.

### **Author contribution(s)**

*Kuru Dindi*: Conceptualization, data collection, methodology, analysis, writing, reviewing.

*Anil Kumar K*: Conceptualization, supervision, writing, reviewing and editing.

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None to be declared.

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