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EPIDEMIOLOGICAL PROFILE OF INDIGENOUS CANCER PATIENTS: A RETROSPECTIVE STUDY FROM A COMPREHENSIVE CANCER CARE CENTRE IN NORTHERN KERALA, INDIA DURING THE PERIOD 2016 TO 2020

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List of acronyms and abbreviations

AI/AN	American Indians and Alaska Natives
APL	Above Poverty Line
BMI	Body Mass Index
BPL	Below Poverty Line
Ca	Cancer
CDC	Centers for Disease Control and Prevention
GLOBOCAN	Global Cancer Observatory
HBCR	Hospital Based Cancer Registry
ICD	International Classification of Diseases
ICMR	Indian Council of Medical Research
INR	Indian Rupees
LMIC	Low and Middle Income Countries
MSB	Multi Specialty Board
NCD	Non Communicable Diseases
NHM	National Health Mission
PHC	Primary Health Centre
PVTG	Particularly Vulnerable Tribal Group
SDGs	Sustainable Development Goals
SES	Socio Economic Status
ST	Scheduled Tribe
TNM	Tumour Node Metastasis
TRC	Tobacco Related Cancer
WHO	World Health Organization
UN	United Nations

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Abstract

Background and Aims: Cancer is a significant health issue for Indigenous populations worldwide as it is one of the leading causes of illness and death. India has the second largest Indigenous population in the world, however there is a paucity of studies focusing specifically on the cancer epidemiology and treatment adherence among Indigenous population in the country. Thus, the aim of this study is to investigate the epidemiological profile and adherence to the treatment and follow-up instructions among them.

Materials and Methods: A retrospective study was conducted in a comprehensive cancer care centre in Northern Kerala, India, during the period of 2016 to 2020. The data collection sheets were used to extract the data from the medical records.

Results: A total of 511 Indigenous cancer patients were included in the study with a mean age of 54.53 ±13.67 years. Among them 52% were males and 48% were females. The majority of the population (54%) were illiterate and 74% belonged to low socio-economic group. Fifty-nine percentage of the population had smokeless tobacco consumption. The leading cancer sites were Ca lip and oral cavity (34%), Ca lung (8.41%) and Ca breast (6.84%). Seventy percentage of the patients were diagnosed at advanced TNM stages and 47% were planned for palliative treatment. Majority (86%) followed their treatment plans, and 62% were in active follow-up.

Conclusion: Several socio-economic factors, including high illiteracy rates, low socio-economic status, significant unemployment, and rural residency, create a complex barrier that adversely affects cancer outcomes for this group. Notably, tobacco consumption was high among both men and women, leading to an incidence of Tobacco Related Cancers (TRC). Most cancer cases were diagnosed at an advanced stage, resulting in many patients requiring palliative care. Addressing the modifiable risk factors like tobacco use among the Indigenous population, encouraging early detection, enhancing health literacy, and improving health-seeking behavior can significantly reduce the cancer burden among them. Further extensive research is needed for cancer prevention and control among them.

Keywords: Cancer, Epidemiological profile, Treatment adherence, Indigenous population

1. Introduction

Cancer is a significant public health problem around the world. It is one of the leading causes of mortality worldwide, accounting for nearly 9.7 million deaths. According to the Global Cancer Observatory Report (GLOBOCAN) 2022, global cancer incidence was approximately 19.97 million cases (Ferlay J *et al.*, 2022). As the global burden of cancer escalates, Low and Middle-Income Countries (LMICs) bear a disproportionate impact in terms of both cancer cases and mortalities. Projections indicate that by 2040, more than 70% of cancer-related deaths will occur in LMICs (World Health Organisation, 2022). India, a diverse country with varied socio-economic conditions, showcases significant differences in cancer burden in various regions and among populations (Mathur *et al.*, 2020). The cancer incidence in the country was 1.41 million cases, with 916827 cancer-related deaths, and the prevalence of cancer was approximately 3.25 million cases (Ferlay J *et al.*, 2022).

There are approximately 476 million Indigenous people residing across 90 countries worldwide, constituting 6.2% of the global population. Through the practice of their own traditions, they maintain unique social, economic, cultural and political traits that set them apart from the rest of the world (United Nations, 2024). The enduring effects of colonisation, coupled with continuous marginalisation and disempowerment, result in significant economic, health, and social challenges among the Indigenous population worldwide (Paradies, 2016).

The United Nations Declaration on Rights of Indigenous Peoples (UNDRIP) Article 24 affirms that "Indigenous people have equal right to the best possible standard of physical and mental health and to access social and health services without facing discrimination" (United Nations, 2007). It includes four essential elements such as availability, accessibility, acceptability, and quality of healthcare (World Health Organisation, 2024). However, they face significant health challenges when compared to the general population. They have increased susceptibility to developing cancers and other diseases, resulting in poorer health outcomes (Ghebreyesus, 2018). Although cancer patterns differ from country to country, there were higher incidence and mortality rates of cancers connected to exposure to tobacco, alcohol, malnutrition, physical inactivity, increased Body Mass Index (BMI), and Diabetes Mellitus (DM) than non-Indigenous people living in the same countries. The data concerning cancer among the population is often missing or of insufficient quality, rendering many Indigenous peoples statistically invisible in healthcare analyses and decision-making processes across the world (Ahmed Jemal *et al.*, 2019).

India is home to the second-largest Indigenous population in the world (Ministry of Tribal Affairs, 2022). Within the country, there are approximately 104 million Indigenous population (8.6 % of the total population) who are often referred as "Adivasis" or Scheduled Tribe (ST) communities (Ministry of Health & Family Welfare and the Ministry of Tribal Affairs, 2018). The country has a diverse Indigenous population, consisting of 705 tribes and 75 groups identified as Particularly Vulnerable Tribal Groups (PVTGs) characterised by a level of development comparable to pre-agricultural societies, a stagnant or declining population, very low literacy rates, and an economy based on subsistence living. India officially recognises more than 500 Indigenous groups under Article 342 of its Constitution. These Indigenous groups, which often have overlapping communities spanning multiple states, are dispersed throughout different states and union territories across the country. They possess diverse traditions, cultures, and heritage, characterised by distinctive lifestyles and customs (Ministry of Tribal Affairs, 2023).

Despite being a diverse group, the Indigenous population in India shares common challenges such as poor health indicators, high morbidity and mortality rates, and limited access to healthcare services including, cancer care (Ministry of Health & Family Welfare and the Ministry of Tribal Affairs, 2018). Reducing the disparities in health outcomes between the Indigenous and non-Indigenous populations in the nation is still a major concern (Kumar *et al.*, 2020). Indigenous communities are the country's most marginalised social group, and there is limited and inconsistent information on the real burden and pattern of various diseases they suffer (Jain et al., 2015). India's socio-economic transformation will remain incomplete unless the concerns of vulnerable populations, including Indigenous groups, are addressed. The achievement of the United Nations Sustainable Development Goals (SDGs), which the country India has committed itself to alongside other nations, hinges on ensuring the inclusion and upliftment of these marginalised groups (United Nations India, 2024).

Moving to a specific geographical context, Kerala, a state in southern India, presents a unique landscape for understanding the health challenges faced by Indigenous populations. According to the Kerala state census data 2011, the Indigenous populations comprise 484,839 individuals belonging to 36 distinct groups living in 119,788 family units. They represent 1.45 % of the state's total population (Government of Kerala, 2017). The majority, 89.33%, reside in villages, while only 10.67% live in urban areas within the state. Five communities belong to the Particularly Vulnerable Tribal Groups (PVTGs). Indigenous population have a low literacy rate and socio-economic status compared to the general population of Kerala (Government of Kerala, 2017). People of the Indigenous communities in Kerala value traditional medicines and healers for maintaining health and well-being. Alternative medicines were favoured for treating acute and chronic illnesses because they were easily accessible (George *et al.*, 2020). Although these communities recognise the benefits of modern healthcare services, there was reluctance to utilise them due to concerns about potential time constraints in the hospitals and felt discrimination from the healthcare professionals (George *et al.*, 2020) (Mithrason and Thomas, 2023).

The Indigenous population experienced a significant growth rate during the 2011 census, increasing by 26.62% from the previous census. This growth represents an 11.86% rise from the growth rate observed in the 2001 census (Government of Kerala, 2017). They have witnessed a notable increase over the past decade, reflecting demographic shifts within the state. However, alongside this growth, they also confront many health challenges that significantly impact their well-being. Some of these challenges include

- Malnutrition
- Communicable diseases
- Non-communicable diseases
- Addictions to tobacco, alcohol
- Mental health disorders (Mutalik, PK and Kumar, 2019)

This complex disease burden collectively contributes to their overall health challenges (Ministry of Health & Family Welfare and the Ministry of Tribal Affairs, 2018). One crucial aspect that underscores the significance of studying the health status of Indigenous populations is their limited access and underutilisation of healthcare services. This disparity becomes significantly pronounced when considering specialised healthcare needs, such as cancer care, where Indigenous communities often face substantial socio-economic and cultural barriers compared to non-Indigenous groups (Garvey and Cunningham, 2019). Considering the above challenges and disparities, it becomes imperative to delve deeper into understanding the health profile of Indigenous communities in the state of Kerala.

Limited published research was done on cancer among Indigenous populations, leaving a significant gap in the available data regarding the epidemiology of various cancers affecting the Indigenous communities and their adherence to the treatment and follow-up status (Pullishery, 2018) (Vinod Mohandas *et al.*, 2024). Understanding the incidence, pattern, sociodemographic factors, risk factors, disease related factors, and adherence to the treatment of cancer among Indigenous populations reported in a cancer care centre in the state of Kerala will be crucial for developing targeted interventions and strategies for improving cancer care outcomes and overall wellbeing of this population. Considering the substantial proportion of the Indigenous population in Kerala and their unique health-related challenges, the study aims to investigate the epidemiological profile and also to evaluate the extent of adherence to the treatment and follow-up instructions among Indigenous patients reported in a comprehensive cancer care centre, Northern Kerala, India during the period 2016 to 2020.

2. Background

Cancer is a significant health concern for Indigenous populations worldwide as it is a leading cause of illness and death. However, the data concerning cancer incidence, pattern, prevalence, risk factors, treatment-related factors, and mortality are often unreliable, resulting in many Indigenous peoples being statistically overlooked. There is no centralised database specifically dedicated to collecting and maintaining data on cancer among Indigenous populations across the world and in India to date. Most of the existing data on cancer reported comes from a few high-income countries, such as the United States, Australia, New Zealand and Canada. New Zealand stands alone as the country that systematically documents and reports cancer statistics at the national level for its Indigenous population (Ahmed Jemal *et al.*, 2019). In many Low and Middle-Income Countries (LMICs), the absence of necessary infrastructure and resources to conduct comprehensive health surveys leads to significant gaps in cancer data, particularly in remote or marginalised communities where many Indigenous people live. Moreover, the healthcare sector predominantly emphasises communicable diseases rather than non-communicable diseases such as cancer in LMICs among Indigenous communities (Shah et al., 2019). There are limited published literatures evaluating cancer epidemiology and treatment adherence among the Indigenous population across the world. Most of these studies are conducted in high-income countries (Garvey and Cunningham, 2019).

2.1. Review of existing literatures on cancer epidemiology and treatment adherence in the world

Cancer disparities have been documented in various research studies. A cross-sectional study was conducted in New South Wales, Australia, to investigate the cancer incidence, patterns and survival rates among Aboriginal and non-Aboriginal populations. The study found that the cancer incidence was higher and survival rates were lower among Aboriginal people compared to their non-Aboriginal and cancer was diagnosed at an advanced stage among Aboriginal people (Moroll *et al*., 2012) . Similarly, a retrospective study conducted in Manitoba, Canada, examined cancer epidemiology among Indigenous and non-Indigenous populations. The study found results similar to those in Australia, with higher cancer incidence and mortality rates among Indigenous people (Horrill *et al.*, 2019). Another study conducted in the United States investigated the overall cancer incidence, mortality and cancer pattern among the American Indians and Alaska Natives AI/AN population of Oklahoma, found that the AI/AN population in Oklahoma has an alarmingly higher overall incidence of cancer and death rates compared to the non-Hispanic White (NHW) population. Ca breast, Ca prostate, Ca Lung, Ca colon, Ca Kidney and renal pelvis were common cancer found in the United States (Sambo *et al.*, 2022). A descriptive study compared cancer epidemiology between American Indians and Alaska Natives AI/AN and non-Indigenous populations in United States. The study found that the AI/AN population had higher overall cancer incidence and were often diagnosed at later stages, resulting in significantly higher mortality rates. The research also highlighted that a majority of AI/AN individuals had high tobacco consumption, which is a known risk factor for several cancers (Kratzer et al., 2023). These studies collectively emphasis the disproportionate cancer burden faced by Indigenous populations across different regions.

Qualitative research was conducted on Indigenous Australians to evaluate the experience of cancer care and found that the treatment experience for Aboriginal patients, especially in rural areas, was greatly affected by various factors. Healthcare service challenges found were low accessibility to the healthcare centre, long wait times for the treatment, and a shortage of Aboriginal professionals to communicate with the patients. Patients often delay seeking help due to fear of cancer, denial of symptoms, and factors like shame, embarrassment, and fear of the healthcare system. Additionally, attachment to the land and reluctance to leave home for treatment in cities were significant deterrents (Shahid *et al.*, 2016).

2.2. Review of existing literatures on cancer epidemiology in India

Evaluating the burden and pattern of illness among the Indigenous population in India revealed a high prevalence of cancer, with its incidence continuing to rise (Jain *et al.*, 2015). However published literature on cancer among study population was notably less. Despite the country has the second largest Indigenous population in the world, there is a paucity of studies focusing specifically on the epidemiology and health outcomes related to cancer among Indigenous populations (Ministry of Tribal Affairs, India, 2022) (Vinod Mohandas *et al.*, 2024). Research was conducted to evaluate treatment adherence among Indigenous patients in various parts of the country with tuberculosis and hypertension (Rajan *et al.*, 2019) (Raju *et al.*, 2022) (Ponnusankar *et al.*, 2022). However, no studies have yet evaluated treatment adherence among cancer patients. This lack of research means the country has limited information on the cancer pattern among

Indigenous people, the unique risk factors they may face, and their health outcomes following treatment. This gap highlights the need for research to understand the pattern of cancer among the Indigenous population and how well the study populations are following prescribed cancer treatments, which is crucial for improving health outcomes and tailoring interventions to their specific needs.

To date, there have been no studies evaluating the epidemiological profile and treatment adherence of cancer within the study population in the country. Some studies have evaluated the risk habits among the Indigenous population in various parts of India, revealing high rates of tobacco and alcohol consumption. The studies reported that the use of tobacco products in various forms was significantly higher among Indigenous communities. Studies indicated a notable disparity in tobacco product usage among them with Indigenous males exhibiting higher rates than females and was found increased tobacco usage in illiterate Indigenous populations (Francis, 2018) (Paul *et al.*, 2018) (Agrawal et al., 2023). These risk factors have significant health implications, contributing to various precancerous and cancerous conditions (Kumbhalwar *et al.*, 2022). Recent studies have reported significant findings regarding tobacco consumption and its outcomes among Indigenous populations in the country. In Madhya Pradesh, Central India a cross-sectional study identified a positive association between tobacco use and the prevalence of leukoplakia (Kumar and Muniyandi, 2015). A study conducted among Indigenous population in Nicobar, Union Territory of India, showed 80% of the population uses smokeless tobacco, and 25% exhibit precancerous conditions (Dheeraj et al., 2021). A hospital-based study in Puducherry, South India found that 48% of the Indigenous population had precancerous conditions, predominantly in the buccal mucosa (Muthanandam *et al.*, 2022). Additionally, some other studies in South and Central India did qualitative studies to understand the awareness of Ca cervix and screening procedures among Indigenous women and found that there was lack of awareness among the study population about the Ca cervix and risk factors (Ghosh *et al.*, 2021) (Gupta and Parikipandla, 2023).

2.3. Review of existing literatures on cancer epidemiology in the state of Kerala, India

Moving to the state of Kerala, there have been very few studies evaluating the cancer epidemiology of the Indigenous population. One study was conducted in Central Kerala aimed to understand oral cancer and tobacco-related habits among the Indigenous population. The study found that 27% of the population had oral malignancies. The study also found that 68% of boys aged 10-15 were using tobacco products in various forms, and 34.7% of women reported tobacco use. Additionally, alcohol use was reported by 57% of the study population (Pullishery, 2018). Another hospital-based cross sectional study in Wayanad, Kerala, examined the patterns of cancer among both Indigenous and non-Indigenous populations. The study revealed that premalignant and malignant lesions were more prevalent among the Indigenous population compared to the non-Indigenous population, with a higher prevalence in females. The most common type of cancer observed among the Indigenous population was Ca thyroid, followed by Ca stomach (Vinod Mohandas et al., 2024).

It was important to note that although the majority of the Indigenous population (58%) was located in the northern part of Kerala (Government of Kerala, 2017), to date, there is no such published literature evaluating the epidemiological profile and treatment and follow-up adherence among Indigenous cancer patients in this region. The current study aimed to fill this gap by conducting a retrospective study at a comprehensive cancer care centre in Northern Kerala, which stands as the sole tertiary cancer care centre operating autonomously under the Health and Family Welfare Department, Government of Kerala, in the northern part of the state. The institute encompassed that the study included various types of cancer and treatment outcomes as well as adherence among the Indigenous population in the region. The study findings will provide valuable results in cancer epidemiology and treatment and follow-up adherence. These results will be crucial because they could reveal critical challenges faced by these communities, which are often underrepresented in medical research. Moreover, it will improve the healthcare initiatives and programmes for Indigenous communities in Kerala.

In addressing these unique health challenges, the Government of India has implemented various health schemes and initiatives. Indigenous communities in the country contend with issues such as

- Geographical isolation

- Limited healthcare access
- Socio-economic disparities particularly income disparities
- Cultural differences
- Language barrier (Deb Roy, Das and Mondal, 2023)

Current health schemes include provisions designed to effectively serve these communities and address their diverse needs (Ministry of Health and Family Welfare, 2024).

2.4. Health schemes for the Indigenous population in India

India has implemented several health schemes to improve the Indigenous population's welfare, with the Ministry of Tribal Affairs, established in 1999, playing a pivotal role in addressing their health needs. In 2018, an expert committee was appointed by the Ministry of Tribal Affairs to focus on evaluating health of the Indigenous population in the country by identifying current health status and healthcare provision in Indigenous regions. The committee found various challenges in their health, encompassing communicable diseases, non-communicable diseases, issues of maternal and child healthcare, geographical isolation, poor socio-economic conditions, insufficient healthcare services, scarcity of healthcare professionals willing to work in the remote areas, mismanagement of financial resources, insufficient data on Indigenous health, and political disempowerment. The committee made various suggestions to improve the Indigenous communities welfare. The current healthcare system in India has adopted key suggestions put forth by the expert committee, with support from the National Health Mission (NHM) (Ministry of Health & Family Welfare and the Ministry of Tribal Affairs, 2018).

The National Health Mission (NHM) offers various relaxations to support healthcare among Indigenous populations. Under the "Ayushman Bharat" Programme, Health and Wellness Centres (HWCs) provide comprehensive primary healthcare services, with adjusted population norms for establishing health facilities in vulnerable areas. These norms were reduced to 3,000 for Sub Health Centres (SHCs), 20,000 for Primary Health Centres (PHCs), and 80,000 for Community Health Centres (CHCs). Mobile Medical Units (MMUs) serve remote areas, and initiatives like the National Free Drugs Service and National Free Diagnostic Services help reduce out-of-pocket expenses by ensuring the availability of essential medicines. The NHM also supports recruiting of healthcare workers in remote areas and offers free ambulance services. High-priority districts with below-average health indices in Indigenous areas receive more resources per capita, and states are encouraged to adopt flexible hiring norms and provide incentives to attract healthcare professionals to rural and remote areas (Ministry of Health & Family Welfare and the Ministry of Tribal Affairs, 2022).

Various cancer control programmes are also aimed at Indigenous patients to address the challenges they face in accessing healthcare. One such programme is the “National Programme for Prevention and Control of Cancer, Diabetes, Cardiovascular Diseases, and Stroke (NPCDCS)”. Under this programme, outreach camps are planned to conduct opportunistic screening at various levels within the healthcare delivery system, starting from sub-centres and extending upward, with the goal of management through early diagnosis, treatment and follow-up through setting up of Non Communicable Diseases (NCD) clinics, including common cancers (Ministry of Health and Family Welfare, Government of India, 2024). The National Cancer Control Programme (NCCP), formulated in 1984, focuses on improving cancer prevention by reducing the TRCs, early detection, treatment, and palliative care services across the country, including remote areas. The NCCP promotes awareness campaigns, conducts training programmes for healthcare professionals, and supports establishing cancer treatment centres (Ministry of Health and Family Welfare India, 2020). “Rashtriya Arogya Nidhi” is another scheme which is under the “Ministry of Health Cancer Fund” provides financial assistance for cancer care among underprivileged communities (Ministry of Health and Family Welfare, 2018).

India launched the “Swasthya” online platform to provide insights into the health and nutrition of Indigenous populations. It offers information, research summaries, and best practices from diverse regions, aiming to foster collaboration and knowledge sharing in Indigenous healthcare (Ministry of Tribal Affairs, Government of India, 2020) .

2.5. Health schemes for Indigenous population in Kerala

Moving on to the state of Kerala, the government supports various schemes for socioeconomically disadvantaged communities, including Indigenous groups, within the state. Under the "Comprehensive Health Care Programme for Scheduled Tribes", Indigenous patients in the state will receive complete free cancer treatment. It covers food and travel expenses for the patient as well as one supporter. In a single day, an Above Poverty Line (APL) patient can avail of treatment worth 10,000 Indian Rupees (INR), while a Below Poverty Line (BPL) patient is eligible completely free of cost (Government of Kerala, 2018). "Karunya Arogya Suraksha Padhathi - Ayushman Bharath-Pradhanmanthri Jan Arogya Yojana- (KASP PMJAY)" is a healthcare scheme designed to provide a health cover of 500000 INR per family per year for secondary and tertiary care hospitalisation. It aims to benefit socially disadvantaged families representing the bottom 40% of Kerala's population. It provides cashless treatment for inpatient treatment, daycare chemotherapy, surgery and radiation (State Health Agency Kerala, 2024). "Karunya Benevolent Fund (KBF)" are eligible for patients whose annual income is below 300000 INR. It also provides 200000 INR for all cancer treatments and medicines (State Health Agency Kerala, 2024). "Cancer Suraksha Scheme" is a scheme for children. It is eligible for cancer patients who are 18 years old or younger and belong to Below Poverty Line (BPL) groups to qualify for completely free treatment. This scheme will cover all costs for cancer screening tests and treatments.

2.6. Challenges faced by the Indigenous population

Even though there are health programmes and initiatives for improvement of the healthcare of the Indigenous population, including cancer care. It was reported that majority of the Indigenous population do not seek healthcare benefits (Mithrason and Thomas, 2023). India continues to face significant challenges in improving the healthcare of the Indigenous communities due to their unique health-seeking behaviour. Low health literacy, lack of awareness regarding healthcare programmes and initiatives, underutilisation of healthcare services, discriminatory behaviour from healthcare professionals, and insufficient healthcare infrastructure relative to population demand are the significant challenges (Kumar and Kumar, 2022). Financial constraints caused by the indirect expenses, long waiting times for treatment in the public health services, misconceptions about health, language barrier, reliance on traditional healers, and tend to prioritise other concerns over health are some of the other challenges they face (Muthanandam *et al.*, 2022) (Ghosh *et al.*, 2021a) (Gandhi, Verma and Dash, 2017). These issues hinder the effective delivery of healthcare services and limit individuals ability to make informed decisions about their health (Linda *et al.*, 2024). They also have limited understanding of the various diseases, including cancers, and available healthcare facilities. Despite efforts to address these issues through initiatives like the National Health Mission (NHM), much work remains to be done to improve health literacy levels and raise awareness about available healthcare programmes. Enhancing people's health-seeking behaviours and motivating them to take advantage of the resources offered by the healthcare system are also important (Kumar and Kumar, 2022). Increasing education and outreach efforts can play a crucial role in bridging the gaps and ensuring that all individuals have access to the information and resources they need to make informed healthcare choices (Soman *et al.*, 2023).

3. Aims and objectives

1) To study the epidemiological profile of the Indigenous cancer patients reported in a comprehensive cancer care centre, Northern Kerala, India during 2016 to 2020.
2) To study the extent of adherence to treatment and follow-up instructions among the Indigenous population reported in a comprehensive cancer care centre in Northern Kerala, India during the period from 2016 to 2020.

4. Methodology

A descriptive retrospective study design was chosen for the research (Talari and Goyal, 2020).

4.1. Study design and setting

In order to investigate the epidemiological profile and adherence to the treatment and follow-up instructions among Indigenous cancer patients, a retrospective study was conducted in a comprehensive cancer care centre in Northern Kerala, India, during the period of 2016 to 2020. Data was extracted from the medical records of the comprehensive cancer care centre to identify the eligible cases of cancer among the Indigenous patients. The study period was selected based on the availability of the latest data from the Hospital-Based Cancer Registry (HBCR) of the institution, which was published until 2020 for the comparison with general population who received cancer care at the institute.

4.2. Ethical consideration

The study received ethical approval from the Institutional Review Board (IRB) and the Institutional Ethics Committee (IEC) of Malabar Cancer Centre (Post Graduate Institute of Oncology Science and Research), Kerala, India (1617/IRB-IEC/13/MCC/22-08-2023/2). The study also sought permission from the Ethics Committee of Hamburg University of Applied Sciences, HAW Hamburg.

4.3. Study population

All Indigenous patients who belong to the Scheduled Tribe (ST) communities diagnosed with cancer in a comprehensive cancer care centre in Northern Kerala, India, during the period of 2016 to 2020 was selected for the study. All Indigenous cancer cases diagnosed outside the study period, as well as all non-malignant cases diagnosed during the study period, were excluded.

4.4. Data collection

The total number of Indigenous patients registered at a comprehensive cancer care centre in Northern Kerala, India, from 2016 to 2020 was 648. Of these, 137 cases were excluded: 116 were diagnosed as non-malignant cases, 15 cases had unavailable case files, and 6 cases were diagnosed before the study period. Thus, 511 cases were selected for the study. Data collection sheets consisting of all the relevant variables for the study were used to extract data from the medical records of the comprehensive cancer care centre.

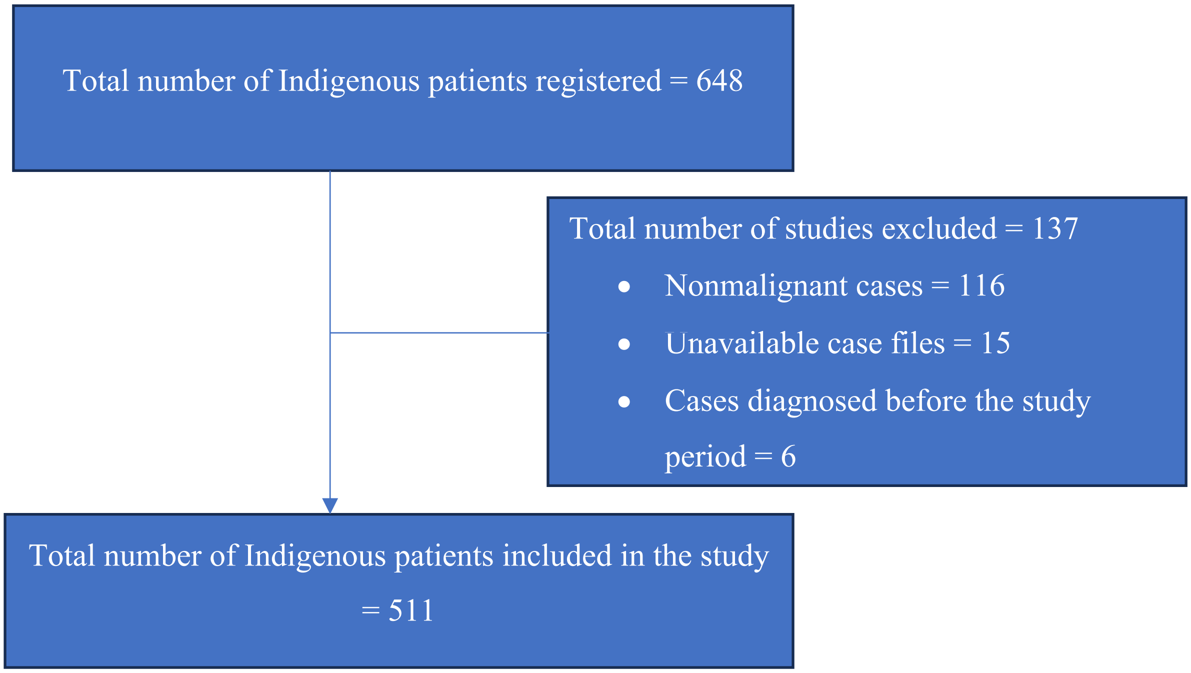


Figure 1 Shows flowchart for inclusion and exclusion details

The epidemiological profile of the patients includes a pattern of cancer reported, sociodemographic factors, risk factors, personal factors and disease related factors (Centers for and Disease Control and Prevention, 2022). The pattern of cancer reported was studied from the case records of new cases registered during the specific period 2016 to 2020.

4.4.1. Sociodemographic factors

The study collected sociodemographic data such as

- Age
- Gender: It was classified into 3 categories
    - Male
    - Female
    - Others
- Place of residence was divided into
    - Rural
    - Urban
- Marital status was classified as per census data 2011on marital status and fertility by Government of India Ministry of Home Affairs.
    - Unmarried
    - Married
    - Divorced
    - Widow/widower (Government of India and Ministry of Home Affairs, 2015)
- Levels of education were categorised based on the classification of the National Centre for Disease Informatics and Research, National Cancer Registry Programme of India (Indian Council of Medical Research, 2020)
    - Illiterate: A person who seven and above cannot both read and write a short simple sentence in any language (Government of India, 2020)
    - Literate: A person aged seven and above who can both read and write with understanding in any language (Government of India, 2020)
    - Primary: Education up to the fourth grade
    - Middle: Education from fifth grade to eighth grade
    - Secondary: Education from ninth and tenth grade (Government of India, 2014)
    - Higher education: Education after secondary education grade (Government of India, 2014)
    - Others
    - Unknown
- The monthly income of the family was recorded in Indian Rupee (INR)

- The occupation was classified based on the occupation classification outlined by Udai Pareek socio-economic status. Udai Pareek's Socio-Economic Status (SES) scale is a comprehensive tool used to assess the socio-economic status of individuals or families in Indian contexts (Wani, 2019).
    - Unemployed
    - Manual labourer
    - Cultivation
    - Business
    - Independent profession
    - Service
    - Others
- SES was determined based on the type of ration card the patients held. A ration card is a document issued by the State Government of India that acts as identity proof and indicates the economic status of the citizen. The economic status was classified (Rahman, 2016)
    - Above Poverty Line (APL)
    - Below Poverty Line (BPL)
    - Most economically Backward (Antyodaya Anna Yojana) (Department of Civil Supplies & Consumer Affairs, Govt of Kerala, 2023)

4.4.2. Risk factors

The study collected data on risk factors, including ever tobacco use such as smoking beedis, cigarettes, chewing tobacco and ever alcohol use.

4.4.3. Personal factors

Personal factors such as Diet, Body Mass Index (BMI) and History of past illness were collected.

- Diet: Patients dietary habits were classified into two categories.
    - Vegetarian: Who does not consume meat, poultry, and seafood (Vegetarian Nutrition | National Agricultural Library, 2023)
    - Non vegetarian: Who do not abstain from consuming meat, poultry, and fish (Rizzo *et al.*, 2013)
- Body Mass Index (BMI): The BMI of each patient was calculated to assess their body weight relative to their height. This was done by following the guidelines provided by the

Centers for Disease Control and Prevention (CDC), which standardize the calculation and interpretation of BMI (CDC, 2022) .

The BMI (kg/m^2) categories used were:

- Underweight: BMI less than 18.5
- Normal weight: BMI between 18.5 and 24.9
- Overweight: BMI between 25 and 29.9
- Obesity: BMI of 30 or greater

- History of past illness: The patients past medical history was collected including
  - History of other comorbidities such as Diabetes Mellitus, Chronic Obstructive Respiratory Disorder, Hypertension, Hypercholesteremia, Tuberculosis, Coronary Artery Diseases, Cerebral Vascular Diseases and treatment undergone
  - History of other cancer and treatment undergone
  - Family history of cancer

4.4.4. Disease related factors

Disease related factors encompassed the site of cancer classified according to International Diseases Classification 10 (ICD 10) (World Health Organisation, 2016) , the clinical stage of diagnosis was according to Tumour Node Metastasis (TNM) staging by the American Joint Committee for Cancer Staging (AJCC) 8th edition (American Joint Committee on Cancer, 2023) , cancer histology, and types of treatments received.

Adherence to the treatment is defined by World Health Organization "as the degree to which the person's behavior corresponds to the agreed recommendations from a health care provider" (Eduardo Sabatè, 2003). It is measured as the treatment taken relative to the treatment recommended (Maddox and Ho, 2011). The study assessed adherence to treatment and follow-up instructions by examining whether patients completed the initial treatment plan recommended by the Multi-Specialty Board (MSB) of the institution and their disease status at the last follow-up. The research also investigated the geographical accessibility of patients to the nearest PHC and comprehensive cancer care centre. Various time points in the cancer patients journey such as patient interval, diagnostic interval and treatment interval were analyzed to describe their treatment progression.

4.5. Data analysis

The data was extracted from the medical records of the institute. The collected data from data collection sheet was manually entered into Microsoft Excel Version 16.85. It was then cleaned and rechecked. Subsequent analysis was performed using both Microsoft Excel and IBM SPSS Statistics (Version 29.0.2.). Categorical variables were described using frequencies and proportions. The mean and standard deviation were calculated for continuous variables with a normal distribution, while non-normally distributed variables were summarized using the median and interquartile range. The normality tests for the continuous variables were done with Kolmogorov Smirnov test.

5. Results

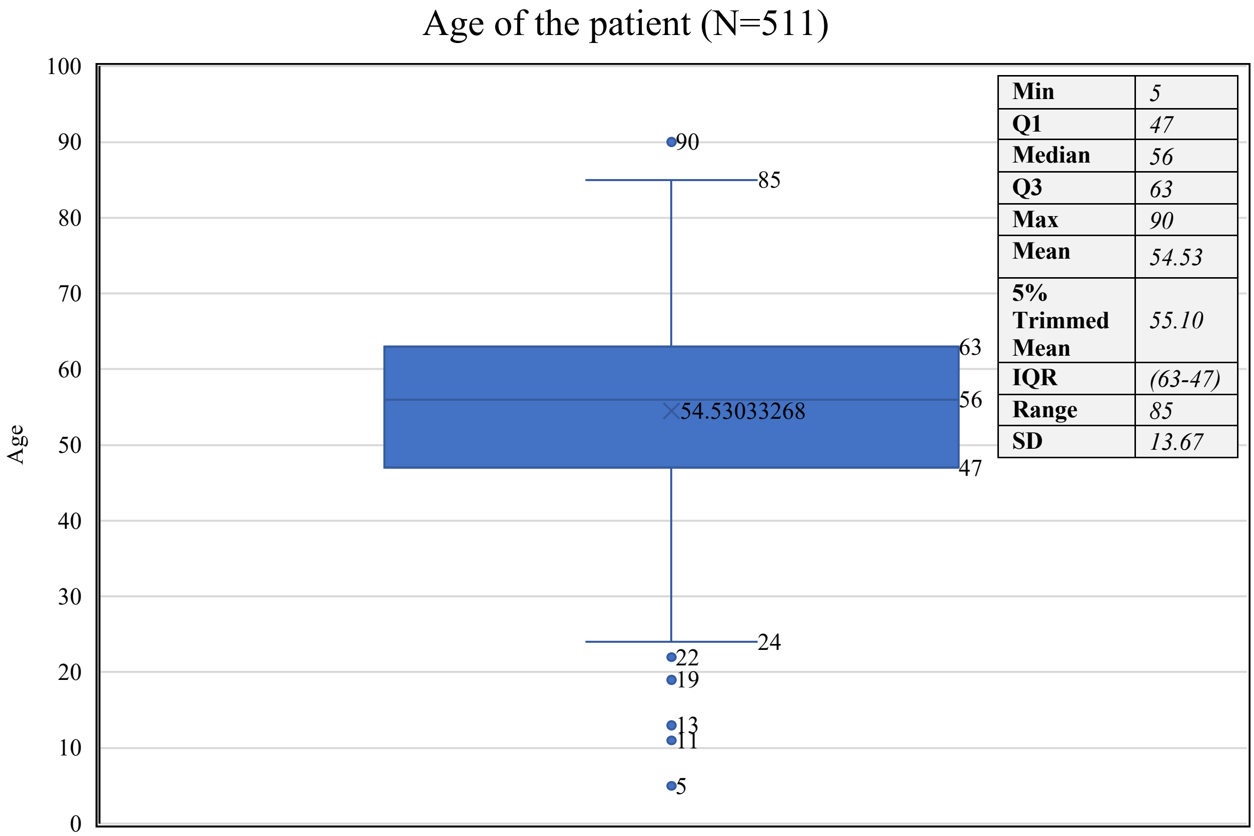
Data from 511 Indigenous cancer patients reported at a comprehensive care centre in Kerala, India during the period 2016 to 2020 were collected and analysed.

5.1. Epidemiological profile of the study population

5.1.1. Sociodemographic factors

a. Age

The mean age of the study population was 54.53 ± 13.67 years. The mean age of the females was 54.42 ±13.06 years, and the mean age of males was 54.62±14.22 years. The median (Inter Quartile Range (IQR)) age of the study population was 56 (63-47) years. The median (IQR) age of the females was 56 (63-15) years. The males showed a similar median (IQR) of 56 (65-48) years. The Kolmogorov Smirnov test showed that the data was not distributed normally.



Min	*5*
Q1	*47*
Median	*56*
Q3	*63*
Max	*90*
Mean	*54.53*
5% Trimmed Mean	*55.10*
IQR	*(63-47)*
Range	*85*
SD	*13.67*

Figure 2 Shows graphical representation of age of the patients

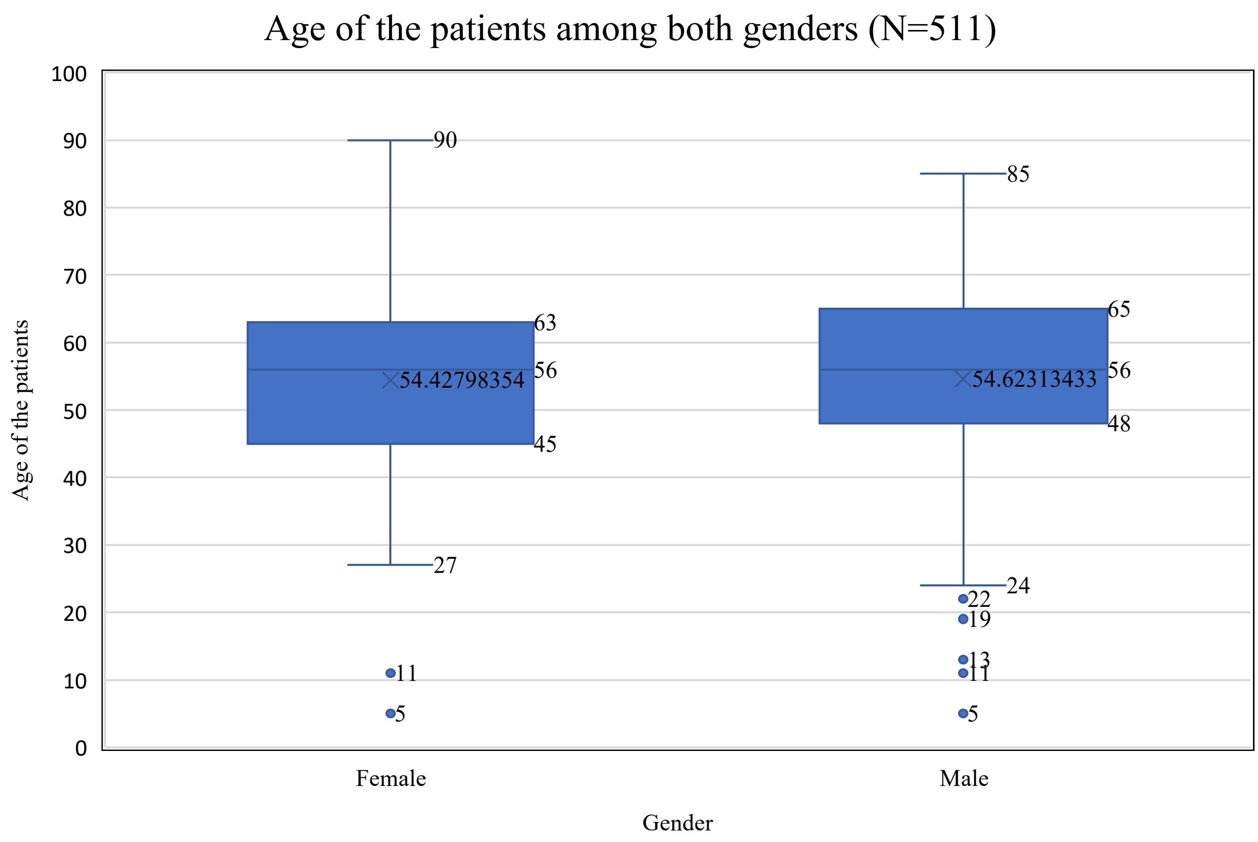


Figure 3 Shows graphical representation of age of the patients among both genders

Table 1 Shows the distribution of age among males and females

	Female (n=243)	**Male (n= 268)**
Minimum (Min)	5	5
Quartile 1 (Q1)	45	48
Median	56	56
Quartile 3 (Q3)	63	65
Maximum (Max)	90	85
Average (Mean)	54.62	54.42
Inter Quartile Range (IQR)	18	17
Standard Deviation (SD)	13.06	14.22
5% Trimmed mean	54.59	55.36
Range	85	80

Five-year age group classification

According to the five-year age classification, the highest number of cancer cases in males was in the 55 – 59 age group: 46 (17.16%). In females, the highest number of cancer cases was in the 60 – 64 age group: 56 (23%).

Table 2 Shows Five-year age group classification

Age in years	Male (n=268)	%	Female (n=243)	%
00 - 04	0	0	0	0
05 – 09	1	0.37	1	0.4
10 - 14	6	2.23	1	0.4
15 - 19	1	0.37	0	0
20 - 24	4	1.49	0	0
25 – 29	4	1.49	4	1.64
30 - 34	8	2.98	9	3.70
35 - 39	10	3.73	13	5.34
40 - 44	15	5.59	19	7.81
45 - 49	35	13.05	34	13.99
50 - 54	29	10.82	30	12.34
55 - 59	46	17.16	23	4.11
60 - 64	40	14.92	56	23
65 - 69	34	12.68	18	7.40
70 - 74	20	7.46	21	8.64
75 +	15	5.59	12	4.93

b. Gender

Among 511 Indigenous cancer patients, 268 (52%) were males and 243 (48%) were females.

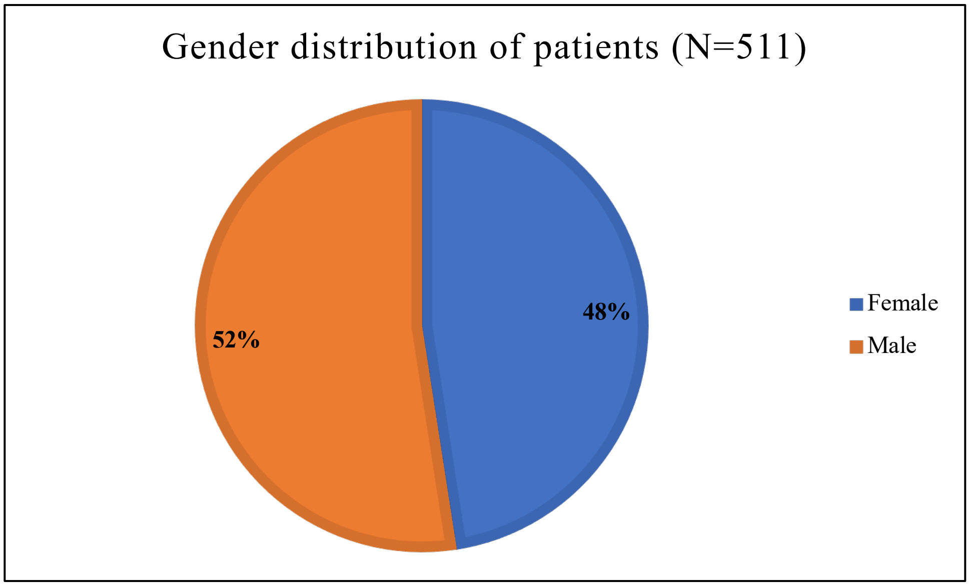


Figure 4 Shows graphical representation of gender distribution of patients

c. Marital status

Most of the Patients were married 422 (83%), 47 (9%) were widow/widower, 37 (7%) were unmarried and five (1%) were divorced.

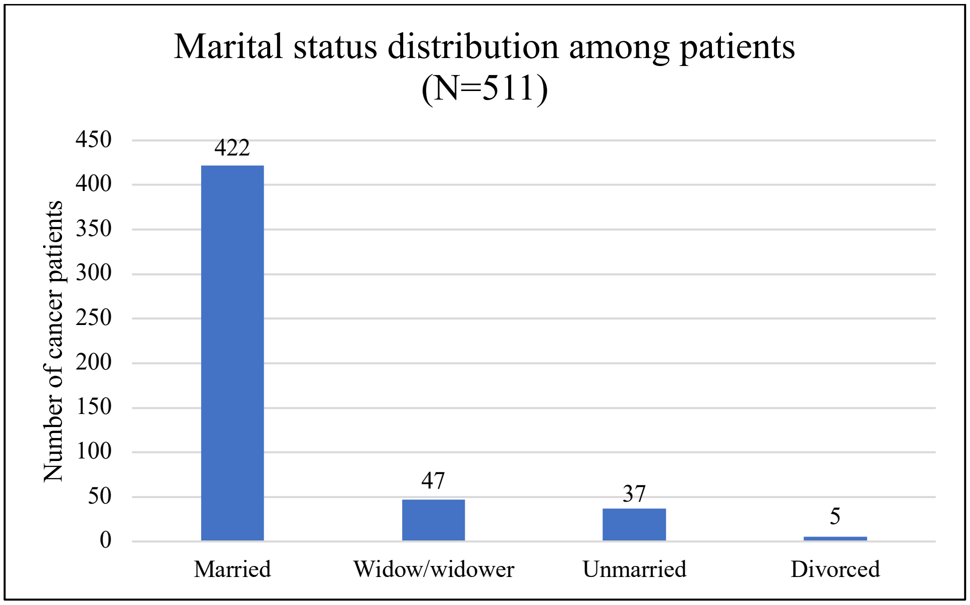


Figure 5 Shows graphical representation of marital status distribution among patients

d. Place of residence

Most of the patients 501(98%) were residing in rural region and 10 (2%) were residing in urban region.

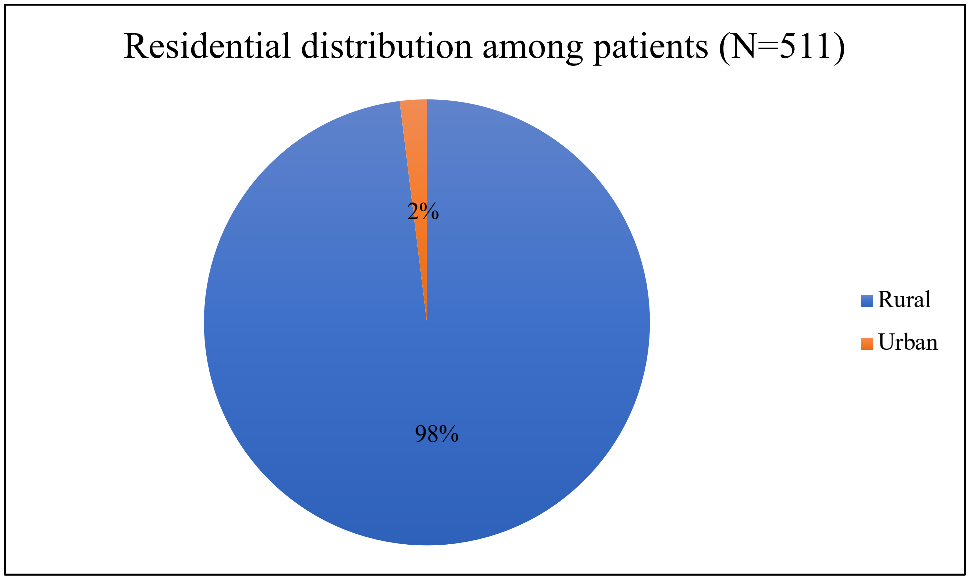


Figure 6 Shows graphical representation of residential distribution among patients

e. Highest educational qualification

Out of 511 patients, 277 (54%) were illiterate, 79 (15%) had completed middle school, 75 (15%) had primary education, 41 (8%) had secondary education, 16 (3%) were literate, and 23 (5%) case records were not available. No individuals had completed college or attained higher education levels.

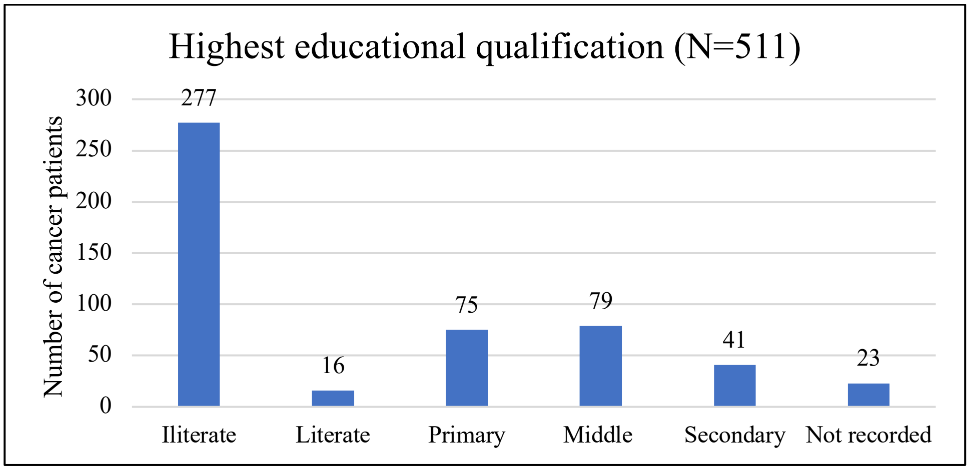


Figure 7 Shows graphical representation of highest educational qualification among patients

f. Occupation

The majority of the patients were either labourers 245 (48%) or unemployed 244 (48%), a small proportion nine (2%) were engaged in agriculture (cultivation) and six (1%) were engaged in other occupations, seven (1%) did not have their occupation recorded. Among the 511 patients, 244 (48%) were unemployed. Of these, 88 (36%) were male, and 159 (64%) were female. The mean age of the unemployed patients was 55.19±15.33 years, and the median (IQR) age was 60 (65-48) years.

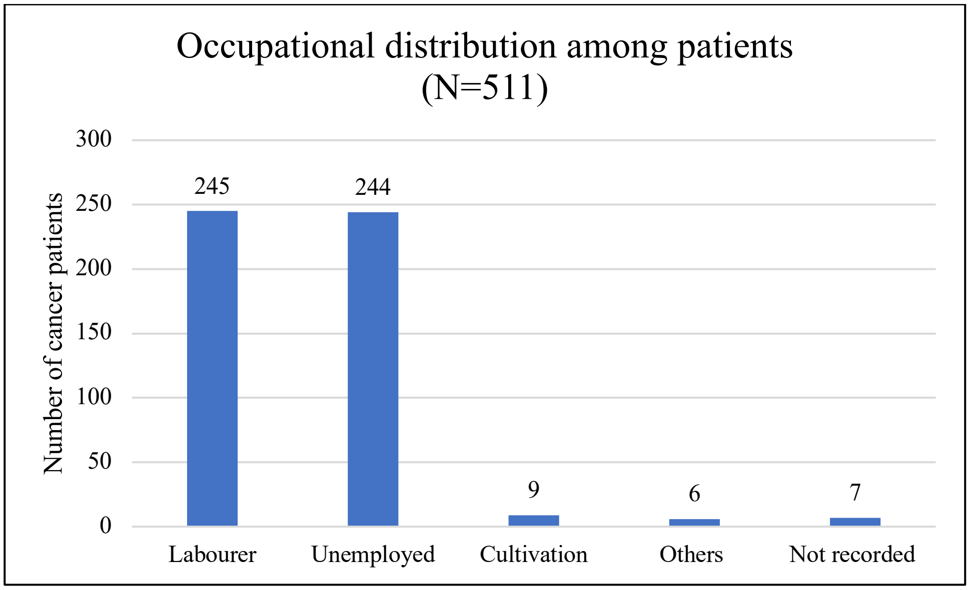


Figure 8 Shows graphical representation of occupational distribution among patients

g. Income of the patients in Indian Rupee (INR)

The mean monthly income of the families was 1015.07 ± 2032.19 INR, and the median (IQR) monthly income of the families was 500 (1000 - 250) INR. The Kolmogorov Smirnov's normality test showed that the data was not normally distributed.

h. Economic status (Ration card type)

Out of the total 511 patients, 376 (74%) were classified as below the poverty line (BPL), 15 (3%) were categorized as Above the Poverty line (APL) according to the economic status of the Government of India, and the records for 120 (23%) patients did not record their economic status.

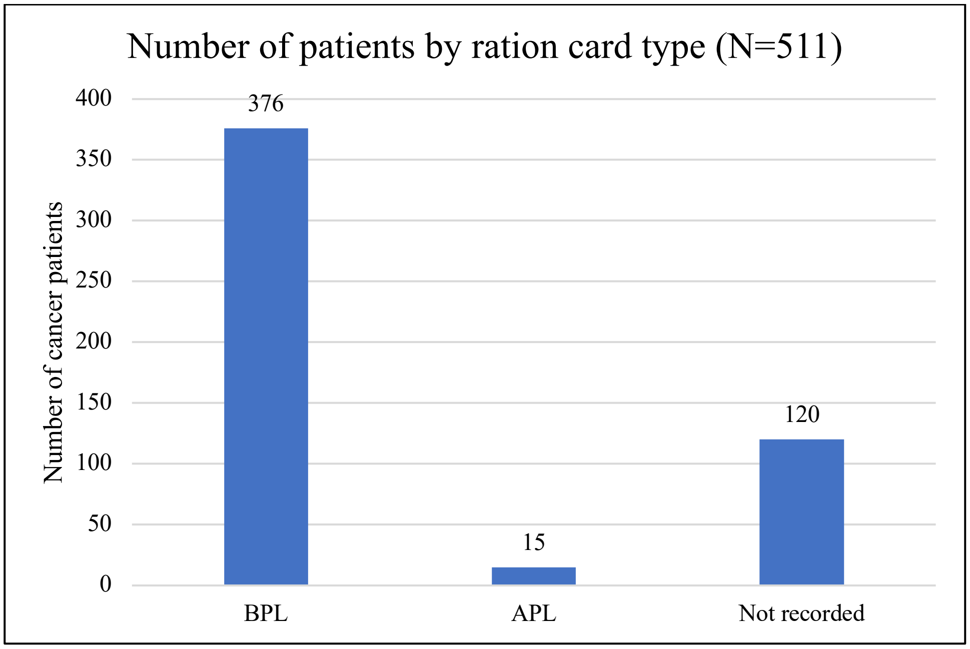


Figure 9 Shows graphical representation of number of patients by ration card type

5.1.2. Risk factors

Among the 511 patients, smoking tobacco was prevalent among 215 (42%). Out of that, 151(70%) were using beedi, and 64 (30%) were using cigarettes. Chewing tobacco was prevalent among most of them, and it was found in the habits of 301 individuals (59%). Alcohol consumption was predominant in 171(33%).

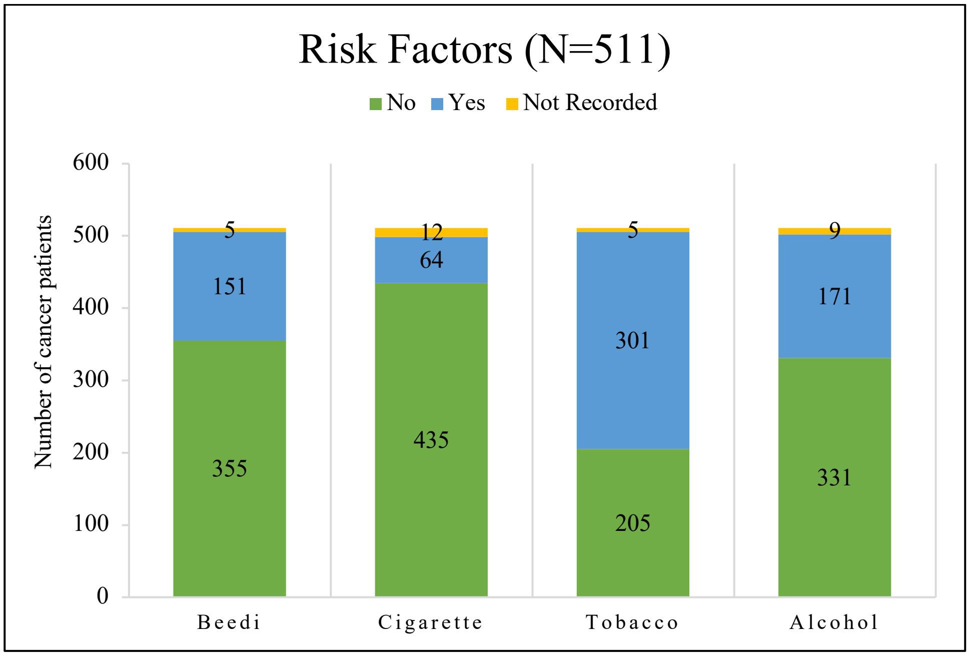


Figure 10 Shows graphical representation of ever smoking beedi, cigarette, chewing tobacco and alcohol use among study population

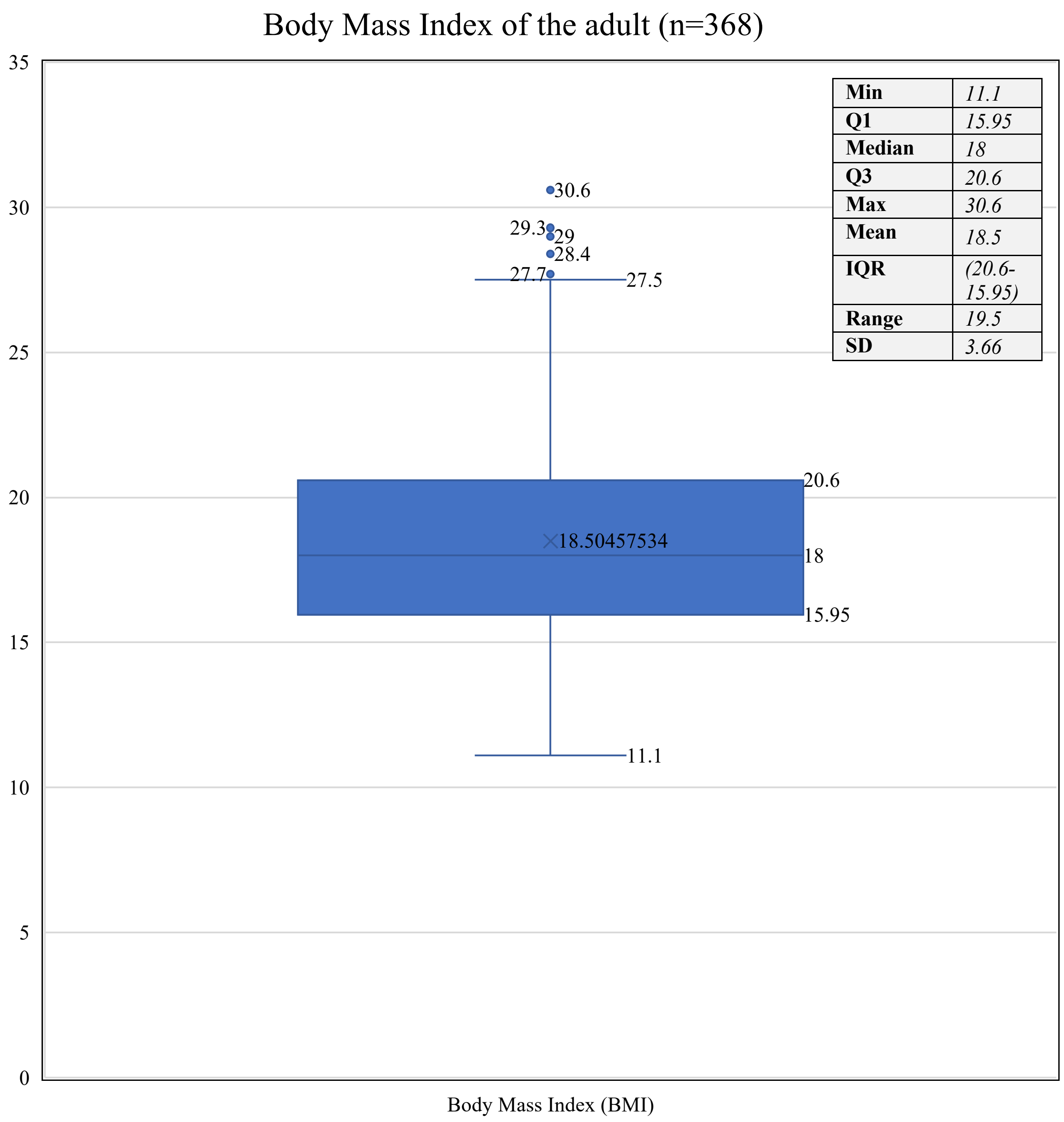
5.1.3. Personal factors

a. Diet

Majority of the patients followed non vegetarian diet 496 (97%), a small proportion 11 (2%) of patients followed vegetarian diet.

b. Body Mass Index (BMI)

Out of 511 patients, 502 individuals were adult and nine were children (who are under the age of 15 years). Among the adult subgroup 368 BMI records and children five records were available. Mean BMI of the adult was 18 ±3.66 kg/m^2. Median (IQR) BMI of the adult was 18.5 (20.6 – 15.9) kg/m^2. This shows that majority of the adult population was underweight.



Min	*11.1*
Q1	*15.95*
Median	*18*
Q3	*20.6*
Max	*30.6*
Mean	*18.5*
IQR	*(20.6-15.95)*
Range	*19.5*
SD	*3.66*

Figure 11 Shows graphical representation of Body Mass Index distribution among adult population

Based on the CDC's BMI indicator, 208 individuals (56.5%) were classified as underweight, 139 individuals (37.7%) were within the healthy weight range, 20 individuals (5.4%) were categorized as overweight, and one individual (0.27%) fell into the obese category.

Table 3 Shows BMI index of the patients in each category

BMI indicator (CDC)	**BMI of the patients Number (%)**
Below 18.5 (Underweight)	208 (56.5%)
18.5-24.9 (Healthy weight)	139 (37.7%)
25-29.9 (Overweight)	20 (5.4%)
30 and above (Obesity)	1 (0.27%)

c. History of other comorbidities

404 (79%) patients found the absence of comorbidities such as Hypertension, Diabetes Mellitus (DM), cardiovascular diseases (CVD), tuberculosis etc.107 (21%) patients were found to have at least one of the above-mentioned comorbidities. Out of a total of 107 patients, 89 individuals (83%) were diagnosed with hypertension, followed by 27 patients (25%) with DM and nine patients (8%) with tuberculosis.

d. History of other cancer and treatment taken

510 (99%) of the individuals had no history of any other cancer. One (0.1%) of the individuals had no available data about their history of other cancers.

e. Family history

473 (93%) had no family history of cancer and 38 (7%) had history of cancer. Among them, specific cancer types were identified, with 18 (47%) cases of Ca buccal mucosa, six (16%) cases of Ca stomach, and three (8%) cases of Ca breast and not recorded 11 (29%).

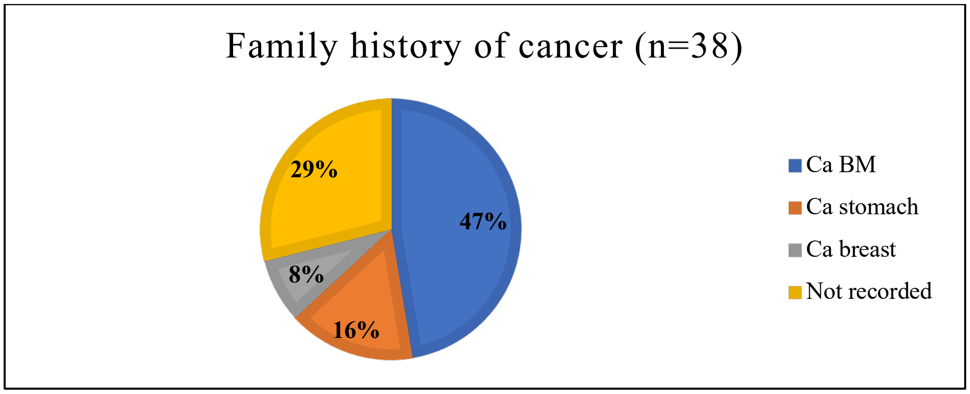


Figure 12 Shows graphical representation of the distribution of family history of cancer

5.1.4. Disease related factors

a. Leading sites of the cancer (ICD-10 classification)

The most common cancer sites among the study population were the Ca lip oral cavity174 (34.05%), the Ca lung 43 (8.41%), the Ca breast 35(6.84%), the Ca stomach 32 (6.26%), the Ca oesophagus 24 (4.69%), Other sites of cancers 203 (39.72%).

In both males and females, the leading cancer site was the Ca lip, oral cavity followed by Ca lung in male and Ca breast in females.

Table 4 Shows Number and Relative proportion of five most common sites of cancer among the Indigenous population, gender-wise distribution

Rank	**All patients (N=511)**	**Number (%)**	**Male (n=268)**	**Number (%)**	**Female (n=243)**	**Number (%)**
1	Ca lip, oral cavity	174 (34.05%)	Ca lip, oral cavity	94 (35.07%)	Ca lip, oral cavity	80 (32.92%)
2	Ca lung	43 (8.41%)	Ca lung	35 (13.05%)	Ca breast	35 (14.40%)
3	Ca breast	35 (6.84%)	Ca stomach	21 (7.83%)	Ca cervix uteri	19 (7.81%)
4	Ca stomach	32 (6.26%)	Ca oesophagus	15 (5.59%)	Ca stomach	11 (4.52%)
5	Ca oesophagus	24 (4.69%)	Ca oropharynx	13 (4.85%)	Ca colorectum	10 (4.11%)
	Other cancers	203 (39.72%)	Other cancers	90 (33.58%)	Other cancers	88 (36.21%)

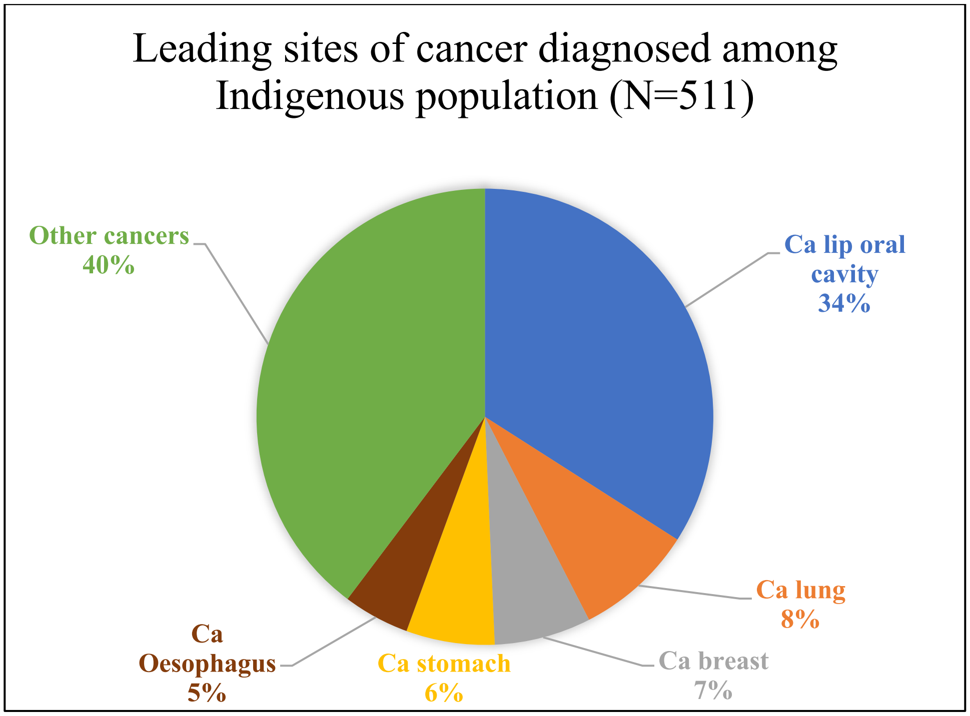


Figure 13 Shows graphical representation of leading sites of cancer diagnosed among Indigenous population

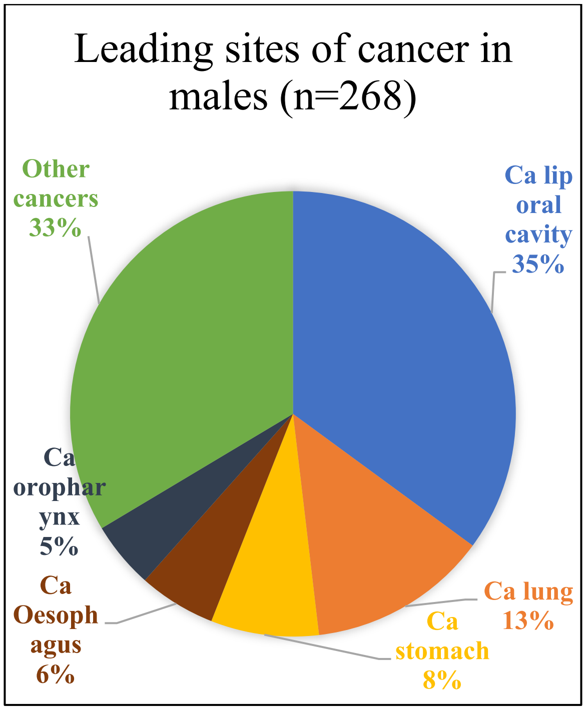


Figure 14 Shows graphical representation of leading sites of cancer in males

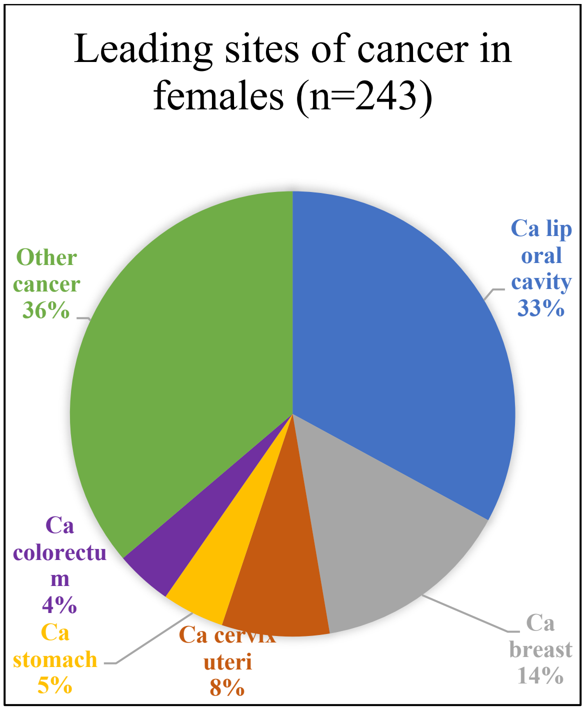


Figure 15 Shows graphical representation of leading sites of cancer in females

Comparison of five leading sites of cancer among general population and Indigenous population (2016 – 2020)

Leading cancer sites among general population were Ca breast 3480 (14%) followed by Ca lung 3150 (13%), among Indigenous population the leading sites were Ca lip, oral cavity 174 (41%) followed by Ca lung 4 (9%).

Table 5 Shows comparison of five leading sites of cancer among general population and Indigenous population at the comprehensive cancer care centre

Rank	**General population (N=24412) Number (%)**		**Indigenous population (N=511) Number (%)**	
1	Ca breast	3480 (14%)	Ca lip oral cavity	174 (41%)
2	Ca lung	3152 (13%)	Ca lung	43 (8.41%)
3	Ca lip, oral cavity	2355 (10%)	Ca breast	35 (8%)
4	Ca colorectum	1818 (7.4%)	Ca stomach	32 (7%)
5	Ca stomach	1113 (5%)	Ca oesophagus	24 (6%)

Comparison of five leading sites of cancer among male and female among Indigenous population – Year wise distribution

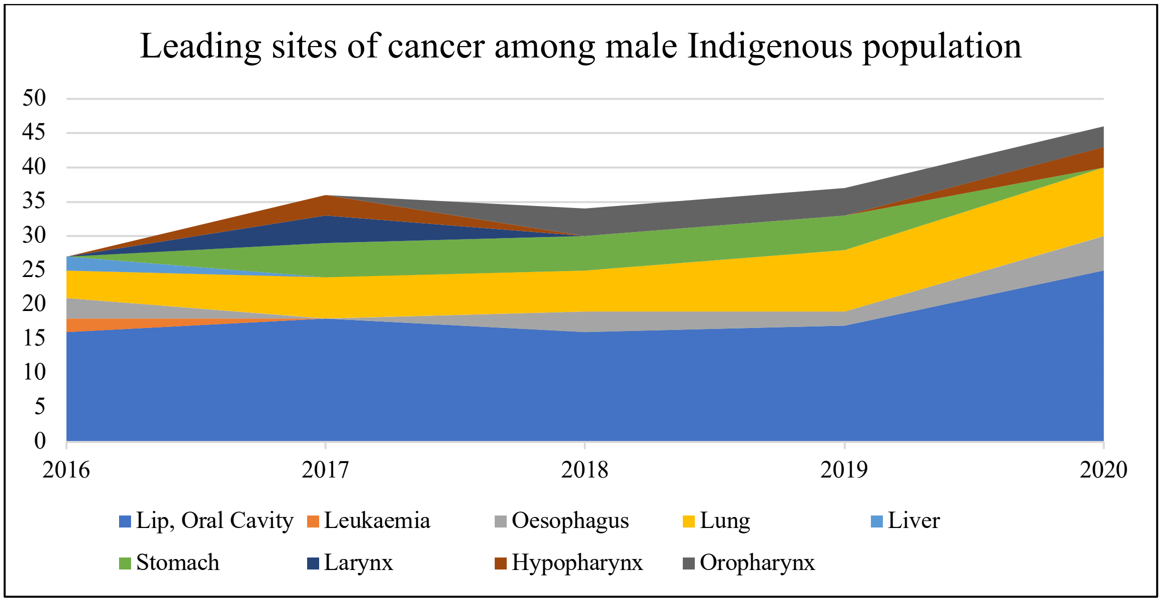


Figure 16 Shows graphical representation of the leading sites of cancer among male Indigenous population

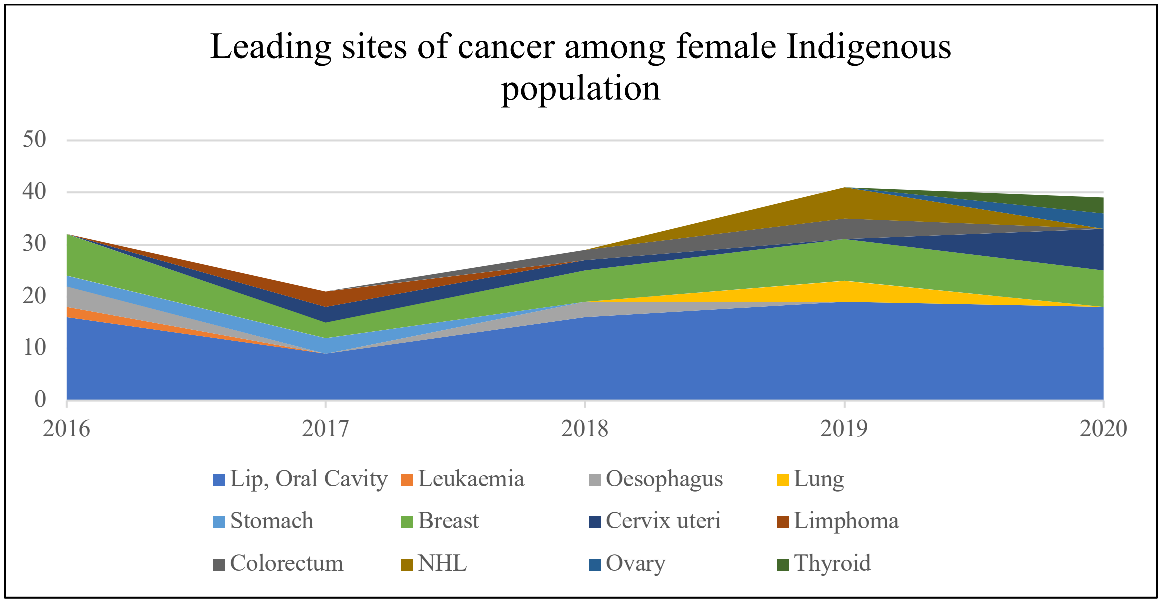


Figure 17 Shows graphical representation of the leading sites of cancer among female Indigenous population

Comparison of five leading sites of cancer among male & female among general population from the comprehensive cancer care centre – Year wise distribution

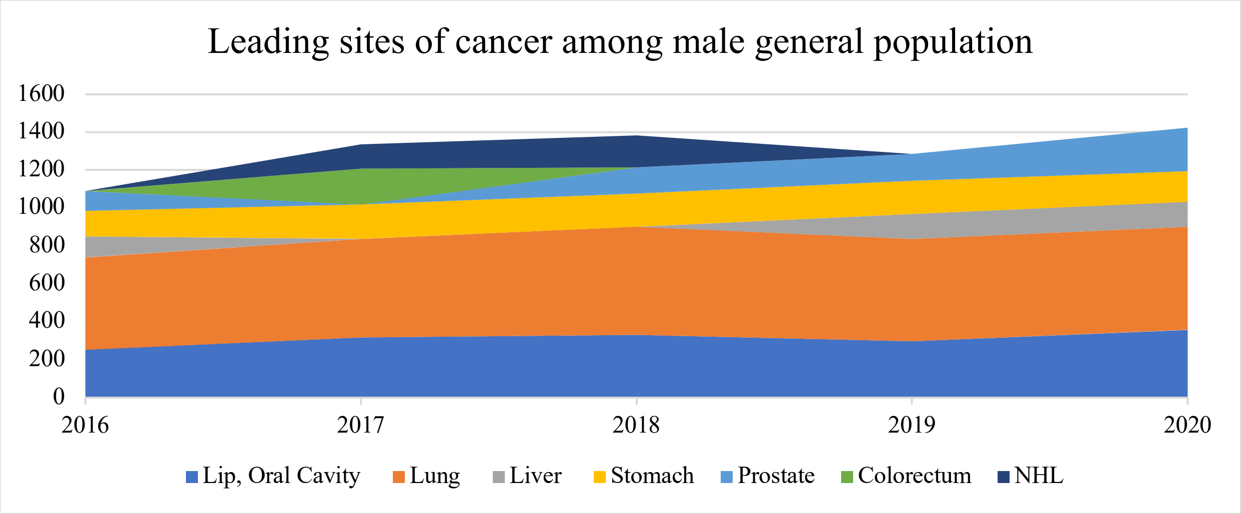


Figure 18 Shows graphical representation of the leading sites of cancer among male general population

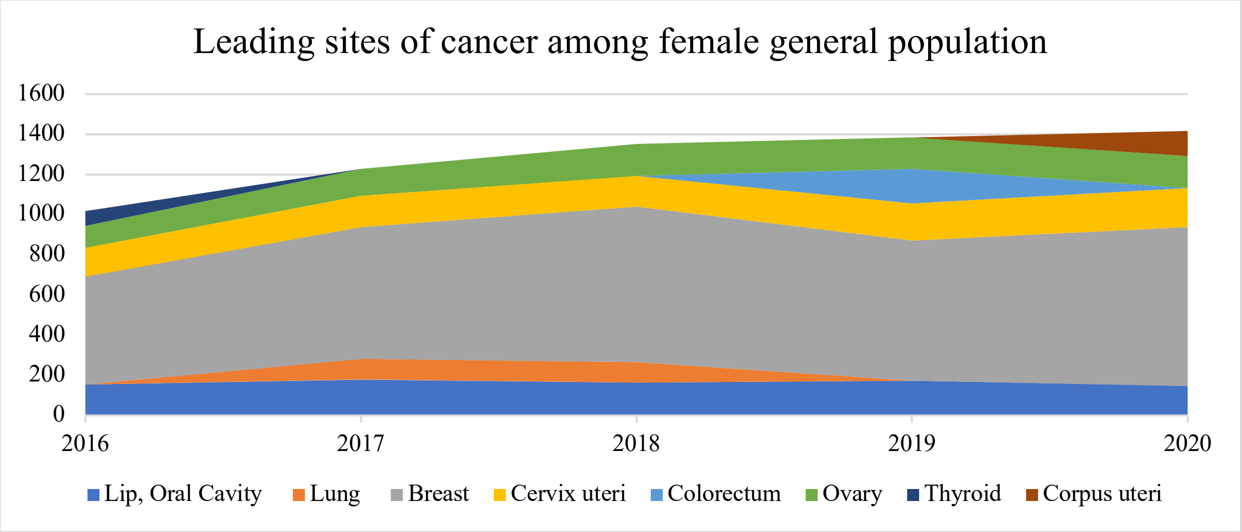


Figure 19 Shows graphical representation of the leading sites of cancer among female general population

b. Tobacco related cancers (TRC) in relative to all sites of cancer

Leading sites of TRC, relative to all sites of cancer were Ca lip, oral cavity: 174 (34.05%), Ca lung: 43(8.41%), Ca oesophagus: 24 (4.69%), Ca oropharynx: 16(3.13%), Ca hypopharynx: 15(2.9%).

Table 6 Shows Tobacco related cancers (TRC) in relative to all sites of cancer

Rank	**Tobacco related cancers (TRC) in relative to all sites of cancer**	**Number**	**%**
1	Ca lip, oral cavity	174	34.05
2	Ca lung	43	8.41
3	Ca oesophagus	24	4.69
4	Ca oropharynx	16	3.13
5	Ca hypopharynx	15	2.9
	All sites	511	100

Tobacco related cancers in relative to all sites of cancer, gender wise distribution

Among 511 Indigenous patients, 285 (56%) belong to TRC. In males, 179 (65%) was TRC; in females, it was 106 (43.6%). In both males and females, leading sites of the TRC were Ca lip oral cavity Male: 94 (35%) and females: 80 (33%), followed by Ca lung: 35 (13%) in males and Ca oesophagus: 9 (3.7%).

Table 7 Shows TRCs in relative to all sites of cancer among males and females

Site of cancer	**No of Males (Number)**	**%**	**No of Females (Number)**	**%**	**Total (Number)**	**%**
Ca lip, oral cavity	94	35	80	33	174	34.05
Ca lung	35	13	8	3.3	43	8.41
Ca oesophagus	15	6	9	3.7	24	4.69
Ca oropharynx	13	3.7	3	1.2	16	3.13
Ca hypopharynx	10	5	5	2	15	2.9
Ca larynx	11	4	0	0	11	2.15
Ca bladder	1	0.37	1	0.4	2	0.39
Total TRC	179	65	106	43.6	285	56
Other cancer sites	268	100	243	100	511	100

c. Tobacco Related Cancers (TRC)

Five leading sites of TRC in patients were Ca lip oral cavity:174 (62.81%), Ca lung: 43 (15.08%), Ca oesophagus: 24 (8.66%), Ca oropharynx 16 (5.61%) and Ca hypopharynx 15 (5.26%). Among males, 94 (53%) of the TRC were Ca lip oral cavity, followed by Ca lung: 35 (20%) and Ca Oesophagus: 15 (8%). In females, 80 (75%) of tobacco-related cancers were Ca lip, oral cavity, followed by Ca oesophagus: 9 (9%), Ca lung: 8 (8 %).

Table 8 Shows Number and Relative proportion of Tobacco Related Cancers (TRC)

Site of cancer	**Male (Number)**	**%**	**Female (Number)**	**%**	**Total cases (Number)**	**%**
Ca lip, oral cavity	94	53	80	75	174	61.05
Ca lung	35	20	8	8	43	15.08
Ca oesophagus	15	8	9	9	24	8.66
Ca oropharynx	13	7	3	3	16	5.26
Ca hypopharynx	10	6	5	4	15	5.61
Ca larynx	11	6	0	0	11	3.85
Ca bladder	1	1	1	1	2	0.70
TRC	179	100	106	100	285	100

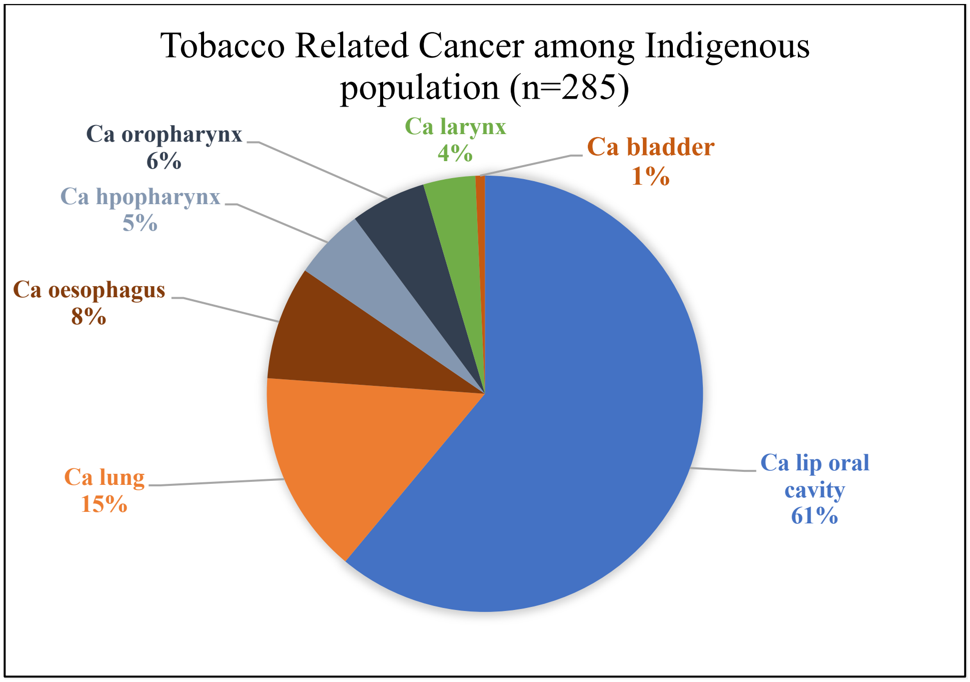


Figure 20 Shows graphical representation of TRC among Indigenous population

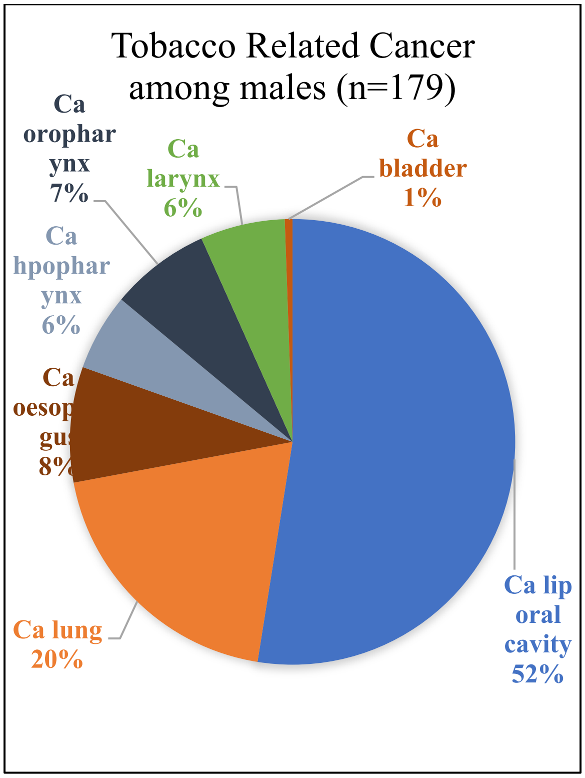


Figure 21 Shows graphical representation of TRC among males

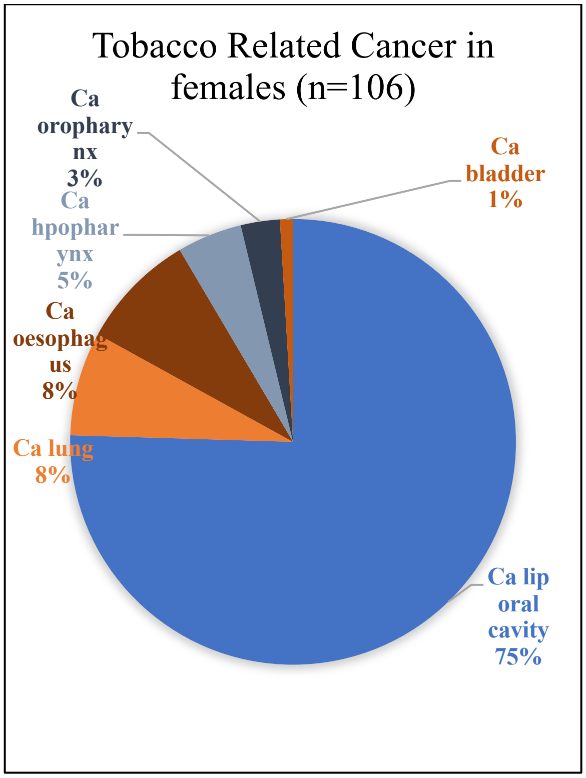


Figure 22 Shows graphical representation of TRC among females

Comaprison of TRC among general and Indigenous population

Leading sites of tobacco related cancer in Indigenous population were Ca lip,oral cavity 174 (61.05%) followed by Ca lung 41 (15.08%). Leading sites of tobacco related cancer in general population were Ca lung 3152 (39.5%) followed by Ca lip,oral cavity 2357 (29.57%). In non Indigenous population leading sites were Ca lung 3109 (40.4%) followed by Ca lip,oral cavity 2183 (28.3%)

Table 9 Shows the comparison of Tobacco Related Cancer among general and Indigenous population at the comprehensive cancer care centre

	Indigenous population (n=285)		**General population (n=7960)**		**Non Indigenous population (n=7675)**	
Site of cancer	**N**	**%**	**N**	**%**	**N**	**%**
Ca lip, oral cavity	174	61.05	2357	29.57	2183	28.3
Ca lung	43	15.08	3152	39.5	3109	40.4
Ca oesophagus	24	8.42	680	8.5	656	8.5
Ca hypopharynx	15	5.26	370	4.6	355	4.6
Ca oropharynx	16	5.61	394	4.9	378	4.9
Ca larynx	11	3.85	634	7.9	623	8
Ca bladder	2	0.70	365	4.5	363	4.7
Ca pharynx	0	0	8	0.1	8	0.10
Total TRC	285	100	7960	100	7675	100

Three Leading cancer sites and year wise distribution among Indigenous population

The number of cancer cases in the lip, oral cavity, and breast exhibited an upward trend during the period 2016-2020 while cancer in the lung demonstrated an initial increase, followed by a slight decrease and then a gradual decline.

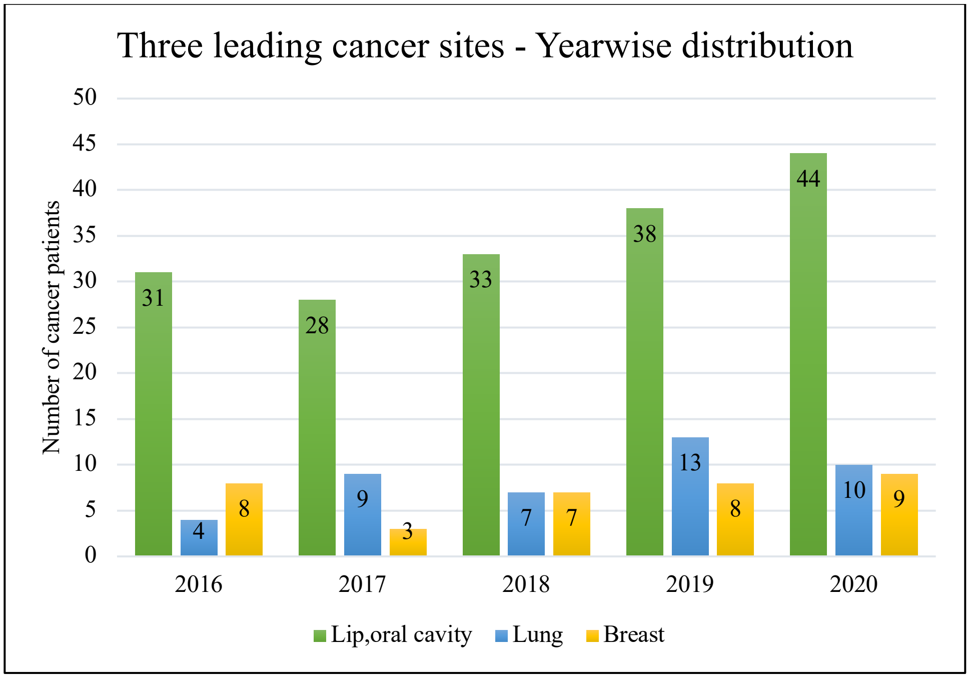


Figure 23 Shows graphical representation of leading cancer sites - Year wise distribution among study population

Table 10 Shows three leading cancer sites and year wise distribution

Year	**Ca lip, oral cavity (n)**	**Ca lung (n)**	**Ca breast (n)**
2016	31	4	8
2017	28	9	3
2018	33	7	7
2019	38	13	8
2020	44	10	9

Comparison of annual number of cases among Indigenous and general population

During the period from 2016 to 2020, the annual number of cancer cases reported at the comprehensive cancer care centre, was 511(2%) cancer cases among Indigenous patients, while the corresponding cases within the general population was reported as 24,412. Annual number of Indigenous cancer patients from 2016 to 2020 as follows 2016:79, 2017:99, 2018:103, 2019:110 and 2020:120. Annual number of cancer patients in the was as follows 2016: 3924, 2017: 4627, 2018: 5195, 2019: 5207, 2020: 5459.

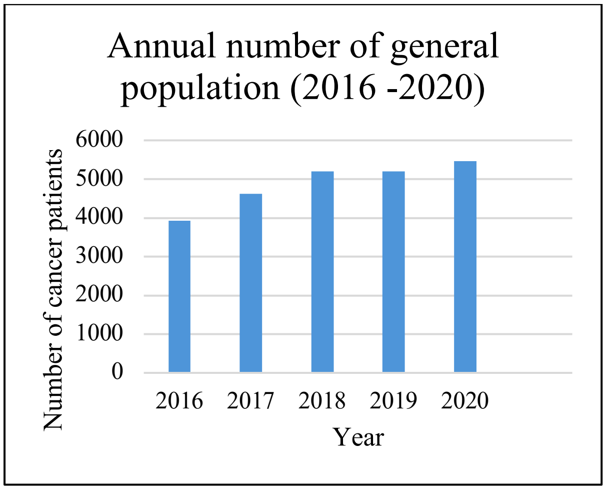


Figure 24 Shows graphical representation of annual number of cancer cases among general population (2016 - 2020)

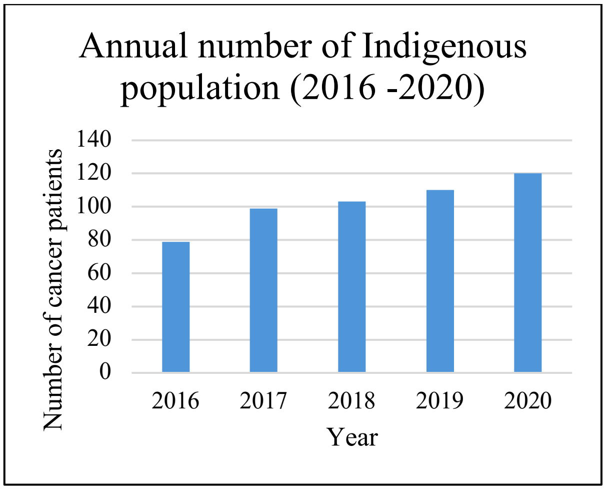


Figure 25 Shows graphical representation of annual number of cancer cases among Indigenous population (2016 - 2020)

d. Histology of cancer

The majority of individuals were diagnosed with 247 (48%) squamous cell carcinoma followed by adenocarcinoma 43 (8.4%).

e. Stages of cancer according to TNM system

The majority being diagnosed at stage 4: 246 (48%), followed by stage 3: 111 (22%), stage 2: 82 (17%), and a smaller percentage 34 (6%) at stage 1.

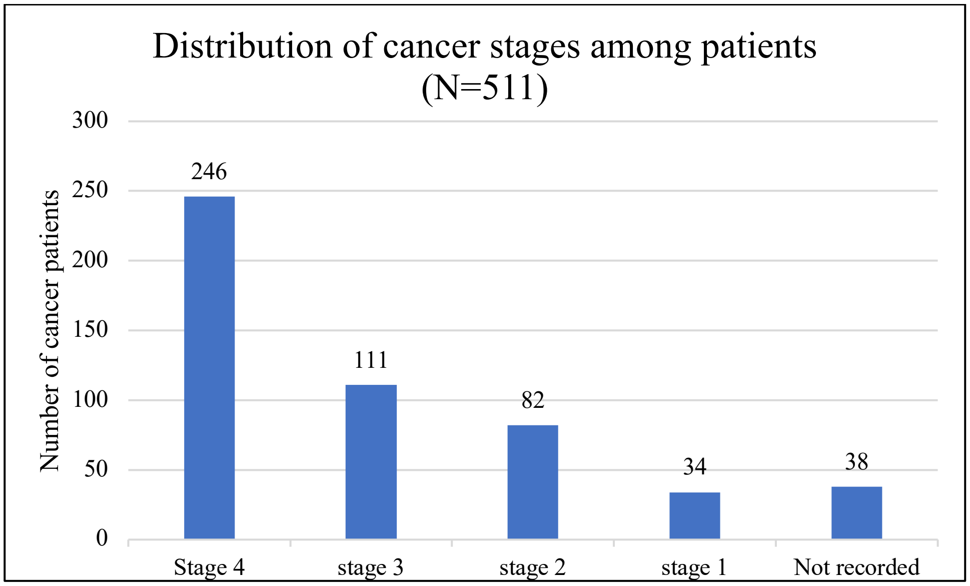


Figure 26 Shows graphical representation of distribution of cancer stages

Gender wise distribution of stages of cancer

Among males,

- 15 cases (44%) were diagnosed with stage 1
- 39 cases (48%) with stage 2
- 55 cases (50%) with stage 3
- 138 cases (56%) with stage 4

Among females,

- 19 (56%) were in stage 1
- 43 (51%) in stage 2
- 56 (50%) in stage 3
- 109 (44%) in stage 4

Cancer stage distribution among three leading sites among study population

- Out of 174 cases in the Ca lip and oral cavity, 10 (6%) were in stage 1, 17 (10%) were in stage 2, 19 (11%) were in stage 3, and 121 (70%) were in stage 4.
- In Ca lung, out of 43 cases, 2 (5%) was in stage 1, four (9%) were in stage 2, 16 (38%) were in stage 3, and 17 (40%) were in stage 4.
- In Ca breast, out of 35, two (6%) were in stage 1, seven (20%) were in stage 2, 16 (46%) were in stage 3, and nine (26%) were in stage 4.

Table 11 Shows Number and Relative proportion of patients by cancer stage distribution among three leading sites

Site of the cancer	**Stage 1 n (%)**	**Stage 2 n (%)**	**Stage 3 n (%)**	**Stage 4 n (%)**	**Stage not recorded n (%)**	**Total cases n (%)**
Ca lip, oral cavity	10 (5%)	17 (10%)	19 (11%)	121 (70%)	7 (4%)	174 (100%)
Ca lung	2 (5%)	4 (9%)	16 (38%)	17 (40%)	4 (9%)	43 (100%)
Ca breast	2 (6%)	7 (20%)	16 (46%)	9 (26%)	1 (2%)	35 (100%)

f. Initial treatment plan by Multi Specialty Board (MSB) of the institute

238 (47%) of the patients were planned for palliative treatment by the institution and 227 (44%) were scheduled for curative treatment and 46 (9%) do not undergone any treatment at the comprehensive cancer care centre.

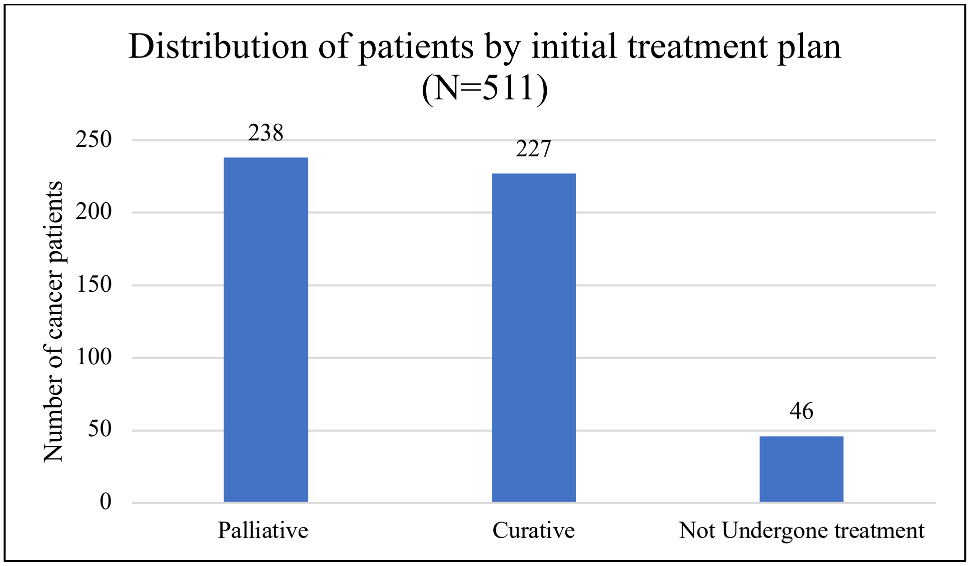


Figure 27 Shows graphical representation of distribution of patients by initial treatment plan

g. Type of treatment received at the comprehensive cancer care centre

102 (20%) had taken radiotherapy, 50 (10%) underwent only surgery, 46 (9%) underwent chemotherapy, 50 (10%) underwent chemotherapy and radiotherapy,43 (8%) undergone surgery and radiation therapy, surgery radiotherapy and chemotherapy 39 (7%), surgery and chemotherapy 18 (4%), surgery and hormone therapy one (0.19%), hormone and radiotherapy three (0.5%). Others including Best Supportive Care (BSC) 94 (18%). 65 (13%) has not any treatment at the comprehensive cancer care centre.

Table 12 Shows Number and Relative Proportion of patients according to type of treatment given at the comprehensive cancer care centre.

Treatment received	**Number (n)**	**%**
Radiotherapy	102	20
Surgery	50	10
Chemotherapy	46	9

Surgery + Radiotherapy (S+R)	43	8
Surgery + Chemotherapy + Radiotherapy (S+C+R)	39	7
Surgery + Chemotherapy (S+C)	18	4
Surgery + hormone therapy (S+H)	1	0.19
Chemotherapy + Radiotherapy (C+R)	50	10
Hormone + Radiotherapy (H+R)	3	0.5
Others	94	18
Not done any treatment	65	13

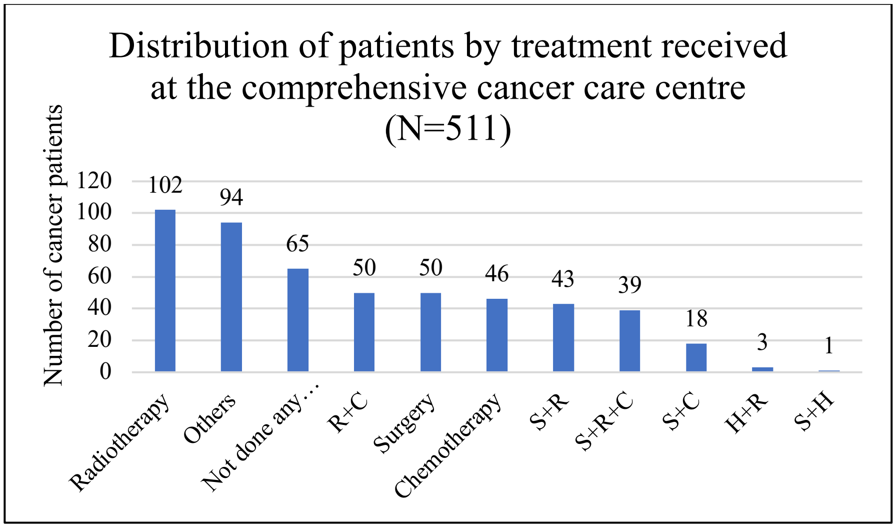


Figure 28 Shows graphical representation of patients by treatment received at the comprehensive cancer care centre.

Treatment received for three leading cancers among the study population

Out of 174 patients with Ca lip and oral cavity cancer,48 (27.5%) underwent radiotherapy. In the case of Ca lung cancer, among 10 cases (23.2%) underwent radiotherapy, 12 (27.9%) did not undergone any treatment, 11(25.5%) were given other treatment (Best Supportive Care), and for Ca breast, out of 35 cases, nine patients (25.71%) received surgery, radiotherapy, and chemotherapy.

Table 13 Shows Number and Relative Proportion of patients according to type of treatment given at the comprehensive cancer care centre for three leading cancers

	Ca lip, oral cavity (n=174)		**Ca lung (n=43)**		**Ca breast (n=35)**	
Treatment received	**n**	**%**	**n**	**%**	**n**	**%**
Radiotherapy	48	27.5	10	23.2	3	8.57
Surgery	20	11.4	2	4.6	3	8.57
Chemotherapy	0	0	3	4.9	3	8.57
Surgery + Radiotherapy	34	19.5	0	0	3	8.57
Surgery + Chemotherapy + Radiotherapy	21	12	1	2.3	9	25.71
Surgery + Chemotherapy	3	1.7	0	0	3	8.57
Surgery + hormone therapy	0	0	0	0	1	2.8
Chemotherapy + Radiotherapy	13	7.4	5	11.6	1	2.8
Hormone + Radiotherapy	0	0	0	0	3	8.57
Others	23	13.2	11	25.5	3	8.57
Not done any treatment	12	6.8	12	27.9	3	8.57

5.2. Univariate analysis of extent of adherence to the treatment and follow-up instructions

5.2.1. Completion of initial treatment plan by Multispecialty Board (MSB)

The majority of patients, totaling 437 (86%), successfully completed their initial treatment plan as prescribed by the Multispecialty Board (MSB) of the institution. 26 individuals (5%) did not fulfill their treatment plan. A total of 48 individuals (9%) ended their treatment prior to the MSB treatment evaluation.

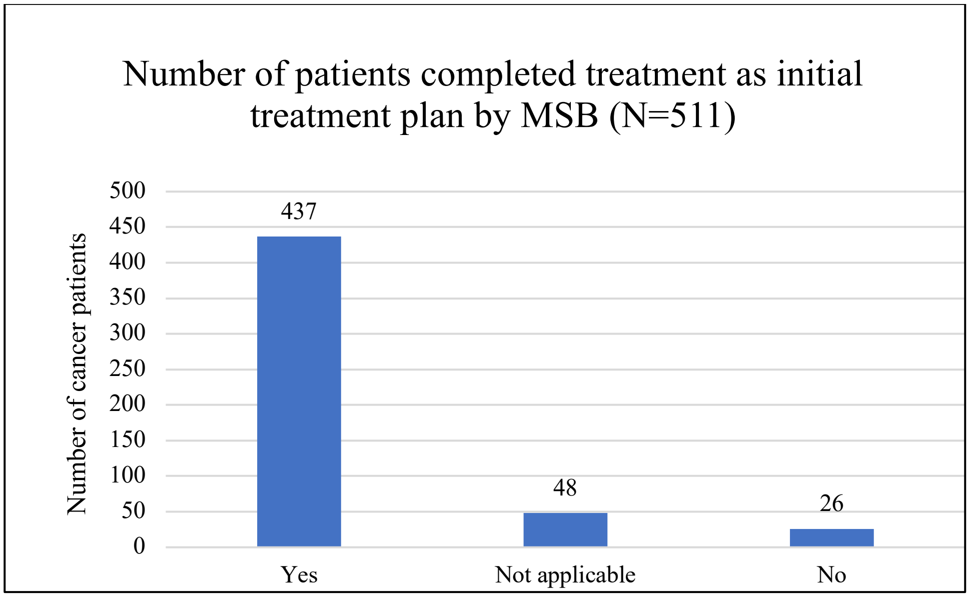


Figure 29 Shows graphical representation of Number of patients completed treatment as initial treatment plan by MSB

Number of patients completed treatment as per MSB decision among leading three cancers

The majority of patients with Ca lip and oral cavity, comprising 155 individuals (89%), have successfully completed the treatment as per the decision made by the medical review board (MSB). In the case of Ca lung, 30 patients (70%) have completed the treatment, and for Ca breast, 33 patients (94%) have completed their prescribed course of treatment.

Table 14 Shows Number and Relative proportion of patients completed treatments as per MSB decision

Treatment completed as per MSB decision	**Ca lip, oral cavity (n=174) (Number)%**	**Ca lung (n=43) (Number)%**	**Ca breast (n=35) (Number)%**
Yes	155 (89%)	30 (70%)	33 (94%)
No	7 (4%)	4 (10%)	1 (2.8%)
Not recorded	12 (7%)	9 (20%)	1 (2.8%)
Total cases	174	43	35

5.2.2. Follow-up plan

Most of the patients was receiving supportive care at local hospitals 218 (43%), 293 (57%) were undergoing follow-up at the comprehensive cancer care centre.

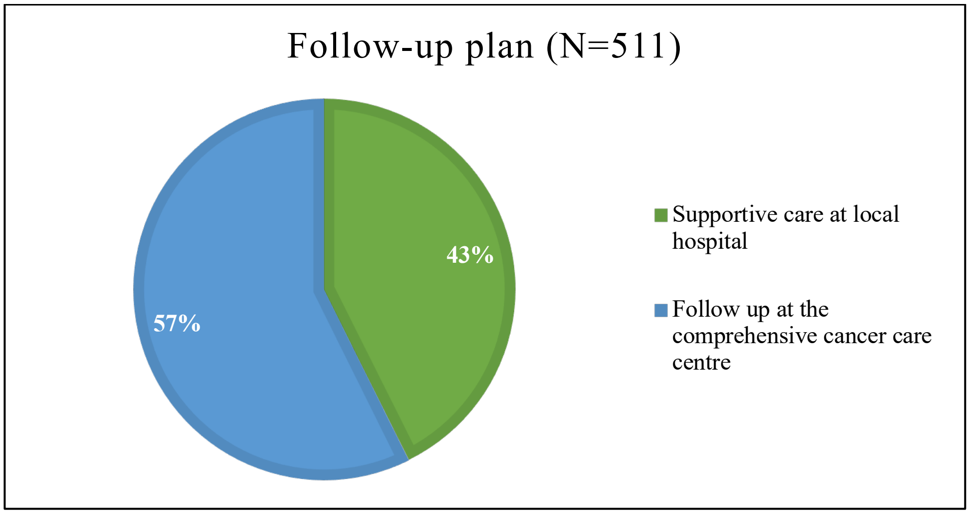


Figure 30 Shows graphical representation of follow-up plan

Out of 293 patients who underwent treatment at the comprehensive cancer care centre, 181 (62%) individuals were on follow-up and 112 (38%) were not on follow-up.

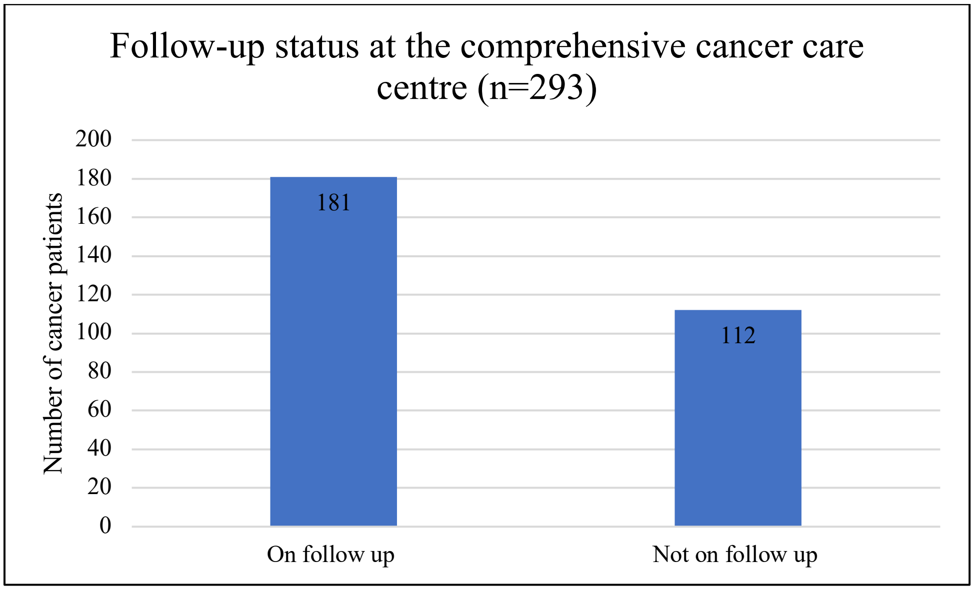


Figure 31 Shows graphical representation of follow- up status at the comprehensive cancer care centre

Gender wise follow-up status

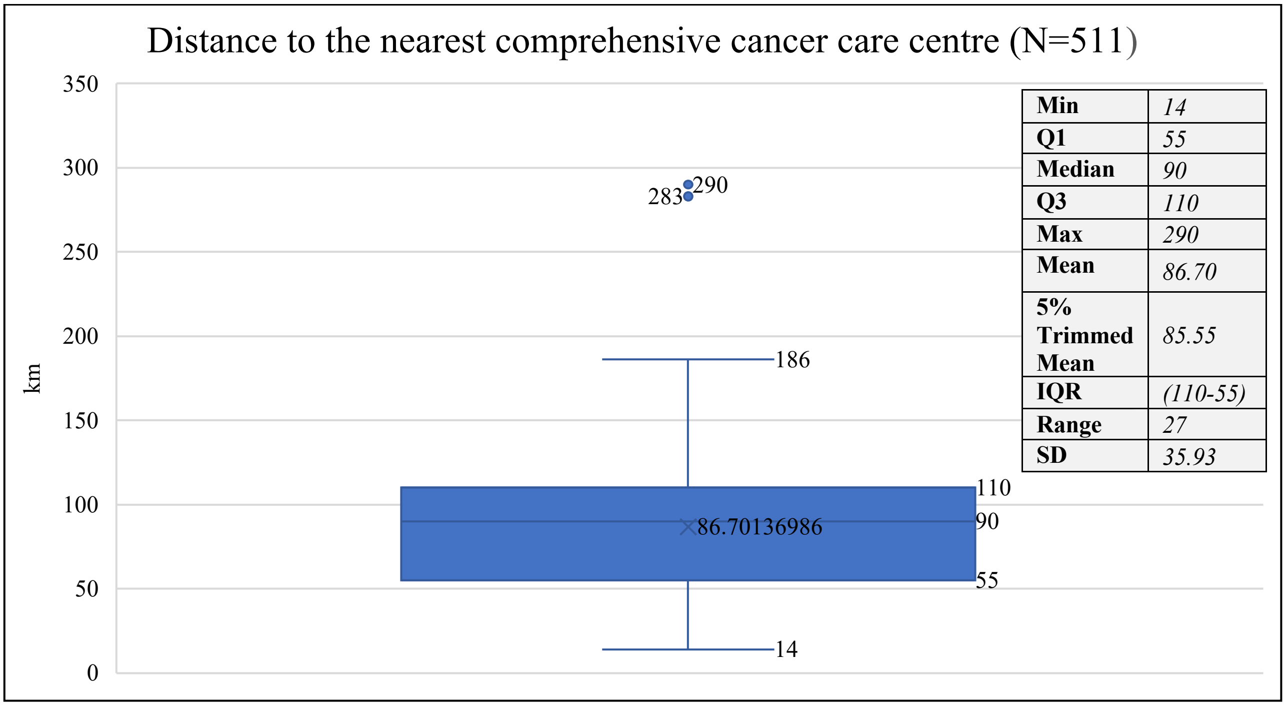
Out of a total of 511 patients, 293 were undergoing follow-up at the comprehensive cancer care centre. Among males, 92 individuals (51%) were on follow-up, while among females, 89 individuals (49%) were undergoing follow-up. In the male group, 63 individuals (56%) were not on follow-up, whereas in the female group, 49 individuals (44%) were not on follow-up at the comprehensive cancer care centre.

Table 15 Shows Number and Relative proportion of patients by follow-up status at the comprehensive cancer care centre

Follow-up status (n=293)	**Male (n=156) (Number)%**	**Female (n=137) (Number)%**	**Total cases (n=293) (Number)%**
On follow-up	92(51%)	89 (49%)	181(100%)
Not on follow-up	63 (56%)	49 (44%)	112 (100%)

5.2.3. The distance from patient's home to the comprehensive cancer care centre in kilometres

The mean distance to the comprehensive cancer care centre was 86.70 ± 35.93 km. Median (IQR) distance to the comprehensive cancer care centre was 90 (110-55) km. The Kolmogorov-Smirnov test showed that the age data was not normally distributed.

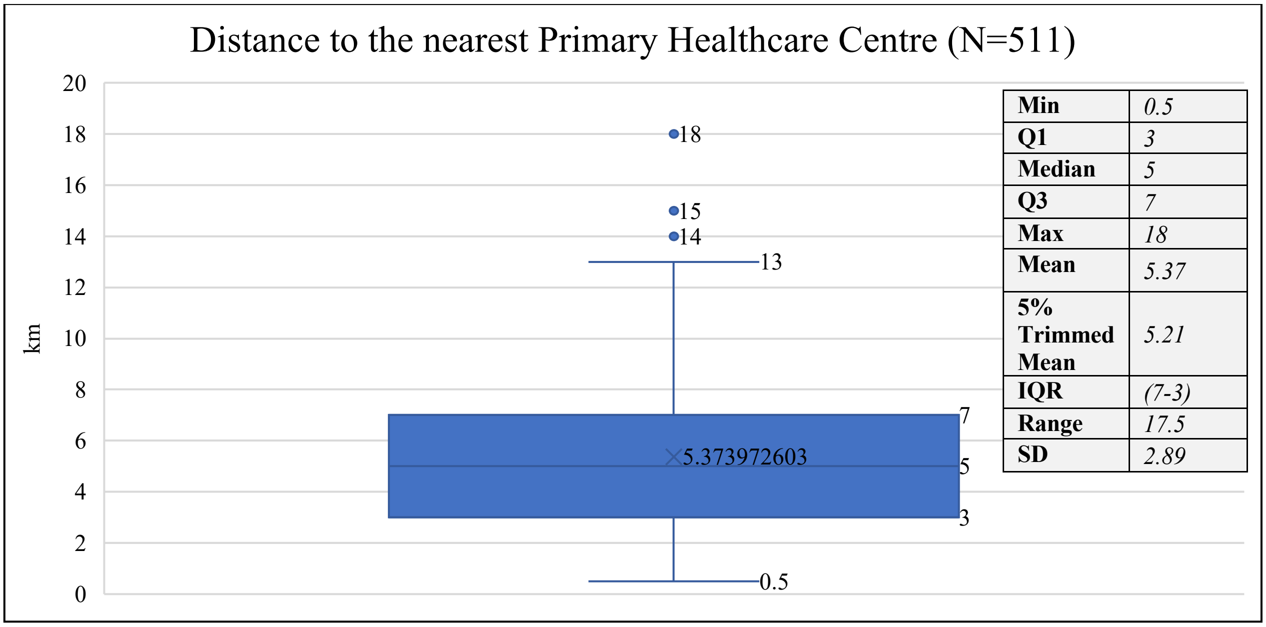


Min	*14*
Q1	*55*
Median	*90*
Q3	*110*
Max	*290*
Mean	*86.70*
5% Trimmed Mean	*85.55*
IQR	*(110-55)*
Range	*27*
SD	*35.93*

Figure 32 Shows graphical representation of distance to the nearest comprehensive cancer care centre

5.2.4. The distance from patient's home to the nearest Primary Healthcare Centre (PHC) in kilometres

The mean distance to the nearest PHC was 5.37 ± SD =2.89 km and median (IQR) distance to the nearest PHC was 5 (7-3) km. The Kolmogorov-Smirnov test showed that the age data was not normally distributed.



Min	*0.5*
Q1	*3*
Median	*5*
Q3	*7*
Max	*18*
Mean	*5.37*
5% Trimmed Mean	*5.21*
IQR	*(7-3)*
Range	*17.5*
SD	*2.89*

Figure 33 Shows graphical representation of distance to the nearest Primary Healthcare Centre

5.2.5. Various time points in the treatment journey of Indigenous cancer patients

Various time points consist of patient interval, diagnostic interval and treatment interval.

- Patient interval: The duration from the onset of the disease to the first presentation to a healthcare professional.
- Diagnostic interval: The duration from the first presentation at the healthcare professional to the diagnosis of the cancer
- Treatment interval: The duration from the diagnosis of cancer to the start of the cancer specific treatment (Weller *et al.*, 2012).

The median (IQR) patient interval was 60 (120-30) days (2 months). The median (IQR) diagnostic interval was 60 (21-7) days (2 months). The median (IQR) treatment interval was 21 (60-7) days (3 weeks).

Table 16 Shows various time points in the treatment journey of Indigenous cancer patients

Interval (days)	Median (IQR)	Mean (SD)
Patient interval	60 (120-30)	147.2 ±327.82
Diagnostic interval	10 (21-7)	22.45 ±35.97
Treatment interval	21(60-7)	31.69 ±37.59

Various time points in the patients journey among three leading cancers

In the patient interval Ca breast exhibits the lengthiest duration with a median of 150 days (5 months), with an interquartile range (IQR) from 365 to 60 days. Regarding the diagnostic interval, both Ca lung and Ca breast has a median of 14 days (2 weeks) with an IQR of 30 to 7 days. For the treatment interval, Ca lip, oral cavity shows the highest median duration of 30 days (1 month), with an IQR ranging from 60 to 14 days.

Table 17 Shows various time points in the patients journey among three leading cancers

	Ca lip, oral cavity		**Ca lung**		**Ca breast**	
Interval (days)	**Median (IQR)**	**Mean (SD)**	**Median (IQR)**	**Mean (SD)**	**Median (IQR)**	**Mean (SD)**
Patient interval	60 (120-30)	130.27± 306.07	60 (120-30)	85.05±70.23	150 (365-60)	305.53 ±381.39
Diagnostic interval	7 (14-7)	20.50 ±32.94	14(30-7)	18.0 ±13.53	14 (IQR=30 -7)	29.06 ±39.9
Treatment interval	30 (60-14)	41.56 ±34.57	25.5 (52.50-7.75)	33.21± 36.4	30 (60-14)	37.81 ±30.69

6. Discussion

This retrospective study aimed to find out the epidemiological profile of Indigenous cancer patients reported in a comprehensive cancer care centre, Northern Kerala, India during the time period from 2016 to 2020 and to study the extent of adherence to the treatment and follow-up instructions among them.

A total of 511 Indigenous cancer patients were included in the current study, with a mean age of 54.53 ±13.67 years. Among the study population, 52% were males and 48% were females. Most of the population (54%) were illiterate, and 74% belonged to low socio-economic groups. Fifty-nine percent of the population consumed smokeless tobacco. The leading cancer sites were Ca lip and oral cavity (34%), Ca lung (8.41%) and Ca breast (6.84%). Seventy percent of the patients were diagnosed at advanced TNM stages. Palliative treatments were recommended for 47% of the study population. The majority (86%) followed their treatment plans, and 62% were in active follow-up.

The study revealed that among the Indigenous population, the mean age of cancer diagnosis was 54.53 ±13.67 years. Females were diagnosed at a mean age of 54.43 ± 13.06 years, while males were diagnosed at 54.62 ± 14.22 years, indicating mean ages of cancer diagnosis of both genders closely align with those of the overall study population. This age was lower compared to the general population within the comprehensive cancer care centre, where males were diagnosed at a mean age of 59 ± 16.1 years and females at 56 ± 15.0 years (Malabar Cancer Centre, 2020). Similar trends were observed among Indigenous communities of Australia and Brazil diagnosed with cancer, showing a significantly younger age compared to their non-Indigenous population. In Brazil, the mean age of diagnosis for Indigenous populations was 54 years (Aguiar *et al.*, 2016). In Australia, the average age of diagnosis for Indigenous populations was 54.3 years, compared to 62.0 years for non-Indigenous individuals (Alkandari et al., 2023). Studies suggests potential common factors in healthcare disparities or lifestyle factors affecting Indigenous populations in different regions.

The incidence of cancer varies in terms of gender distribution. Among the study population 52% of Indigenous individuals diagnosed with cancer were male, while 48% were female. Compared to the general population of the institution, 54% were males, and 46% were females (Malabar Cancer Centre, 2020). In contrast, a study conducted among Indigenous populations in North India revealed a significant gender disparity, with 82% of diagnosed individuals being male and only 17.86% being female (Patel, Sinha, & Mitra, 2012). This trend mirrors broader patterns observed across India, where cancer incidence is consistently higher in males compared to females (Sung H *et al.*, 2020).

The majority of the Indigenous population (54%) were illiterate, with none having completed college or attained higher education levels. In contrast, according to the HBCR reports of the comprehensive cancer care centre, only 11% of the general population was illiterate during the period from 2016 to 2020 (Malabar Cancer Centre, 2020). The literacy rate of the studied population was 41%. This was markedly lower than both the state-level literacy rate (94%) (Census India, 2011) and the national literacy rate (76.32%) (India: Literacy rate 1981-2022, 2023). The literacy rate falls below that of the Indigenous population in Kerala (75.8%) and in overall India (58.96%) (Government of India, 2023). Among the Indigenous population in India 6.7% who are above the age of 18 years have attained higher education (Ministry of Health & Family Welfare and the Ministry of Tribal Affairs, 2018). Similarly, the disparity in literacy rates was evident in other parts of the world. A comparable study focusing on the Indigenous population in Bangladesh also revealed that 69% of the population was illiterate (Rahman *et al.*, 2021). Such a significant gap highlights the entrenched educational inequities faced by Indigenous communities, exacerbated by historical marginalisation, limited access to quality education, socio-economic barriers, geographical isolation and cultural differences (Acharya, 2022).

The economic situation among Indigenous populations in different regions of India reveals significant challenges. In the current investigation, a substantial 74% of the Indigenous population was classified as Below Poverty Line (BPL), highlighting prevalent economic adversity. Forty-eight percent were unemployed and 48% were manual labourers. The findings from another cross-sectional study conducted among Indigenous populations in Kashmir, North India, showed that 94.3% were falling under the low-income category (Ganie et al., 2020). A similar study in Tamil Nadu, South India, indicated that a majority of the Indigenous population was engaged in manual labour (47%) and was BPL, emphasising the widespread economic struggles experienced by these communities within the country. As per the Ministry of Tribal Affairs in India, 43% of the

Indigenous population was engaged in manual labour or agriculture and 40% of the tribal population was categorised as BPL by the economic status of the Government of India (Ministry of Tribal Affairs, 2022).

The socio-economic status of Indigenous patients was compared to that of non-Indigenous patients in another retrospective study in North India. A higher proportion of Indigenous patients (39.29%) came from impoverished families and belong to lower socio-economic backgrounds, contrasting with the non-Indigenous population, who are predominantly from middle socio-economic strata (34.88%) (Patel, Sinha and Mitra, 2012). The reports from the United Nations also indicate that Indigenous peoples worldwide remain disproportionately represented among the poor, illiterate, and unemployed (United Nations, 2023).

Low economic status contributes to the undernutrition observed within Indigenous communities (Horta et al., 2013). In the present study, 56.5% of the population fell under the category of underweight based on the Centers for Disease Control and Prevention (CDC) Body Mass Indicator (BMI). One study comparing the prevalence of underweight among the Indigenous population in Northern Kerala found a high burden of underweight among the Indigenous population (46.1%) compared to the general population (24.3%)(Haddad *et al.*, 2012). A cross-sectional study conducted among the population of three different states in Eastern and Western India found that the majority of the study groups were either underweight or obese/overweight, and the prevalence of undernutrition (39.4%) was higher than that of obesity (12.8%) among the population (Kshatriya and Acharya, 2016). But in contrast, among Indigenous Australians 71% were classified as overweight (Australian Institute Health and Welfare, 2023), Canada (Government of Canada, 2015) and the United States (U S Department of Health & Human Services, 2023). These results highlight the significant issue of malnutrition among the Indigenous population worldwide. Socio-economic factors such as poverty, low literacy rates, and unemployment were significant contributors to malnutrition among Indigenous population (Wong *et al.*, 2015).

Indigenous communities experience a disproportionately higher incidence and mortality rate of cancer compared to non-Indigenous communities within the country. This disparity can be attributed to preventable cancer risk factors such as exposure to environmental carcinogens, tobacco use, alcohol consumption, malnutrition, lack of physical activity, and diabetes mellitus among Indigenous populations (Ahmed Jemal *et al.*, 2019). According to the Ministry of Tribal Affairs of India, there were alarmingly high rates of tobacco usage among Indigenous men, with 72% using tobacco products (Ministry of Health & Family Welfare and the Ministry of Tribal Affairs, 2018). In India, smokeless tobacco stands out as the predominant form of tobacco consumption, featuring commonly used products such as betel quid with tobacco, khaini, gutkha and zarda (World Health Organization, 2024). Among the study population smoking tobacco were prevalent among 42%. Out of that 70% were using beedi and 30% were using cigarettes. Chewing tobacco was also prevalent among most of them, found in the habits of 59%. When considering gender distribution, 54% of smokeless tobacco users were males, while 46% were females, highlighting that a significant proportion of both genders were engaged in tobacco consumption. Alcohol consumption was predominant in 33%. These findings underscore the substantial burden of risk factor mainly tobacco use, within this demographic.

Several research studies corroborate these findings. A longitudinal study assessing the prevalence of tobacco use among the Indigenous population of India found that around 46% of the populations were tobacco users. Specifically, 19% of individuals reported smoking, while nearly 32% used smokeless tobacco (Murmu *et al.*, 2023). Another study highlighted even higher prevalence rates, with 64.55% of adults using tobacco, comprising 29.1% smokers and 63.4% smokeless tobacco users. Alcohol use was also high among the Indigenous population (Ray *et al.*, 2018). On a global scale, Australian Aboriginals exhibited higher tobacco product usage compared to non-Aboriginal population (Australian Institute of Health and Welfare, 2023). Similar trends were observed among Aboriginals of Canada, with a tobacco usage rate of 57%, contrasting with the general population’s rate of 20% (National Collaborating Centre for Indigenous Health, 2013) and in Minnesota, United States, American Indians exhibited significantly higher commercial tobacco usage rate of 59% compared to the general population (14.5%) (Department of Health, Minnesota, 2022).

According to the Global Adult Tobacco Survey (GATS 2) conducted between 2016 and 2017, tobacco use was reported by 28.6% of the population in India aged 15 years and above, 12.7% of the population in Kerala State. Out of these, 28.6 percent tobacco users in India consist of 7.2% smoking tobacco, while 17.9% using smokeless tobacco. The same comparison for Kerala was 7.3% using smoking tobacco and 3.4% using smokeless tobacco. Smoking was higher among males and smokeless tobacco was consumed by both men and women (World Health Organization, 2018). This indicates a significant trend where the prevalence of smokeless tobacco use was notably higher among both the Indigenous study population and the general population of India. However, in the state of Kerala, there was a comparatively lower consumption of smokeless tobacco among the general population. Among Indigenous communities use of tobacco was firmly embedded within the social customs and cultural traditions of the study population, presenting challenges for intervention. These habits persist due to societal approval and adherence to longstanding norms, leading to the widespread acceptance of tobacco consumption. The increased availability and easy accessibility of tobacco products further contributed to the rise in consumption (Agrawal *et al.*, 2023). There are certain misconceptions that smokeless tobacco is a safer alternative to smoking, resulting in higher rates of consumption, early initiation among users, and the normalisation of its use in both genders (Solhi *et al.*, 2021).

Tobacco usage contributes to a quarter of all cancer incidences (World Health Organisation, 2024). Among the risk factors, tobacco stands as the primary cause of cancer incidence and mortality. Beyond Ca lung cancer, various other TRC were Ca mouth, Ca throat, Ca larynx, Ca oesophagus, Ca stomach, Ca kidney, Ca pancreas, Ca liver, Ca bladder, Ca cervix, Ca colorectum and acute myeloid leukaemia (CDC, 2019). According to the Indian Council of Medical Research (ICMR), TRCs constituted 27% of India's cancer burden in 2020 (National Cancer Registry Programme, India, 2021). This indicates that a considerable proportion of cancer cases in India were directly attributable to tobacco use. The incidence of TRC among study population was also high 56% whereas it was 32% among non-Indigenous populations in the same institute (Malabar Cancer Centre, 2020). This revealed the tobacco consumption plays a substantial role in contributing cancer cases within the study group. Leading sites of TRC in Indigenous population, were Ca lip, oral cavity (61.05%) followed by Ca lung (15.08%). In non Indigenous population leading sites, were Ca lung (40.4%) followed by Ca lip, oral cavity (28.3%) (Malabar Cancer Centre, 2020). Despite the fact that the India's numerous tobacco control programmes and acts, including The Cigarettes and Other Tobacco Products (Prohibition of Advertisement and Regulation of Trade and Commerce, Production, Supply, and Distribution) Act, COTPA, 2003, and The National Tobacco Control Programme (NTCP), have made strides in reducing the tobacco burden in the country (National Tobacco Control Programme, India, 2021). However, the taxation of Smokeless Tobacco (SLT) remains an area of insufficient research and requires greater attention for policymakers to yield more effective outcomes (Murmu *et al.*, 2023).

Cancer incidence has shown a global increase over the past few decades. The projected number of new cancer cases in 2050 is expected to surpass 35 million, marking a substantial 77% rise from the estimated 20 million cases in 2022 (Ferlay J et al., 2024). A similar trend was observed among Indigenous patients and the general population at the comprehensive cancer care centre. The study findings revealed a consistent increase in the number of Indigenous cancer patients over the five-years, with figures rising from 79 cancer cases in 2016 to 120 cancer cases in 2020. Similarly, the overall number of patients diagnosed with cancer reported at the institute exhibited a notable rise each year, with the figures escalating from 3924 cases in 2016 to 5459 cases in 2020, showing a growing burden of cancer in the community (Malabar Cancer Centre, 2020). Analysing these trends will be crucial for healthcare planning, resource allocation, and the development of effective cancer prevention and treatment strategies for patients (Sathishkumar *et al.*, 2022).

The most common cancers among the study population were as follows Ca lip, oral cavity (34.05%), Ca lung (8.41%), Ca breast (6.84%), Ca stomach (6.26%), Ca oesophagus (4.69). It is imperative to emphasise that most of them were TRCs. Four out of the five common cancers were TRCs. Among them, Ca lip and oral cavity emerged as the most prevalent cancer site, constituting 34.05% of cases. Among the general population of the comprehensive cancer care centre and of India, the incidence of lip and oral cavity cancer was lower at a rate of 10%. In contrast, as per the 2022 GLOBOCAN data for India, Ca breast was the most common cancer. The same holds with the general population of the comprehensive cancer care centre (Ferlay J et al., 2022) (Malabar Cancer Centre, 2020). It was also significant that the Ca lip, oral cavity was the most common cancer among both male and female within the study group. This underscores the significant role of smokeless tobacco consumption among the population which may be driving the high incidence of Ca lip and oral cavity within this demographic. This was followed by Ca lung accounted for 8.4% of cases, while it was 13% among the general population in the comprehensive cancer care centre during the period 2016 to 2020 (Malabar Cancer Centre, 2020). However, in the broader context of the general population in India, Ca lung constituted 5.8% of cases as per the cancer incidence data given by the GLOBOCAN for the year 2022 (Ferlay J et al., 2022). Upon a global comparison, Ca lung was identified as the most common cancer among the Indigenous populations across four countries: Australia (Aboriginal and/or Torres Strait Islanders), New Zealand (Māori), Canada (First Nations, Métis, or Inuit), and the United States (American Indians/Alaskan Natives)

(Garvey, 2017). This was attributed to the high prevalence of tobacco smoking and the lower use of chewing tobacco products among the population, which was the leading risk factor for Ca lip and oral cavity (Van der Sterren *et al.*, 2021).

Ca breast incidence was lower (6.84%) among the Indigenous population compared with the general population as per the HBCR data of the comprehensive cancer care centre (14%) and the general population in the country as per the GLOBOCAN data 2022 (13.6%) (Ferlay J et al., 2022) (Malabar Cancer Centre, 2020). Similar results were observed across India. A study was conducted among Indigenous women in West Bengal, Eastern India, to evaluate the incidence of Ca breast showed 74% did not show malignant changes in the breast (Mukherjee *et al.*, 2015). Comparable results were seen among Indigenous populations worldwide. In a cross-sectional study of Indigenous women in Brazil, the majority (82%) showed no signs of breast cancer in mammographic evaluations (Secco *et al.*, 2017). In Australia, Aboriginal women have a lower rate of breast cancer compared to non-Aboriginal women (Christie *et al.*, 2022). The lower rate of breast cancer cases among Indigenous women may be attributed to their reduced prevalence of hormonal and reproductive risk factors, coupled with higher levels of physical activity (Gómez-Flores-Ramos *et al.*, 2022).

Ca stomach was 6.26% among Indigenous population and 4.5% among the general population in the comprehensive cancer care centre and 4.6% among the general population in India according to the cancer incidence data provided by GLOBOCAN for the year 2022 (Ferlay J et al., 2022) (Malabar Cancer Centre, 2020). Helicobacter pylori infection was more common among Indigenous societies. This infection, which was frequently linked to destitution and crowded living conditions, may be a factor in their increased risk of Ca stomach. (Ahmed Jemal *et al.*, 2019). Alcohol consumption which was prevalent among the Indigenous communities would also increase the risk of Ca stomach (Ma *et al.*, 2017). Ca oesophagus was 4.69% among the study population and 5% among the general population in India and but found to be lower (2.7%) among the general population of the comprehensive cancer care centre (Ferlay J et al., 2022) (Malabar Cancer Centre, 2020). Preventing tobacco use among the Indigenous population would involve a comprehensive strategy that includes multiple activities such as empowering Indigenous leadership, ensuring sustained community engagement and providing culturally appropriate health initiatives and programmes, which could also reduce the incidence of TRCs among them (Minichiello *et al.*, 2016).

In gender-specific cancer distribution, Ca lip and oral cavity emerged as the predominant cancer sites in both male (35%) and female (33%) groups of the study population. Following this, in males, Ca lung (13.05%), Ca stomach (7.8%), Ca oesophagus (5.59%), and Ca oropharyngeal (4.8%) were observed as the following most common types. It was evident that all these cancers were attributed to Tobacco Related Cancer. When comparing with the general male population in both the comprehensive cancer care centre and as per the data of GLOBOCAN 2022 in India, Ca lung stood out as the most frequently diagnosed cancer. Among the top five most common cancers, a consistent trend was noted among the general population of the institute as well as in India that they were all TRC (Ferlay J et al., 2022) (Malabar Cancer Centre, 2020). This suggests the influence of tobacco use on the occurrence of cancers in males.

In females, it is important to emphasise that Ca lip and oral cavity were the most common cancers among the study group. In contrast, Ca breast was the most common cancer in both the general population of the comprehensive cancer care centre and in India, as per the data of GLOBOCAN 2022 in India (Ferlay J et al., 2022) (Malabar Cancer Centre, 2020). This was followed by Ca breast (14%), Ca cervix (7.8%,) Ca stomach (4.5%) and Ca colorectum (4.1%). Most of them were attributed to TRC. This underscores the broad impact of tobacco use on cancer incidence among both males and females of the study group. The study population exhibits lower incidences of Ca breast and Ca cervix compared to the institute's general population and India (Ferlay J et al., 2022) (Malabar Cancer Centre, 2020). However, the increasing cancer incidences observed could be attributed to a lack of disease awareness and a reluctance to engage in screening programmes within the study population (Ghosh *et al.*, 2021).

The stage of diagnosis holds significant importance as a prognostic factor for survival for various cancer types. Generally, individuals identified at earlier stages tend to exhibit more survival outcomes (World Health Organization, 2024). About two-thirds of cancer-related deaths worldwide occur in developing countries, where higher case fatality rates are observed due to late stage diagnosis and limited access to treatment (World Health Organization, 2017) .

In the current study, it was important to note that 70% of the cases were diagnosed in late stages (stages 3 and 4). Another study in North India, the Indigenous population presented with oral cancer were in advanced stage 3 (51.79%), whereas non-Indigenous patients were diagnosed at an earlier stage 2 (31.40%) (Patel, Sinha and Mitra, 2012). When examining globally, in Manitoba, Canada, 41% of the Indigenous population was diagnosed with stages 3 and 4, and in Australia, 59% were at later stages of cancer (Wong *et al.*, 2015), (Moore *et al.*, 2014). A cancer epidemiological study on Indigenous and non-Indigenous populations in Western Australia found that 86% of the Indigenous population were diagnosed at late stages and it was 66% among the non-Indigenous population (Reyes-Chicuellar *et al.*, 2024). Multiple factors contribute to late diagnosis, including limited access to healthcare services, cultural influences, reliance on traditional medicines, insufficient health literacy, and socio-economic conditions (Shahid *et al.*, 2016).

Analysis of the adherence to the treatment among the study population showed that 86% completed the initial treatment plan by the institution which indicated that the majority of the population was committed to adhering to the prescribed treatment plans or medical recommendations. Among them, most of the patients in the study population (51%) were recommended palliative treatment and 49 % underwent curative treatment at the institute. A comparative study assessing cancer treatment among the Indigenous population in Australia found that 48% was intended palliative treatment (Moore *et al.*, 2011). However, comparing the same with the general population, a study conducted among general population in a cancer care centre, North India showed that 62% were undergone curative treatment and only 31% were in palliative treatment (Roy *et al.*, 2020). This suggests the recommendation for palliative treatment among Indigenous patients may be influenced by factors such as the later stage of diagnosis, their overall health status, and the feasibility of curative treatment (Banham *et al.*, 2019).

Regarding follow-up status, 62% were undergoing follow upon the institution which was crucial for managing and improving health outcomes. There was no such published literature specifically focused on treatment adherence and follow-up status in cancer among Indigenous population in India. In a qualitative study conducted among the Indigenous population in Tamil Nadu, South India, on tuberculosis (TB) treatment also observed that the study population were compliant with their treatment regimens. This adherence was attributed to the supervised treatment approach, wherein therapy was administered under the direct observation of medical professionals, particularly in remote areas, to ensure that patients completed their entire treatment course. Healthcare providers attending remote areas also received incentives to accomplish their duties (Joseph, Krishnan and Anilkumar, 2019). Study suggests that the structured medical support along with close supervision of treatment, can lead to high compliance rates in treatments, particularly in challenging environments like remote areas among Indigenous communities.

In contrast prospective study conducted among aboriginals in Malaysia regarding medical adherence and beliefs found that the non-adherence was more prevalent among Aboriginals compared to non-Aboriginals. This disparity was attributed to concerns about the long-term effects of the treatment (Yean, Zhuang and Azmi, 2020). The high adherence observed among the study population emphasises the importance of implementing healthcare interventions specifically designed to meet the cultural needs of the Indigenous communities, proving their effectiveness.

Notably, the average distance to the nearest Primary Healthcare Centre (PHC) for the study population was 5.37± 2.89 kilometre (km). The mean distance aligned with the WHO's recommendation that healthcare facilities be within 5 km to ensure geographical accessibility (World Health Organisation, 2022). The average distance to the nearest comprehensive cancer care centre was 86.70 ± 35.93 km. In Northern part of Kerala, PHCs were notably accessible. In contrast, rural areas in other parts of India face different challenges. A study conducted to evaluate the access to healthcare services in Indigenous areas in Assam, North East India found that the average distance to the nearest PHC was between 5 to 15 km which exceeds the WHO's recommended distance for convenient healthcare access (Boro and Saikia, 2020).

Furthermore, in remote Indigenous regions of Orissa, India, healthcare services were even more sparse, with extremely remote areas located beyond five km and up to 20 km from the nearest healthcare facilities (Nallala *et al.*, 2023). Similar findings were observed among the Indigenous population of Bangladesh, where the average distance to the nearest Primary Healthcare Centre (PHC) was 12 km (Akter *et al.*, 2019). This distance highlights challenges in accessing essential healthcare services for these communities worldwide, emphasising the need for improved healthcare infrastructure and accessibility initiatives tailored to remote and underserved populations.

The disparities in cancer patterns observed among the Indigenous population highlight the complex interplay of cultural, socio-economic, and environmental factors. Identifying these differences is essential for developing targeted prevention, screening, and treatment measure tailored to the specific needs of the vulnerable population. Furthermore, addressing modifiable risk factors such as tobacco use among the Indigenous population, promoting early detection, improving health literacy, and access to healthcare services can help mitigate disparities in cancer burden across diverse communities in the state of Kerala as well as worldwide.

6.1. Strength of the study

- The study covers a substantial period of five years, allowing for a comprehensive analysis of the epidemiological profile and treatment adherence of the Indigenous cancer patients reported in the comprehensive cancer care centre, and the study included a large sample size.
- By focusing on Indigenous cancer patients reported in the comprehensive cancer care centre, the study addresses a critical and often under-researched group, providing valuable insights into their specific epidemiological profile, adherence to the treatment and follow up instructions for cancer. The findings from the study can contribute to improving cancer prevention and control and provide better health outcomes for Indigenous populations.
- By explicitly examining the cancer incidence within the Indigenous population, the study contributed to the understanding of the cancer burden among the study group.
- The study analysed the epidemiological profile, including sociodemographic factors, risk factors, disease related factors. The study provides a detailed analysis of the cancer outcomes among the Indigenous population reported in comprehensive cancer care centre, Northern Kerala, India. The study also evaluated an essential aspect of cancer care by investigating adherence to treatment and follow-up instructions among the Indigenous population.
- The study evaluated various time points in the cancer journey like patient interval, diagnostic interval and treatment interval
- The study used a structured data collection sheet, which was approved by the comprehensive cancer care centre facilitated systematic and organised data gathering. This

approach ensured consistency in data collection processes, minimised potential for data entry errors, and enabled efficient data analysis.

6.2. Limitations of the study

- As the study was retrospective in nature, it relied on existing medical records.
  However, occasional missing or incomplete data in existing medical records as well as variations in documentation practices could have limited comprehensiveness of the study findings.
- The study population was limited to patients who sought care at the comprehensive cancer centre, Northern Kerala which may not fully represent the entire Indigenous population of the state. This can limit the generalizability of the results to the broader Indigenous population in the state as well as in the country. Variations in socio-economic, cultural, and environmental factors across regions can limit the generalizability of the findings.
- Information on risk factors such as tobacco and alcohol were self-reported by patients, which can lead to underreporting or overreporting due to social desirability bias or recall bias.
- The latest data on cancer among Indigenous population could not be assessed because the study findings were compared with data from Hospital-Based Cancer Registry (HBCR) of the comprehensive cancer care centre which was updated until 2020. Consequently, more recent cancer data on the Indigenous population was not accessible for the current study.
- The study's reliance on quantitative data limits its ability to capture the underlying reasons and motivations behind risk habits and delayed cancer diagnosis. The study could not fully explain the personal, social, and systemic factors influencing the health behaviours among the study population.
- The study was descriptive in nature and did not provide in-depth analysis of the lived experiences and health challenges faced by the Indigenous population and also the healthcare professionals perspectives on cancer control and prevention.

7. Conclusion

This study comprehensively evaluated the epidemiological profile and adherence to the treatment and follow-up instructions among Indigenous cancer patients reported in a comprehensive cancer care centre, Northern Kerala, India and revealed the unique challenges faced by this study population. Notably the combination of high illiteracy, low socio-economic status, significant unemployment and rural residency forms a complex socio-economic barrier that could severely impact health outcomes of the study population. These factors could have collectively hindered the access to healthcare, reduced health literacy, limit economic and social resources necessary for maintaining good health. Addressing these barriers will be crucial for cancer prevention, diagnosis and treatment.

There was an increasing trend in the incidence of cancer among the study population as in the general population across the country. It was also noted that there was a high prevalence of tobacco consumption in the population, with both smoking tobacco and using smokeless tobacco across both genders. The most common cancer sites with the highest incidence were all tobacco-related, with Ca lip and oral cavity being the most common observed in both male and female. This aligns with the widespread use of smokeless tobacco among the study population. Existing tobacco control programmes and initiatives should prioritize reaching illiterate individuals, rural residents, and those from low socio-economic backgrounds. By focusing efforts on these vulnerable populations, public health initiatives can better address the socio-economic and educational barriers that contribute to ongoing tobacco use and reduce the high incidence of Tobacco Related Cancers (TRC) among the study population.

Ca breast was the most common cancer among the general population of the comprehensive cancer care centre and across India. But it was also significant to highlight that the incidence of Ca breast was lower within the study population than among the general population in the study institute could be due to environmental, behaviour, genetic or other factors. Further research is needed to investigate these factors. Implementing preventive measures targeting them could benefit the broader population by potentially reducing the incidence of Ca breast incidence.

The observation that cancer was diagnosed at an advanced stage for most patients, who then received palliative treatment, underscores the critical need for early detection and intervention strategies in these communities. Despite existing health schemes offering free cancer screening and treatment for Indigenous patients, the study reveals significant shortcomings in their effectiveness. Many patients were diagnosed at advanced stages of cancer, limiting the benefits these schemes intend to provide. It was important to highlight that, despite the presence of a PHC within five kilometres, as recommended by WHO, the Indigenous population in this region was not benefiting healthcare services from it. Consequently, cancer was often diagnosed at later stages. This underscores the need for targeted interventions to improve awareness about available healthcare services and benefits, reduce barriers to accessing timely diagnosis and treatment, also to enhance the overall effectiveness of health schemes through better implementation strategies.

A positive finding from the study is the commendable adherence to treatment plans among Indigenous cancer patients once they access healthcare services. This adherence underscores the importance of facilitating early access to cancer care and maintaining continuity of care throughout the treatment journey. Educating the population about the benefits of early detection, encouraging proactive health-seeking behaviors, and providing support for follow-up care are critical strategies to ensure that once patients initiate treatment, they continue to receive the necessary support and interventions for improved health outcomes.

There should be more extensive research to understand the epidemiology of cancer among Indigenous populations comprehensively. This includes gathering more detailed data on incidence, treatment outcomes, socio-economic determinants of health, and barriers to accessing healthcare. By filling these knowledge gaps, researchers and policymakers can develop evidence-based strategies to address cancer burden effectively and improve health outcomes for Indigenous communities.

8. Recommendations

1) Improve health literacy through targeted health education programmes to raise awareness and enhance knowledge about overall health including cancer prevention, diagnosis, treatment and existing health schemes and benefits for the Indigenous population.
2) As there was a high incidence of Tobacco-related cancer (TRC) among the study population, strengthen the tobacco control by expanding existing tobacco control initiatives and programmes focusing on rural, illiterate, and low socio-economic groups with culturally appropriate awareness campaigns and cessation programmes.
3) Implement targeted screening programmes focused on early detection and treatment of H. pylori infections among Indigenous populations, especially considering their high incidence of Ca stomach.
4) Increase healthcare service availability in rural areas through mobile clinics and telemedicine. Develop support systems for continuous care and follow-up throughout cancer treatment. Establishing cancer screening facilities at the primary care level would enhance cancer screening practices among Indigenous communities.
5) Collaborate with Indigenous communities through partnerships and leverage local leaders to advocate for cancer care and other health initiatives. Developing culturally relevant programmes collaboratively with community leaders can reduce risk factors and promote cancer screening programmes.
6) Train and empower community health workers from Indigenous communities to deliver culturally appropriate health education, support screenings, and aid in cancer prevention and treatment.
7) Further extensive research is needed to comprehensively study cancer epidemiology and treatment adherence among Indigenous populations in the country, as the current research was conducted retrospectively in a comprehensive cancer care centre in Northern Kerala. Foster partnerships between researchers, healthcare providers, and Indigenous communities to conduct participatory research aimed at understanding and effectively addressing cancer burden.
8) Qualitative research should be conducted to evaluate the factors causing delayed diagnosis among the study population and to understand the patient and healthcare providers perspectives related to cancer prevention and control among Indigenous people.

9) The country should develop, maintain, and report national-level cancer statistics specifically because it has the second largest Indigenous population in the world.

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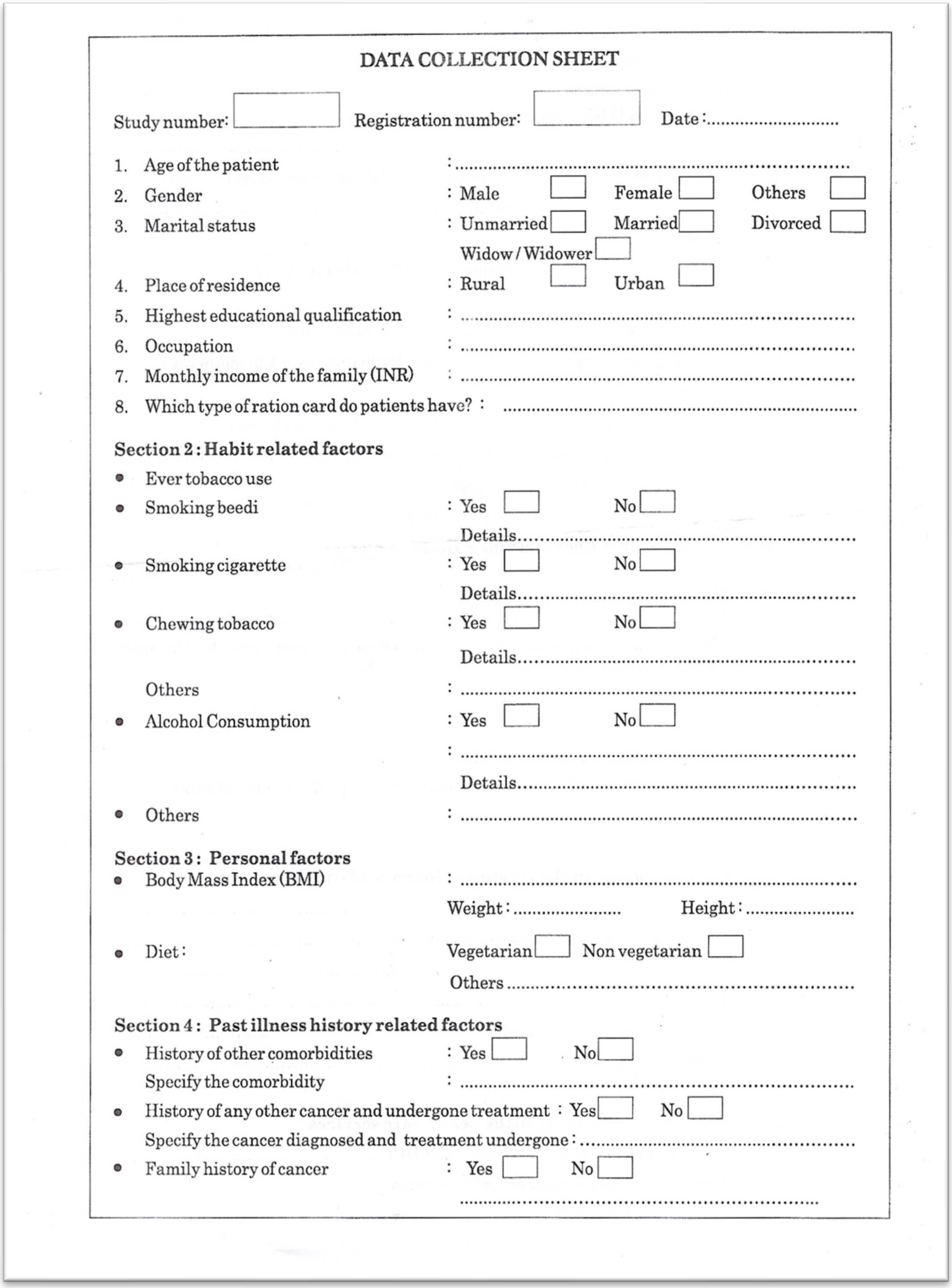
10. Appendices

10.1. Data collection sheet



DATA COLLECTION SHEET

Study number: ☐ Registration number: ☐ Date :..........................

1. Age of the patient : ....
2. Gender : Male ☐ Female ☐ Others ☐
3. Marital status : Unmarried ☐ Married ☐ Divorced ☐ Widow / Widower ☐
4. Place of residence : Rural ☐ Urban ☐
5. Highest educational qualification : ....
6. Occupation : ....
7. Monthly income of the family (INR) : ....
8. Which type of ration card do patients have? : ....

Section 2 : Habit related factors

- Ever tobacco use
- Smoking beedi : Yes ☐ No ☐
  Details..
- Smoking cigarette : Yes ☐ No ☐
  Details..
- Chewing tobacco : Yes ☐ No ☐
  Details..

  Others : ....
- Alcohol Consumption : Yes ☐ No ☐
  : ....
  Details..
- Others : ....

Section 3 : Personal factors

- Body Mass Index (BMI) : ....
  Weight :...................... Height :......................
- Diet : Vegetarian ☐ Non vegetarian ☐
  Others ....

Section 4 : Past illness history related factors

- History of other comorbidities : Yes ☐ No ☐
  Specify the comorbidity : ....
- History of any other cancer and undergone treatment : Yes ☐ No ☐
  Specify the cancer diagnosed and treatment undergone : ....
- Family history of cancer : Yes ☐ No ☐
  ....

Section 5: Disease related factors

- Site of cancer (ICD10 classification) : ....
- Clinical stage of diagnosis (TNM Staging) : ....
- Histology of cancer : ....
- Initial treatment planned : Curative ☐ Palliative (Best supportive care) ☐

  Details : ....
- Treatment received : ....

  Surgery ☐ Radiotherapy ☐

  Chemotherapy ☐

  1. Surgery + Radiotherapy
  2. Surgery + Chemotherapy
  3. Radiotherapy + Chemotherapy
  4. Surgery + Radiotherapy + Chemotherapy
- **Hormone therapy** ☐
  1. Surgery + Hormone therapy
  2. Radiotherapy + Hormone therapy
  3. Chemotherapy + Hormone therapy
  4. Surgery + Radiotherapy + Hormone therapy
  5. Surgery + Chemotherapy + Hormone therapy
  6. Radiotherapy + Chemotherapy + Hormone therapy
  7. Surgery + Radiotherapy + Chemotherapy + Hormone therapy
- **Palliative care** ☐
- Others Details :..
- Whether the patient have completed the proposed initial treatment plan by the multi speciality board (MSB) of the institution : Yes ☐ No ☐

  Details :
- Disease status of the patient during the last follow up

  Disease free ☐ On treatment ☐ Recurrence of cancer ☐

  Details :

Section 6: Various time points in the treatment journey of cancer patients:

- Date of first symptom: ....
- Date of first visit in the comprehensive cancer care centre : ....
- Date of diagnosis :..
- Date of start of treatment :..
- Treatment completion date :..
- Last Follow up date :..

Section 7: Geographical accessibility to the health care services

- Distance to the nearest primary health care centre (PHC): ....
- Distance to the nearest comprehensive cancer care centre: ....

STATUTORY DECLARATION

I hereby declare that the master's thesis entitled **"Epidemiological Profile of Indigenous Cancer Patients: A Retrospective Study from a Comprehensive Cancer Care Centre in Northern Kerala, India during the Period 2016 to 2020"** is entirely my own work, that I wrote it myself without the assistance of others, and that I have used only the materials and sources declared as such within it. I further declare that I have fully referenced all ideas and verbatim quotations taken from other works.

Date: 07.08.2024 Signature:

Place: Hamburg Lakshya Ramadas Krishnaprasad