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Titled

Understanding the Correlation Between Social Determinants of Delays in Diagnosis, Management and Outcomes for Solid Cancers in Tamil Nadu - A Multicentric Mixed Method Study

Submitted by

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TABLE OF CONTENTS

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INTRODUCTION

Cancer is a devastating disease that affects millions of people worldwide. Solid cancers refer to tumors that form in tissues such as the breast, lung, prostate, and colon, as opposed to blood cancers like leukemia. These tumors are made up of cells that do not involve the blood or lymph systems. According to recent statistics, cancer is one of the leading causes of death worldwide, with millions of new cases being diagnosed each year. Data from the International Agency for Research on Cancer shows that in 2020, there were an estimated 19 - 19.6 million[1]. In Tamil Nadu, the impact of cancer is significant, and there are various social determinants that play a crucial role in the delay of cancer diagnosis. Understanding these factors is essential in order to address the issue and improve outcomes for individuals affected by cancer in the region.

The delay in cancer diagnosis can be attributed to a myriad of factors, including socioeconomic status, access to healthcare facilities, awareness and education about cancer, cultural beliefs and practices, and the availability of screening programs. By delving into these factors, we can gain a comprehensive understanding of the challenges that individuals face when it comes to timely cancer diagnosis in Tamil Nadu.

This study aims to explore the social determinants that contribute to the delay in cancer diagnosis, as well as the outcomes associated with such delays. By shedding light on these issues, we can pave the way for interventions and strategies that aim to reduce the burden of delayed cancer diagnosis in Tamil Nadu.

In this comprehensive examination, we will delve into the various factors affecting cancer diagnosis delays, including their impact on the overall healthcare landscape in Tamil Nadu. By uncovering these nuances, we can work towards developing targeted interventions that address the specific needs of the population and facilitate earlier cancer diagnosis.

Through this study, we aspire to not only identify the factors contributing to cancer diagnosis delays but also to propose actionable recommendations for policymakers, healthcare providers, and community stakeholders. These recommendations will be centred around creating a more accessible and efficient healthcare system, raising awareness about the importance of early cancer detection, and addressing the social and cultural barriers that hinder timely diagnosis.

Ultimately, the goal of this study is to contribute to the body of knowledge on the social determinants of cancer diagnosis delays in Tamil Nadu and provide insights that can drive positive change in the healthcare ecosystem. By understanding the intricate web of factors influencing cancer diagnosis delays, we can move closer to ensuring timely and effective care for individuals impacted by this debilitating disease in the region.

PROBLEM STATEMENT

Global Scenario:

Cancer is the second leading cause of death globally, accounting for an estimated 9.6 million deaths, or one in six deaths, in 2018[1]. Globally, the most common causes of cancer death are solid tumours like the lung (1.59 million deaths), liver (745000 deaths), stomach (723000 deaths), colorectal (694000 deaths), breast (521000 deaths), and oesophageal cancer (400000 deaths).[2]

Indian Scenario:

The incidence of cancer in India is between 90 and 100 per 1,00,000 population[2]. Nearly 19.1% of the non-communicable disease premature deaths that occurred during the year 2016 were due to cancer[3]. Public expenditure on cancer in India remains below US$10 per person (compared with more than US$100 per person in high-income countries), and overall public expenditure on health care is still only slightly above 1% of gross domestic product[4].

Tamil Nadu Scenario:

According to Tamil Nadu Cancer Registry, 69517 new cancers were diagnosed with the female preponderance (1.2:1) during the year 2021. The overall incidence rate of cancer was 87.9 per 1,00,000 population. The highest Crude Incidence Rate (CIR) among cancers and both sexes together was seen in Chennai (143.0) and least reported in The Nilgiris district. (53.5).[5] Cancer deaths among people under the age of 15 were 12 per million in 1988; the age-standardized incidence of cancer among people under 18 years old was 137.5 million people from 1997 to 2005.[6]

There are effective and proven screening methods for very few solid tumours. breast cancer, colon cancer, cervical cancer, etc. Also, in low-middle-income countries (LMICs) like India, cost and staff constraints make universal screening difficult. About 30-50% of cancers are preventable by eliminating risk factors and using evidence-based medical prevention strategies.[7]

Fifty nine percent of all childhood cancers are solid tumors.[6] Delays in diagnosis may explain these late presentations and influence outcomes. Identifying the possible causes of

these delays can help address these trends. At the same time, it is important to avoid delays in diagnosis and initiation of treatment for a better outcome for tumours.

Delays in Cancer Diagnosis and Management:

The following are the various delays commonly seen in cancer diagnosis and management:

a) Delays in the presentation to the first healthcare contact (primary care clinician/GP/ any specialist other than oncologist) (also called primary delay)

b) Diagnostic delay (also called secondary delay)

c) Delay in the initiation of treatment after diagnosis/presentation to an oncologist (tertiary delay)

Expediting assessment and management of symptomatic individuals and reducing these delays can bring about a stage shift from locally advanced to early-stage cancers and hence improve disease outcomes in low-resource settings like India.

Factors Influencing Cancer Delays

Several social and geographical factors influence the delay in cancer diagnosis and management e.g., access to healthcare facilities, availability of screening programs, and socioeconomic status. Limited access to medical facilities in rural areas can contribute to delayed diagnoses, as patients may need to travel long distances to receive necessary care. Additionally, areas with lower socioeconomic status may have less access to preventive screenings and early detection programs, leading to delays in diagnosis. Understanding these social and geographical determinants is crucial for developing targeted interventions to reduce cancer diagnosis delays and improve outcomes for patients.

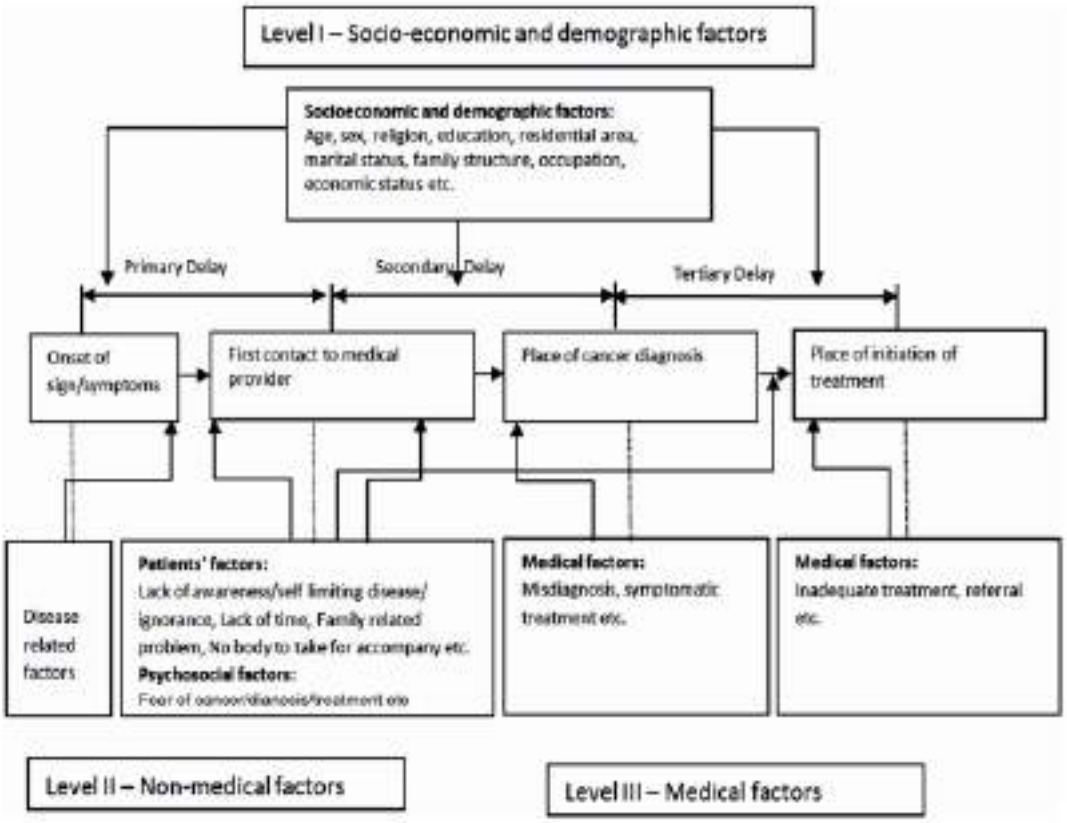


Figure 1: Schematic Representation of Determinants of Cancer Delays

From: A. K. Dwivedi et al. Health 4 (2012) 66-79

REVIEW OF LITERATURE

The Tamil Nadu Health Reforms Programme through their Operational research programme mandated us to look at causes for delays in Oral Cancer (including lip), lung cancer and gastrointestinal tract cancers.

Understanding Gastrointestinal Cancers: Causes and Risk Factors

Gastrointestinal cancers refer to a group of cancers that affect the digestive system, including the oesophagus, stomach, liver, pancreas, gallbladder, and intestines. Understanding the causes and risk factors for GI cancer is essential for prevention and early detection. Several factors can contribute to the development of GI cancer, including genetics, lifestyle choices, and environmental exposures. Risk factors such as smoking, excessive alcohol consumption, obesity, a diet high in processed and red meats, and chronic inflammation of the GI tract can increase the likelihood of developing GI cancer.

Preventive measures focus on maintaining a healthy lifestyle, including regular exercise, a balanced diet high in fruits, vegetables, and whole grains, limited alcohol intake, and avoiding tobacco products. Additionally, individuals with a family history of GI cancer or certain genetic syndromes may benefit from early screening and monitoring.

Understanding the causes and risk factors for GI cancer empowers individuals to make informed decisions about their health and take proactive steps to reduce their risk. Early detection through screening and timely medical intervention can significantly improve outcomes for individuals at risk of GI cancer.

Epidemiological Insights into Gastrointestinal Cancers

Epidemiological studies have provided valuable insights into the prevalence and trends of gastrointestinal cancer. According to recent data, GI cancer remains a significant global health burden, with variations in incidence and mortality rates across different regions and populations.

Specifically, gastric cancer, which affects the stomach, is one of the most common types of GI cancer worldwide. It is particularly prevalent in Eastern Asia, parts of Central and South America, and Eastern Europe. In contrast, colorectal cancer, which affects the colon or rectum, is more common in developed countries, such as the United States and Western European nations.

Furthermore, epidemiological research has highlighted disparities in GI cancer incidence based on socioeconomic status, access to healthcare, and certain demographic factors. Understanding these disparities is crucial for implementing targeted interventions and public health initiatives to reduce the burden of GI cancer in underserved communities.

Moving forward, continued research into the epidemiology of GI cancer can inform the development of effective prevention strategies and screening protocols tailored to high-risk populations. By addressing these insights, healthcare providers and policymakers can work towards reducing the global impact of GI cancer and improving outcomes for individuals affected by this disease.

Strategies for the Prevention of Gastrointestinal Cancer

Prevention is a key aspect of managing gastrointestinal cancer. Several strategies can help reduce the risk of developing GI cancer and improve overall health.

1. Healthy Diet: Incorporating a diet rich in fruits, vegetables, and whole grains while limiting processed and red meats can lower the risk of GI cancer. Consuming a variety of nutrients and antioxidants from plant-based foods can support digestive health and reduce inflammation.
2. Regular Physical Activity: Engaging in regular exercise not only helps maintain a healthy weight but also reduces the risk of developing GI cancer. Physical activity can also contribute to improved overall well-being and reduced inflammation in the body.

3. Moderation in Alcohol Consumption: Limiting alcohol intake can lower the risk of developing GI cancer. For individuals who choose to drink, moderation is key to minimizing potential health risks.
4. Tobacco Avoidance: Avoiding tobacco products, including smoking and smokeless tobacco, is essential for preventing GI cancer and other associated health conditions. Seeking support in quitting smoking can significantly reduce the risk of developing GI cancer.
5. Regular Screening and Monitoring: Individuals with a family history of GI cancer or those with certain genetic syndromes should undergo regular screening and monitoring as recommended by healthcare professionals. Early detection can lead to timely intervention and improved outcomes.

Understanding Lung Cancer: Causes and Risk Factors

Lung cancer is a complex disease that can be caused by a variety of factors. While smoking is the leading cause of lung cancer, non-smokers can also develop the disease due to factors such as exposure to second-hand smoke, radon gas, asbestos, air pollution, and genetic predisposition.

Risk factors for lung cancer include a history of smoking, exposure to carcinogens in the workplace or environment, a family history of lung cancer, and certain medical conditions such as chronic obstructive pulmonary disease and tuberculosis.

Understanding the causes and risk factors for lung cancer is crucial for identifying individuals who may be at higher risk and for implementing preventive measures and early detection strategies.

Epidemiology of Lung Cancer: Analysing the Data

Looking at the data, lung cancer is a significant public health issue, with a high mortality rate globally. According to the World Health Organization, it is the most common cancer worldwide, with the highest incidence and mortality rates occurring in low- and middle-income countries.

In the United States, lung cancer is the leading cause of cancer deaths among both men and women. The American Cancer Society estimates that there will be over 200,000 new cases of lung cancer and over 130,000 deaths from the disease in the United States in the current year.

Understanding the epidemiology of lung cancer is essential for public health planning and resource allocation, as well as for identifying specific populations that may benefit from targeted interventions and screening programs.

Diagnosing Lung Cancer: Addressing Delays

Delay in the diagnosis of lung cancer can have significant consequences for patients, as early detection is crucial for successful treatment and improved outcomes. However, diagnosing lung cancer can be challenging due to the nonspecific nature of early symptoms and the lack of routine screening for the disease.

Common symptoms of lung cancer may include persistent cough, chest pain, hoarseness, weight loss, and shortness of breath. Unfortunately, these symptoms are often attributed to other less serious conditions, leading to delays in diagnosis.

To address these delays, efforts are being made to increase awareness among healthcare providers and the general public about the importance of recognizing and investigating potential symptoms of lung cancer. Additionally, advancements in diagnostic imaging technologies and the development of effective screening programs are helping to facilitate earlier detection and diagnosis of lung cancer. By addressing delays in the diagnosis of lung cancer, we can improve patient outcomes and survival rates, ultimately reducing the burden of this devastating disease.

Strategies for Lung Cancer Prevention

Preventing lung cancer involves addressing modifiable risk factors such as tobacco use, exposure to environmental carcinogens, and promoting a healthy lifestyle. Smoking cessation remains the most effective strategy for preventing lung cancer among both smokers and non-smokers exposed to second-hand smoke. Public health campaigns and smoking cessation programs play a crucial role in reducing the prevalence of smoking and preventing new cases of lung cancer.

In addition to tobacco control efforts, reducing exposure to carcinogens in the workplace and environment is important for lung cancer prevention. This includes measures to minimize exposure to radon gas, asbestos, and air pollutants in high-risk occupational settings and residential areas.

Furthermore, advocating for policies that promote clean air and environmental regulations can help reduce the overall burden of lung cancer in the population. Educational initiatives aimed at raising awareness about the dangers of environmental toxins and their association with lung cancer can also contribute to prevention efforts.

It is important for individuals to prioritize their respiratory health by seeking regular medical check-ups, particularly if they have a history of smoking or other identified risk factors for lung cancer. This proactive approach can lead to early detection of any potential lung abnormalities and facilitate timely intervention.

In conclusion, a multi-faceted approach that integrates tobacco control, environmental protection, and early detection strategies is essential for effective lung cancer prevention. By implementing these strategies, we can work towards reducing the incidence and impact of lung cancer on a global scale.

Treatment Options for Lung Cancer

Once lung cancer has been diagnosed, it is crucial to explore the available treatment options. The choice of treatment depends on several factors, including the type and stage of the cancer, as well as the overall health and preferences of the patient.

Surgery, chemotherapy, radiation therapy, targeted therapy, and immunotherapy are some of the main treatment modalities for lung cancer. Surgery may be used to remove the tumour and nearby lymph nodes, while chemotherapy and radiation therapy are often used in combination to destroy cancer cells and shrink tumours. Targeted therapy and immunotherapy are newer approaches that aim to specifically target cancer cells or enhance the body's immune response against the cancer.

In recent years, there have been remarkable advancements in precision medicine and personalized treatment approaches for lung cancer. Genetic testing of the tumour can help identify specific mutations or genetic alterations that may guide the choice of targeted therapy. Immunotherapy, which harnesses the body's immune system to fight cancer, has also shown promising results in certain cases.

It is important for patients to have open and informed discussions with their healthcare team to fully understand the potential benefits and risks of each treatment option. Additionally, supportive care and palliative care play an integral role in managing symptoms and improving the quality of life for patients with lung cancer, especially in advanced stages of the disease.

By staying informed about the latest treatment advances and actively participating in shared decision-making with healthcare providers, patients can be empowered to make choices that align with their individual goals and values.

In the next section, we will delve into the importance of ongoing research and clinical trials in advancing the field of lung cancer treatment. prevention of lung cancer is crucial in reducing its incidence and impact on a global scale (Esposito et al., 2021).

Understanding Oral Cavity Cancer: Causes and Epidemiology

Oral cavity cancer is a type of cancer that can affect the lips, tongue, cheeks, floor of the mouth, hard and soft palate, sinuses, and pharynx. The causes of oral cavity cancer are multifactorial, involving a combination of genetic, environmental, and lifestyle factors. Tobacco use, heavy alcohol consumption, and the human papillomavirus infection are known to significantly increase the risk of developing oral cavity cancer.

In terms of epidemiology, oral cavity cancer is more common in older individuals, particularly those over 55 years old. Men are also more likely to be diagnosed with oral cavity cancer than women. Geographically, the incidence of oral cavity cancer varies globally, with higher rates reported in South Asia, Southeast Asia, and parts of Europe.

Factors Contributing to the Development of Oral Cancer

The development of oral cancer is influenced by a variety of factors, including genetic predisposition, environmental exposures, and individual behaviours. Genetic mutations and inherited traits can predispose individuals to a higher risk of developing oral cavity cancer. Additionally, exposure to environmental carcinogens such as tobacco smoke, alcohol consumption, and the human papillomavirus infection can contribute to the development of oral cancer.

Furthermore, certain lifestyle behaviours, such as poor oral hygiene and a diet lacking in fruits and vegetables, have also been linked to an increased risk of oral cavity cancer. Understanding these factors is critical for implementing targeted prevention strategies and promoting behavioural changes that can reduce the incidence of oral cancer.

Understanding the causes and epidemiology of oral cavity cancer is crucial for prevention and control efforts. By addressing the modifiable risk factors such as tobacco and alcohol use, promoting HPV vaccination, and increasing awareness about oral hygiene and

regular dental check-ups, the burden of oral cavity cancer can be reduced. Early detection through screening and prompt treatment is also essential for improving outcomes for individuals at risk of or affected by oral cavity cancer.

Delays in Diagnosis and Treatment of Oral Cavity Cancer

Despite efforts to increase awareness and early detection, delays in the diagnosis and treatment of oral cavity cancer remain a significant concern. These delays can stem from various factors including limited access to healthcare, lack of knowledge about symptoms, and fear or stigma associated with cancer diagnosis.

Recognizing the signs and symptoms of oral cavity cancer, such as persistent mouth sores, pain, difficulty swallowing, and changes in voice, is crucial for prompt medical intervention. However, individuals may delay seeking medical attention due to misconceptions about the disease or reluctance to confront the possibility of cancer.

Addressing delays in diagnosis and treatment requires a multi-faceted approach, including community education, improving access to healthcare services, and reducing barriers to seeking care. Moreover, healthcare providers play a pivotal role in facilitating timely diagnosis through comprehensive screenings and efficient referral systems for further evaluation and treatment.

Prevention and Control Strategies for Oral Cavity Cancer

In addition to early detection, prevention and control strategies are essential in mitigating the impact of oral cavity cancer. Public health initiatives aimed at reducing tobacco and alcohol consumption, promoting healthy lifestyles, and advocating for regular dental check-ups can contribute significantly to preventing the development of oral cavity cancer.

Furthermore, implementing vaccination programs for the human papillomavirus and raising awareness about its link to oral cavity cancer can play a crucial role in reducing the incidence of the disease. Collaboration between healthcare professionals, public health authorities, and community organizations is vital for the successful implementation of these strategies and fostering a comprehensive approach to oral cavity cancer prevention and control.

Few studies have been conducted on the effects of therapy and diagnostic delays on the prognosis of haematological malignancies, especially in patients with diffuse large B-cell lymphoma (DLBCL). We queried our database of DLBCL patients treated between 2002 and

2010. To ascertain the correlation between delays and sociodemographic or disease-specific characteristics, univariate and multivariate analyses were carried out. The effect of delays on survival was determined using Cox Regression analysis. Patients (n = 278) averaged 4 weeks in between visits to the doctor. A non-haematology doctor needed an average of eight weeks to diagnose DLBCL and recommend a patient to a haematologist. There was a median delay of 3 weeks between seeing a specialist and starting treatment. When performing multivariate logistic regression analysis, the chances ratio for bone marrow involvement.[8]

At the time of diagnosis, almost one-third of the patients had no symptoms. The median patient interval for individuals who had symptoms was typically shorter than the diagnosis period for the majority of disorders. Diagnostic intervals differed significantly: for acute myeloid leukaemia, they were 41 days (interquartile range [IQR]: 17–85), whereas for diffuse large B-cell lymphoma, they were 98 days (IQR 53–192) and 163 days (IQR 84–306) for myeloma. While many symptoms matched those listed in the UK Referral Guidelines, some were infrequently reported (such as soreness after consuming alcohol). On the other hand, other issues—like stomach and intestinal issues—were more common yet weren't covered in the guidelines. While fatigue and pain were shared by all diseases, there was some subtype specificity, such as lymphadenopathy in lymphoma and bleeding and bruises in acute leukaemia[9].

Of the 37,588 patients who received a new cancer diagnosis, 20,535 (54.6%) had a symptom that was noted in the year before the diagnosis and were considered for the analysis. Between 2001–2002 and 2007–2008, there was a 5.4-day (95% CI: 2.4–8.5; P<0.001) decrease in the overall mean diagnosis interval. The following cancers showed evidence of significant reductions (mean, 95% confidence interval): bladder (16.4 days, 6.6-26.5; P≤0.001), colorectal (9.0 days, 3.2-14.8; P=0.002), oesophageal (13.1 days, 3.0-24.1; P=0.006), pancreatic (12.6 days, 0.2-24.6; P=0.04), kidney (20.4 days, -0.5 to 41.5; P=0.05), head and neck (21.2 days, 0.2-41.6; P=0.04), and bladder (16.4 days, 6.6-26.5; P≤0.001). Patients (all malignancies in both cohorts) with NICE-qualifying symptoms had shorter diagnosis intervals than those without them. Myeloma (156 days) and lung (112 days) had the longest median diagnosis intervals for the 2007–2008 cohort of malignancies, while breast and testicular tumours had the smallest (26 days) and 44 days, respectively. For certain tumours, the values for the 90th centiles of the distributions are still extremely high[10].

According to participant testimonies, several characteristics of lymphoma may influence how patients and healthcare professionals (HCPs) react when the disease first manifests. Three features stand out: the rarity of the disease, its variable expression, and the sometimes-inconclusive nature of the available research choices. The interviewees explained that neither they nor any HCPs had ever heard of lymphoma and that they hardly ever thought it was a plausible cause of their symptoms. The reported symptoms were quite varied, often nonspecific, and first believed to be related to a number of benign, self-limiting causes. Although blood tests and other examinations may sometimes identify anomalies, they were not a reliable indicator of cancer. The opportunity for improvement in information gathering, communicating ambiguity, and re-presenting recommendations for non-resolving/progressive health problems among HCPs was reported by interviewees[11].

The median interval (IQR) between the onset of a symptom or sign and a diagnosis of CLL was 63 days for the 5086 patients that were examined. Age ≥75 (OR 1.45 [1.27-1.65]), gender (OR 1.22 [1.07-1.39]), living in an urban area (OR 1.46 [1.19 to 1.79]), having ≥1 comorbidity (OR 2.83 [2.45-3.28]), and receiving care in a teaching hospital (OR 1.20 [1.05-1.38]) were among the factors that predicted delay. Survival was not correlated with a delayed diagnosis (HR 1.11 [0.99-1.25]); rather, it was correlated with receiving flow cytometry thirty days before to or following diagnosis (HR 0.84 [0.76-0.91])[12].

The overall delay was 98 days on average (IQI 57-168). The patient (median 21 days (7–56) and system (median 55 days (32–93)) delays accounted for the majority of the overall delay. The GP delay was 0 (0–2) days on average. Patients with ovarian (median 60 days (45-112)), breast (median 65 days (39-106)), and bladder (median 134 days (93-181) cancers had the highest total delays, followed by patients with prostate (median 130 days (89-254)).[13]

Patients (n = 278) averaged 4 weeks in between visits to the doctor. A non-haematology doctor needed an average of eight weeks to diagnose DLBCL and recommend a patient to a haematologist. There was a median delay of 3 weeks between seeing a specialist and starting treatment. Bone marrow involvement [odds ratio (OR) = 0·41, P = 0·018], Charlson comorbidity index (OR = 1·42, P = 0·017), and urgent inpatient chemotherapy (OR = 0·40, P = 0·012) were found to be linked with diagnostic delays >6 weeks in multivariate logistic regression analysis. The only predictor that could predict treatment delays longer than four weeks independently was the absence of a pathological diagnosis at the time of haematology

referral (OR = 8·25, P < 0·01). Delays in diagnosis or therapy had no effect on progression-free survival or overall survival.[14]

The primary patient-mediated factor contributing to longer times to presentation across all cancer sites is the failure to recognise the severity of the symptoms. There is compelling evidence linking higher age to delayed diagnosis of breast cancer, poorer socioeconomic position to delayed diagnosis of upper gastrointestinal and urological malignancies, and lower educational attainment to delayed diagnosis of colorectal and breast cancers. Fear of cancer is a factor in delayed presentation, but other people's approval of help-seeking can be a potent moderator of shorter presentation times. 'Misdiagnosis' resulting from either symptomatically treating patients or associating symptoms with a health issue other than cancer was a significant trend across cancer sites for practitioner delay. Inadequate patient examination, the administration of unsuitable diagnostics, or failure to follow up on negative or unclear test results may also be associated with some malignancies.[15]

It took, on average, 99 days from the onset of a sign or symptom to a myeloma diagnosis. Individuals with co morbidities, back discomfort, and anaemia had higher odds of delayed diagnosis (OR 1.6, 95% CI 1.3-2.0). problems were significantly predicted by diagnosis when hospitalized (OR 2.5, 95% CI 2.2-2.9) and receiving chemotherapy within 6 months of diagnosis (OR 1.4, 95% CI 1.2-1.6); diagnostic delay did not predict problems (OR 0.9, 95% CI 0.8-1.1). According to our findings, difficulties are more closely linked to myeloma severity and health state than they are to delayed diagnosis.[16]

Addressing Geographic Disparities in Cancer Care

Studies have shown that the impact of location on the timeliness of cancer care extends beyond diagnosis and treatment, affecting outcomes following treatment as well. Geographical disparities can influence access to post-treatment care, including follow-up appointments, rehabilitation services, and support programs. This can result in difficulties for cancer survivors in managing their long-term care needs and may lead to lower rates of adherence to survivorship care guidelines.

Efforts to address these disparities require a multifaceted approach, involving collaboration between healthcare providers, community organizations, and policy makers. Strategies such as telemedicine and mobile healthcare units can help bridge the gap in accessing post-treatment care for individuals in remote or underserved areas. Furthermore, targeted

educational campaigns and support services can empower patients to navigate the healthcare system and advocate for their ongoing care needs.

By recognizing and addressing the impact of geographical disparities on the entire continuum of cancer care, we can work towards ensuring that all individuals, regardless of their location, have equitable access to comprehensive and timely cancer care.

NEED FOR THE STUDY

Despite increased access to healthcare and the establishment of Oncology departments in various medical colleges, Tertiary cancer care centres and regional cancer centres by Govt. of Tamil Nadu and an increased number of private cancer hospitals, there are still gaps and barriers in access to healthcare in some geographical locations within Tamil Nadu.

Other system-related causes of delays that can impact cancer outcomes include treatment costs, availability of specialists or oncologists, and availability of infrastructure like scans, LINAC machines, drugs, etc. Further, there are various patient-related causes like socioeconomic factors and educational status that can contribute to these delays.

The purpose of this study is to analyse the various possible patient and system-related causes that contribute to these delays and correlate them with outcomes in patients with solid tumours. Assessing the causes for these delays, their impact on cancer management, and gaps in access to healthcare in specific geographical areas can help the Govt. of Tamil Nadu address these specific issues and strengthen cancer care delivery in appropriate areas or regions.

Oral cavity (14%), lung (10.4%) and Gastro intestinal tract (around 20%) cancers form major proportion of the cancer burden (excluding breast and cervical cancers) in India and Tamil Nadu. Delays in diagnosis and management of these cancers also has a significant impact on the outcomes. The delays and their effects are expected to be more profound in these cancers. The delays can also cause a significant increase in burden of our healthcare systems.

RESEARCH HYPOTHESIS

Geographical and social barriers to healthcare contribute to the diagnosis and treatment delays and therefore to cancer outcomes in patients with solid tumours especially in oral cavity (including lip) cancers, lung cancers and cancers of the Gastro intestinal tract. Identifying these determinants will help address health care gaps in Tamil Nadu, decrease delays and improve cancer outcomes.

AIMS AND OBJECTIVES

Aim of the Study:

To understand the correlation between social determinants of delays in cancer diagnosis, management and cancer outcomes for patients with oral cavity (including lip) cancers, lung cancers and cancers of the Gastro intestinal tract in Tamil Nadu

Objectives:

1. Identify delays in cancer diagnosis and management for patients with oral cavity, lung and Gastro intestinal tract cancers in Tamil Nadu.
2. Identify social determinants and geographical barriers to access healthcare that impact these delays
3. Correlate these delays with cancer outcomes

METHODOLOGY

Study Design:

We designed a Mixed Methods Research study with convergent parallel design (Quantitative and Qualitative)

The study had 2 components:

- **Quantitative component:** Study of 2052 cancer patients
- **Qualitative component:** In-depth interviews of 10 doctors

Study Duration:

10 months (March to December 2023)

Study Population:

Patients with known with oral cavity (including lip) cancers, lung cancers and cancers of the Gastro intestinal tract residing in Tamil Nadu and who are on treatment or follow-up at one of the eligible hospitals in Tamil Nadu.

Inclusion Criteria for patients:

1. Resident of Tamil Nadu
2. Known to have oral cavity (including lip) cancers, lung cancers and cancers of the Gastro intestinal tract (any age and any stage).
3. Diagnosed on or after January 1 2020
4. On treatment or follow-up at one of the hospitals (study centres) in Tamil Nadu. Efforts will be made to include patients who have died or lost to follow-up.
5. Able and willing to give consent for participation in the study (parental assent for children <18 years

Exclusion Criteria for patients:

1. Patients with other cancers, haematological cancers, second cancers or multiple cancers (synchronous or metachronous).
2. Not willing to participate in the study.

Inclusion Criteria for Doctors (qualitative part):

1. Oncologist (Radiation or Medical or Surgical Oncology) directly involved in the care of cancer patients
2. Primary care doctors (primary care clinician/GP/ any specialist other than oncologist) not directly involved in the care of cancer patients but who usually refer patients to specialists

Study areas:

1. Government Hospitals within the state of Tamil Nadu with Oncology departments (Radiation or Medical or Surgical Oncology)
2. Private cancer centres/hospitals within the state of Tamil Nadu with oncology departments (Radiation or Medical or Surgical Oncology)
3. Primary care centres

We included 32 Cancer centres/hospitals across Tamil Nadu in the study. Efforts were made to make the study include patients from all districts of Tamil Nadu and different sections of society. Both private and government hospitals were included. The list of Hospitals is as follows:

WEST ZONE:

1 **PSG IMSR & Hospitals**
P.B. No. 1674, Off Avinashi Road, Peelamedu, Coimbatore-641 004,

2 **Government Coimbatore Medical College Hospital**
Trichy Road Coimbatore – 641018

3 **Aswin Hospitals**
Sathy Main Road, Alamu Nagar Rd, Near GP Theatre, Gandhipuram, Coimbatore -641012

4 **GKNM Hospital**
P.B. No. 6327, Nethaji Road, Pappanaickenpalayam, Coimbatore – 641037.

5 **Erode Cancer Centre**
SH 96, Thindal, Erode, Tamil Nadu 638012

6 **Onco foundation Erode/Sudha Hospitals**

1/1, Nearby Old Sudha Hospital, Poosari Chennimalai Street, Surampatti-638009, Erode

7 **Thangam Hospitals**

54, Dr. Sankaran Road, Trichy Main Rd, Namakkal -637001.

8 **Dharan Hospital**

14, Bye Pass, Selva Nagar, Chinnusamy Nagar, Seelanaickenpatti, Salem -636201

NORTH ZONE:

9 **Govt. Royapettah Hospital, Kilpauk Medical College, Chennai**

1, West Cott Road, Roya pettah, Chennai, Tamil Nadu 600014

10 **Govt. Stanley Medical College and Hospital, Chennai**

1, Old Jail Rd, George Town, Chennai, Tamil Nadu 600001

11 **Tamil Nadu Multi Super Specialty Hospital (TNMSSH), Chennai**

Omandurar Government Estate, Anna Salai, opposite to The Hindu Office, Anna Salai, Triplicane, Chennai, Tamil Nadu 600002

12 **Ramachandra Medical College & Hospitals Chennai**

No.1 Ramachandra Nagar Porur, Chennai - 600 116 Tamil Nadu, India.

13 **Govt. Arignar Anna Memorial Cancer Institute, Kanchipuram**

Chennai Bangalore Highway NH 4, Karapettai, KANCHIPURAM

14 **Cancer Institute Adyar (WIA), Chennai**

Guindy National Park, Adyar, Chennai, Tamil Nadu 600020

15 **Christian Medical College, Vellore**

Christian Medical College, IDA Scudder Rd, Vellore-632004

SOUTH ZONE:

16 **Govt. Madurai Medical College & Rajaji General Hospital, Madurai**

Panagal Rd, Alwarpuram, Madurai, Tamil Nadu 625020

17 **Meenakshi Mission Hospital, Madurai**

Udayampalayam Rd, Gounder Mills, Tamil Nadu 641029

18 **Guru Hospital, Madurai**

4/120-F, Pandi Kovil Ring Rd, near Mattuthavani, Madurai, Tamil Nadu 625107

19 **Govt. Tirunelveli Medical College, Tirunelveli**

Palayamkottai Tirunelveli - 627011 Tamil Nadu, India

20 **Devaki Specialty Hospital, Madurai**

26 Theni Main Road, AA Rd, Madurai, Tamil Nadu 625016

21 **Govt. Kanyakumari Medical College,Kanyakumari**

Asaripallam, Nagercoil, Kanyakumari district – 629201.

22 **Apollo Hospitals, Madurai**

80 Feet Rd, KK Nagar, Madurai, Tamil Nadu 625020

23 **International Cancer Centre, Christian Fellowship Hospital, Neyyoor**

Thiruvattar - Colachel Rd, Neyyoor, Tamil Nadu 629802

EAST ZONE:

24 **Govt. Thanjavur Medical College, Thanjavur**

Medical College Rd, Thanjavur, Tamil Nadu 613004

25 **Vishnu Cancer Centre, Thanjavur**

52, Centre Point Nagar, Kamala Subramaniam School Opp, Pudukkottai Road, Thanjavur-613005

26 **KAP Viswanathan Govt. Medical College and Annal Gandhi Memorial Government Hospital, Trichy**

Collector Office Road, Periyamilaguparai, Cantonment, Tiruchirappalli-620001

27 **GVN Multi Speciality Hospital**

46, Near Super Bazar, Singarathope, Tiruchirappalli, Tamil Nadu 620008

28 **Kaveri Medical Centre Trichy**

No.1, K.C. Road, Tennur, Tiruchirappalli, Tamil Nadu 620017

29 **Silver Line Hospitals, Trichy**

23C, 4th Cross Rd, West Extension, Thillai Nagar, Tiruchirappalli -620018

30 **Thiruvarur cancer Centre, Thiruvarur**

Javulikkara Street, near temple tank, Suriyan Kulam Then Kari, Vasan Nagar, Madappuram, Thiruvarur, Tamil Nadu 610001

31 **Krishna Cancer Centre, Cuddalore**

Thootapattu Village, Nathapattu, Cuddalore

32 **ABC Hospitals, Trichy**

1, Annamalai Nagar Main Rd, Woraiyur, Tiruchirappalli, Tamil Nadu 620018

Sample Size for Quantitative Study:

Estimated Sample size: 2000 patients

Final Sample Size: 2076 patients

Assuming the prevalence rate of delay in cancer diagnosis and management to be 50%, the required sample size was calculated using the following formula:

$N = 4*P*Q/ d^2$

Where N is the required sample

P= Percentage of delay in cancer diagnosis and management taken as 50

Q= 100-P = 100-50=50

d= relative precision as 5% of P (=2.5)

$N = 4*50*50/2.5^2$

= 1600

Non-respondent rate of 20%

Therefore, required sample size, N*100/80= 1600*100/80=2000

The sample size estimated was 2000.

Sample Size for Qualitative Study:

Estimated Sample Size: 20 Doctors: 10 Oncology + 10 Primary care doctors

Final Sample Size: 10 Doctors: 6 Oncology + 4 Primary care doctors

Data Maturity was attained at 10 samples and therefore the qualitative component of the study was completed.

Diagrammatic representation of Sampling:

Figure 2: Diagrammatic representation of Sampling

Ethical and Administrative Approvals:

PSGIMSR was the coordinating institute/hospital for the study and along with Coimbatore Medical College was the nodal centre for the West region. Kilpauk Medical College/Govt. Roya pettah Hospital was the nodal centre for the North, Thanjavur Medical College was the nodal centre for the East and Madurai Medical College was the nodal centre in the South.

Administrative approvals were obtained from all Hospitals through their Head of the institutions/Hospitals. Scientific and Ethical Approval was obtained from the Scientific Advisory Committee, Directorate of Public Health and Preventive Medicine, Tamil Nadu which facilitated ethical and administrative approvals for all Government hospitals included in the study. Separate Ethical approvals from Institutional Ethics committees were obtained for individual hospitals, wherever required (Appendix 1)

Informed Consent:

Written informed consent (for adults aged 18 and above) and parental consent (for paediatric patients < 18 years) were obtained prior to data collection. Consent Waivers/permission for oral consent were obtained from individual IECs if required and used wherever applicable. Informed consent was obtained from the doctors for participation in the qualitative study. ICMR guidelines regarding informed consent were followed.

DATA COLLECTION

Qualitative Study:

The Key Informant Interviews (KII) were undertaken with a purposefully selected sample of 6 cancer treating doctors/ Oncologist and 4 primary care doctors who were currently practicing in our study multi centric places. The purpose of the KII was to explore the various determinants of delay for diagnosis and management of cancer.

Interviews were recorded and transcribed for qualitative analysis. Interview questions were structured based on previous literature and experiences so that we can gather doctors' opinions on what they think the delay in cancer diagnosis and management is and how they think it affects the outcome of patients with solid cancer.

Quantitative study:

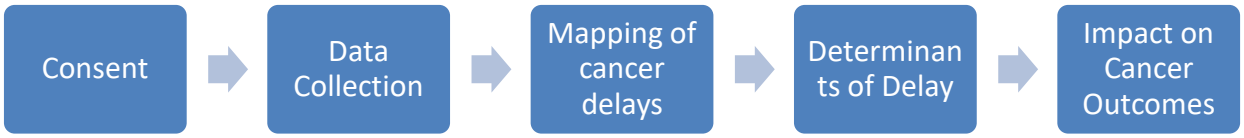


Figure 3 Quantitative Study Process

Patients were identified from hospital records and cancer registries. After obtaining consent, the data collected was from the patients and caregivers' records/memory and if available, hospital records. Strict confidentiality of patients was maintained. The treatment of patients was at the discretion of their doctors as per their hospital policy. The study was purely observational and ambispective, collecting data on past events in the treatment history of the patient and following up the patient through the duration of the study. Participation in the study did not affect their diagnosis or treatment.

Data regarding the sociodemographic profile, causes of delay in treatment, follow-up duration, and recurrence details were collected (using a structured questionnaire) by interviewing the participants. The Case Report Form (Appendix 2) which captured the patient information was designed specifically for the study and validated by TNHSRP to capture the following data:

1. **Demographic Data:**
    a. Age/Gender/Religion

b. Socioeconomic status
c. Educational status
d. Highest educational status of first-degree relatives

2. Geographic Data:

a. Address (with Geographical tagging using Google Maps)
b. Nearest GP/PHC to whom/which the patient usually goes (with Geographical tagging using Google Maps)
c. Nearest Government Hospital or Specialty Hospital with > 50 beds to whom/which the patient usually goes (with Geographical tagging using Google Maps)
d. Nearest Cancer Centre (Government or Private) (with Geographical tagging using Google Maps)
e. Distance between home and current treating hospital (with Geographical tagging using Google Maps)

3. Diagnosis:

a. Type, site, and stage of Cancer (ICD 10 Code):
b. Date of Diagnosis:

4. Cancer Delays:

a. **Primary or Patient Delay:** (Time duration between onset/suspected onset of symptoms to first health care contact - primary care clinician/GP/ any specialist other than oncologist)
b. **Secondary or Diagnostic delay**: (Time duration between the first presentation to any doctor to confirmation of the diagnosis of cancer)
c. **Tertiary or Treatment delay**: (Time duration between confirmation of cancer to initiation of treatment)

5. Proposed/Treatment received:

a. Date of Start of treatment
b. Treatment completed/delayed/not completed/modified
c. If not, why? reason
d. Intent - Curative/ Palliative
e. Treatment
    i. Surgery

ii. Chemotherapy
iii. Radiotherapy
iv. Hormonal therapy
v. Immunotherapy
vi. Alternate Medicine - AYUSH
vii. Others

6. **Cost of Treatment covered by**
    i. Self
    ii. CMCHIS
    iii. AB-PMJAY
    iv. ESI
    v. CGHS/EHS
    vi. Private Health Insurance
    vii. Others
7. **Follow up**
    a. Duration
    b. Regular/irregular
    c. Recurrence?

Operational Definitions for Cancer Delays:

We have based our operational definitions of significant delays on the NHS Cancer Programme's Faster Diagnosis Framework, which sets out a strategic approach to speed up cancer diagnosis and improve patient experience in the UK. NHS recommends a 2-week rule for urgent referrals from General Practitioners (GPs) to Cancer Specialists on suspicion of cancer. For cancer diagnosis, the target is that the patient should not wait more than 28 days from referral to find out whether they have cancer or not. For treatment, the target is that the patient does not wait more than 31 days (1 month) from diagnosis or 62 days (2 months) from referral from the GPs.

For ease of calculation and analysis we have taken any delay more than 4 weeks (28 days) as significant for primary delay, referral delay, secondary delay and tertiary delays. We have considered 8 weeks (56 days) as significant for overall medical related delay and Total Delay (Table 1). This is because, the presentation and referral patterns do not strictly follow the GPs

→ specialist → oncologist pathway in India. The patient may present directly to a specialist or an oncologist for diagnosis and treatment.

Table 1:Operational Definitions for Cancer Delays

Type of Delay	Definition	Significant Delay
Primary/Patient Delay	Time from onset of symptoms to first medical contact in days (or weeks)	4 weeks (28 days)
Secondary/Diagnostic Delay	Time from presentation to a doctor/hospital to diagnosis of cancer in days (or weeks)	4 weeks (28 days)
Tertiary Delay/ Treatment Delay	Time from diagnosis of Cancer to start of cancer treatment in days (or weeks)	4 weeks (28 days)
Referral Delay	Time from presentation to a doctor/hospital to referral to a cancer centre for diagnosis/treatment of cancer in days (or weeks)	4 weeks (28 days)
Total Medical Related Delay	Time from presentation to a doctor/hospital to start of cancer treatment in days (or weeks)	8 weeks (56 days)
Total Delay	Time from onset of symptoms to start of cancer treatment in days (or weeks)	8 weeks (56 days)

OUTCOME MEASURES

1. **Social determinants contributing to delay**
    a. Demographic factors
    b. Socioeconomic factors
2. **Geographical determinants contributing to delay**
    a. Distance between nearest GP/PHC to whom/which the patient usually goes and his or her home (with Geographical tagging using Google Maps)
    b. Distance between nearest Government Hospital or Specialty Hospital with > 50 beds to whom/which the patient usually goes and his or her home (with Geographical tagging using Google Maps)
    c. Distance between nearest Cancer Centre (Government or Private) and his or her home (with Geographical tagging using Google Maps)
    d. Distance between home and current treating hospital (with Geographical tagging using Google Maps)
3. **Delays in cancer diagnosis (Time durations):**
    a. Actual Delays (rounded to the nearest week)
    b. Patient-reported reason for the delay in treatment
    c. Significant delays

>4 weeks => significant delay

4. **Cancer Outcomes:**
    a. Adherence to Treatment – completed/delayed/not completed/modified
    b. Adherence to Follow up - Regular/irregular
    c. Recurrence and Survival data

DATA ANALYSIS

Data entry was done in Microsoft Excel. Data analysis was done using SPSS version 26.0 for windows. Mean ± standard deviation (S.D.), and median (range) were used for numerical variables. Percentages (%) were estimated for categorical variables. Quantitative data analysis was done using statistical software SPSS 24.0. Delays has been correlated with socio-demographic and other health-system-related factors using multivariate linear regression. A Pearson correlation value of more than 0.3 was suggestive of strong correlation. P-value less than 0.05 was considered to be statistically significant.

Qualitative data was analysed after transcribing the interview recordings. A grounded theory-influenced approach was used to explore participants' experience of delay in cancer management. We compared the various codes based on differences and similarities and sort them into categories. Finally, the categories were formulated into themes.

RESULTS – QUANTITATIVE STUDY

Patient Demographics – Age, Gender and Body Mass Index:

We collected data from 32 cancer hospitals across Tamil Nadu. We identified 2116 patients, who met our inclusion and exclusion criteria out of which data was able to be collected from 2076 patients. The patients had a male: female ratio of 2:1 (Table 2 and Figure 4). The mean age of the patients was 56.58 ±12.02 years (range: 4 to 92 years). No. of paediatric patients (less than 18 years) was 7 (0.3%) and no. of elderly patients (more than 60 years) was 811 (39.1%).

Among the elderly population, 594 people were in the age group of 61-70 years, 190 people in 71-80 years age group, and 27 people were above 80 years (super senior citizens). The age distribution is shown in Table 3&4 and Figures 5&6. The mean height of the patients was 1.57 ± 0.11 m, mean weight of the patients was 53.9±12.7 kg with a mean Body Mass Index (BMI) 22 ±4.8 kg/m^2. The BMI categories are shown in Table 5 and Figure 7.

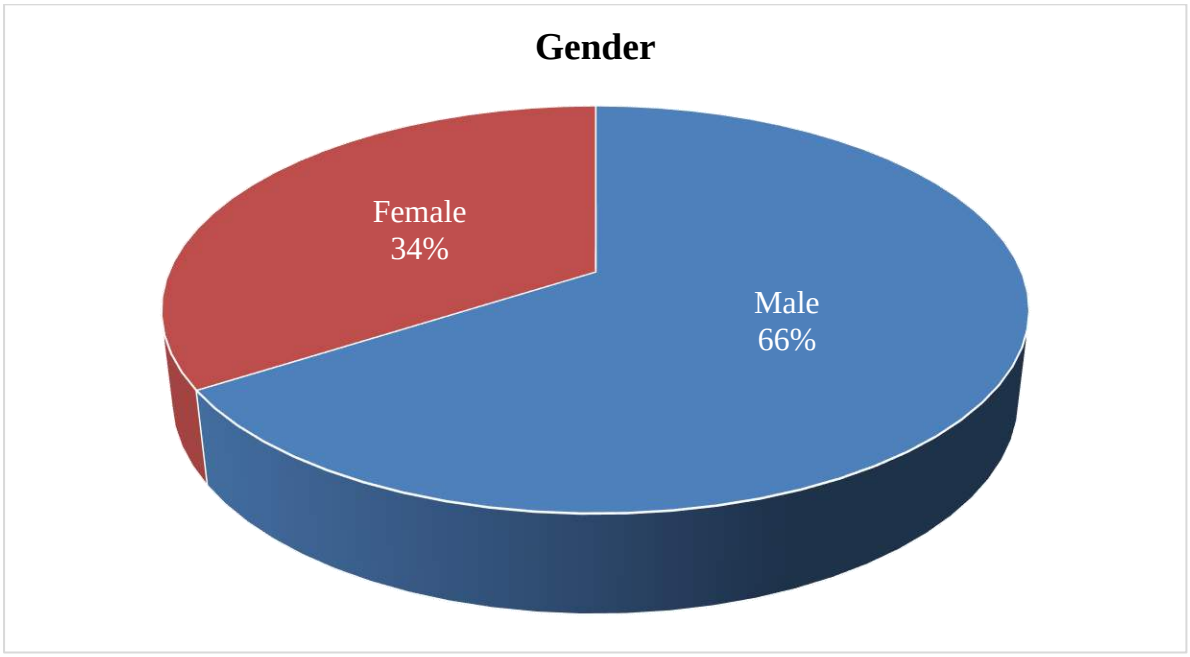


Figure 4:Gender Distribution of Patients

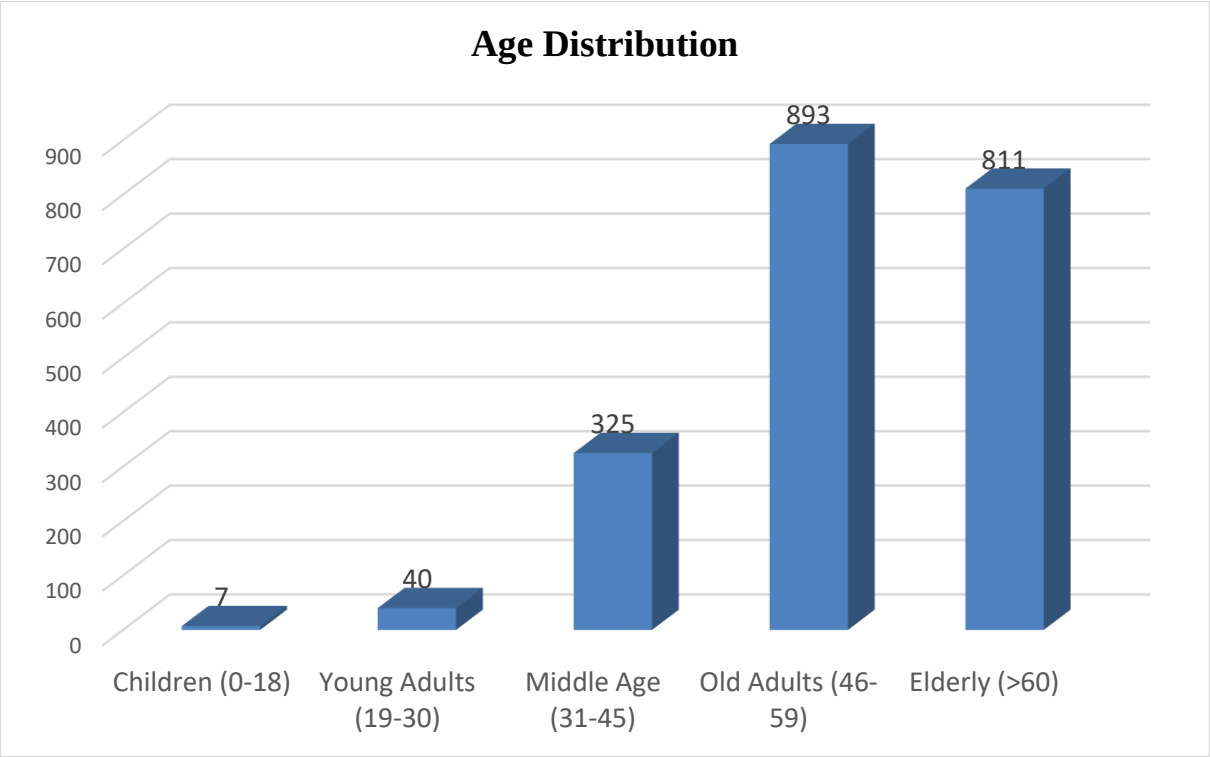


Figure 5:Age Distribution of Patients

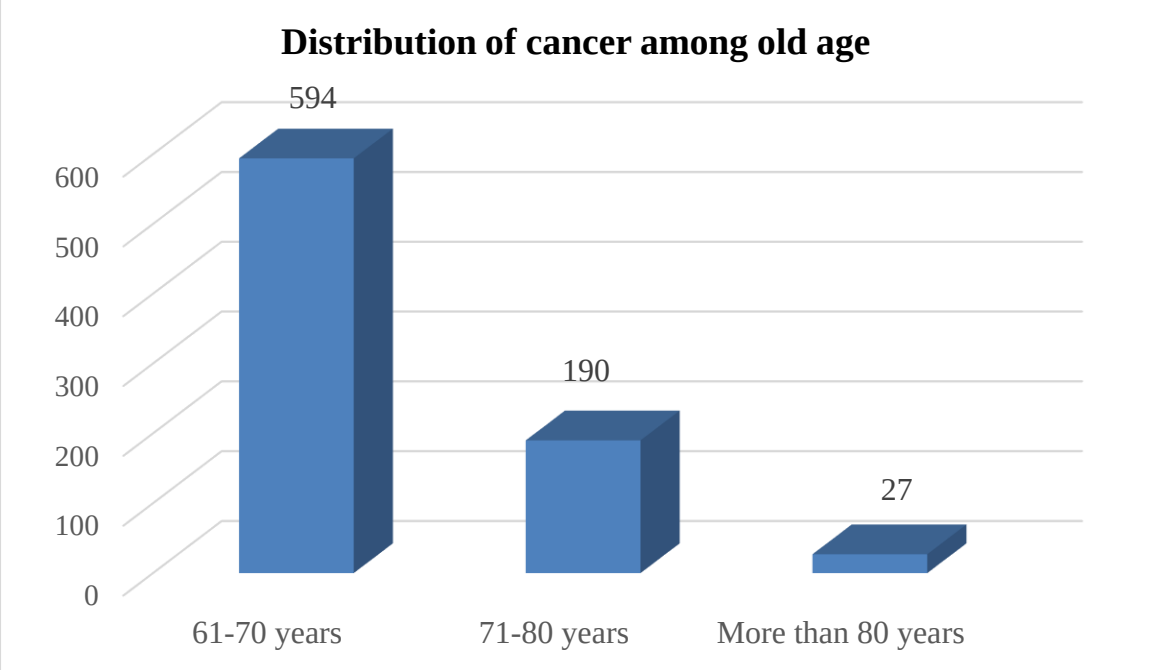


Figure 6:Distribution of cancer among old age

Table 2: Gender Distribution of Patients

Gender	No. of Patients (N)	Percent (%)
Male	1368	65.9
Female	708	34.1
Total	**2076**	**100.0**

Table 3:Age Distribution of Patients

Age Groups (years)	No. of Patients (N)	Percent (%)
Children (0-18)	7	0.3
Young Adults (19-30)	40	1.9
Middle Age (31-45)	325	15.7
Old Adults (46-60)	893	43.0
Elderly (>60)	811	39.1
Total	**2076**	**100.0**

Table 4:Elderly Age Group Distribution

Elderly Age Groups (years)	No. of Patients (N)	Percent (%)
61-70 years	594	28.6
71-80 years	190	9.2
More than 80 years	27	1.3
Total	**2076**	**100.0**

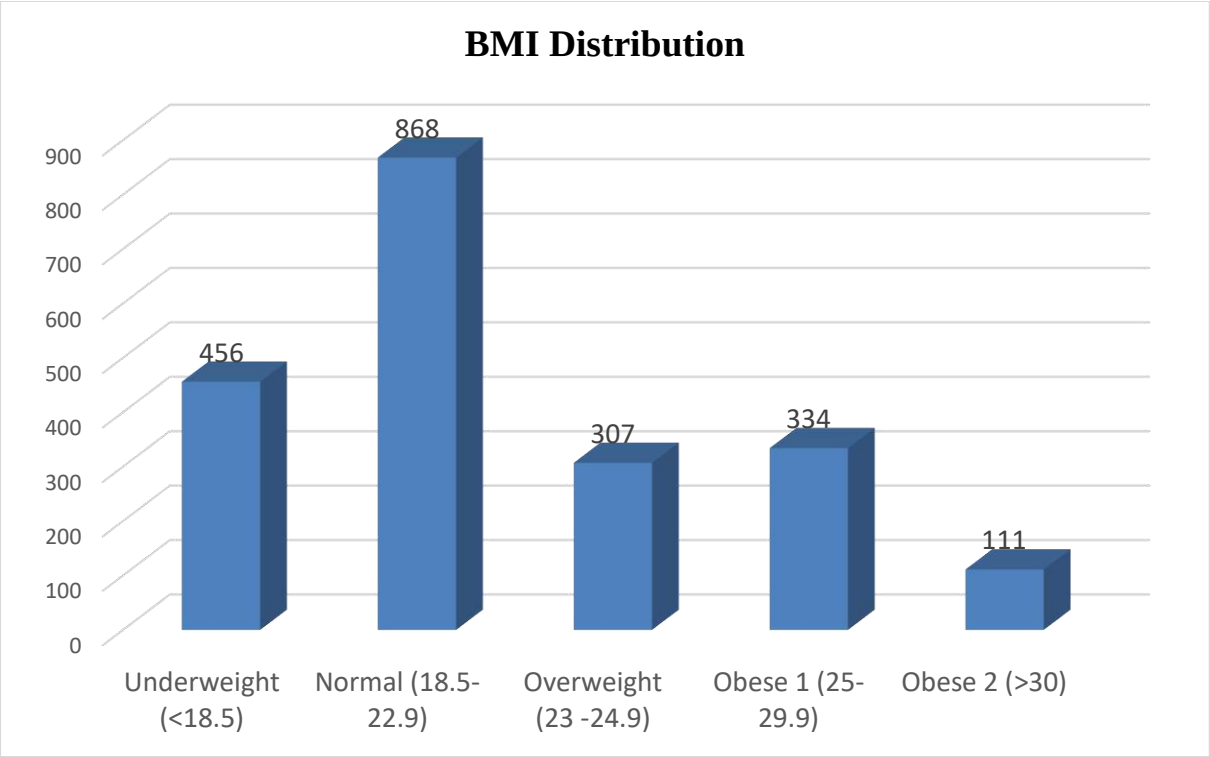


Figure 7: BMI Distribution of Patients

Table 5: BMI Distribution of Patients

BMI CATEGORY (kg/m^2)	No. of Patients (N)	Percent (%)
Underweight (<18.5)	456	22.0
Normal (18.5-22.9)	868	41.8
Overweight (23 -24.9)	307	14.8
Obese 1 (25-29.9)	334	16.1
Obese 2 (>30)	111	5.3
Total	**2076**	**100.0**

Patient Demographics – Geographical Distribution:

The patient population was representative of Tamil Nadu covering all districts with the highest numbers from **Chennai (217 patients), Coimbatore (159 patients), Thanjavur (114 patients), Thoothukudi (141 patients) and Madurai (116 patients) districts.** The geographic distribution of patients is shown in Table 6 and Figures 8 and 9. The patient population was equally divided between urban and rural areas with tribal population forming less than one percent of the population (Table 5 and Figure 6).

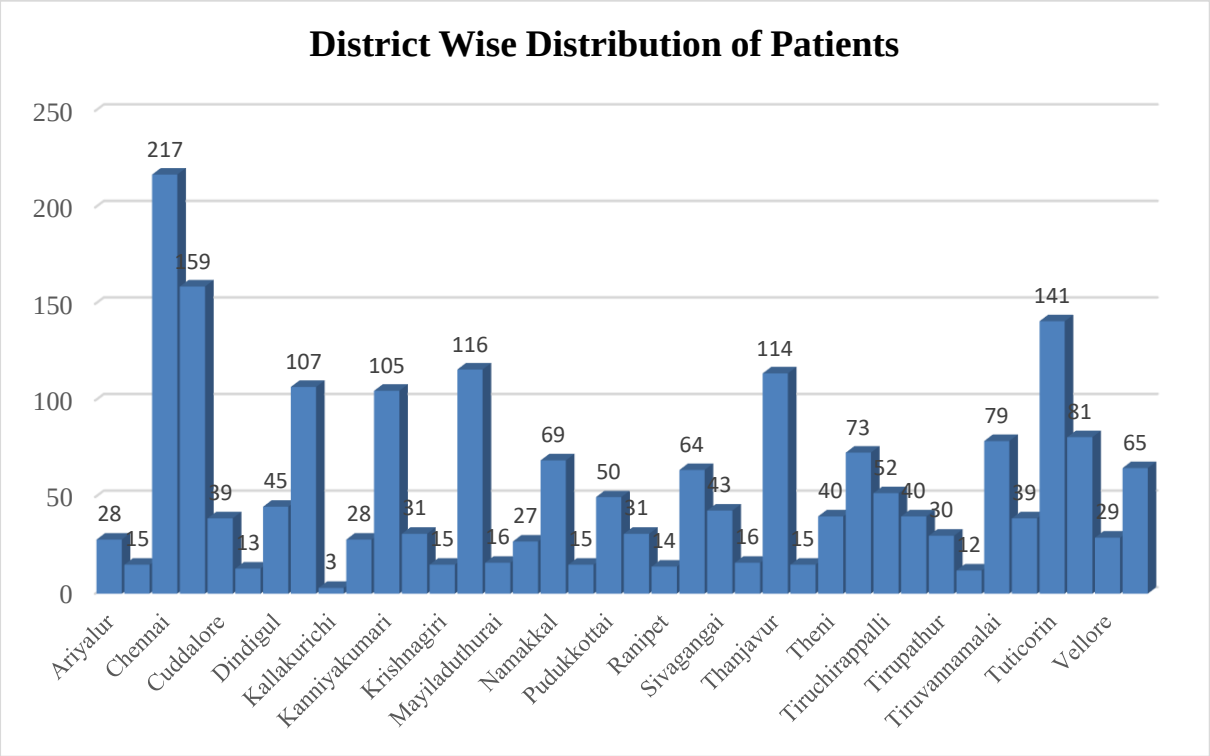


Figure 8: District wise Distribution of Patients

Table 6: District wise Distribution of Patients

District	Patients (N)	Percent (%)	District	Patients (N)	Percent (%)
Ariyalur	28	1.3	**Ramanathapuram**	31	1.5
Chengalpattu	15	0.7	**Ranipet**	14	0.7
Chennai	217	10.5	**Salem**	64	3.1
Coimbatore	159	7.7	**Sivagangai**	43	2.1
Cuddalore	39	1.9	**Thenkasi**	16	0.8
Dharmapuri	13	0.6	**Thanjavur**	114	5.5
Dindigul	45	2.2	**The Nilgiris**	15	0.7
Erode	107	5.2	**Theni**	40	1.9
Kallakurichi	3	0.1	**Thiruvallur**	73	3.5
Kanchipuram	28	1.3	**Tiruchirappalli**	52	2.5
Kanniyakumari	105	5.1	**Tirunelveli**	40	1.9
Karur	31	1.5	**Tirupathur**	30	1.4
Krishnagiri	15	0.7	**Tiruppur**	12	0.6
Madurai	116	5.6	**Tiruvannamalai**	79	3.8
Mayiladuthurai	16	0.8	**Tiruvarur**	39	1.9
Nagapattinam	27	1.3	**Tuticorin**	141	6.8
Namakkal	69	3.3	**Viluppuram**	81	3.9
Perambalur	15	0.7	**Vellore**	29	1.4
Pudukkottai	50	2.4	**Virudhunagar**	65	3.1

Figure 9: Tamil Nadu district Map showing highest number of cancer patients

Table 7: Place of Residence

Place of Residence	**No. of Patients (N)**	**Percent (%)**
Rural	1018	49.0
Urban	1053	50.7
Tribal	5	0.2
Total	**2076**	**100.0**

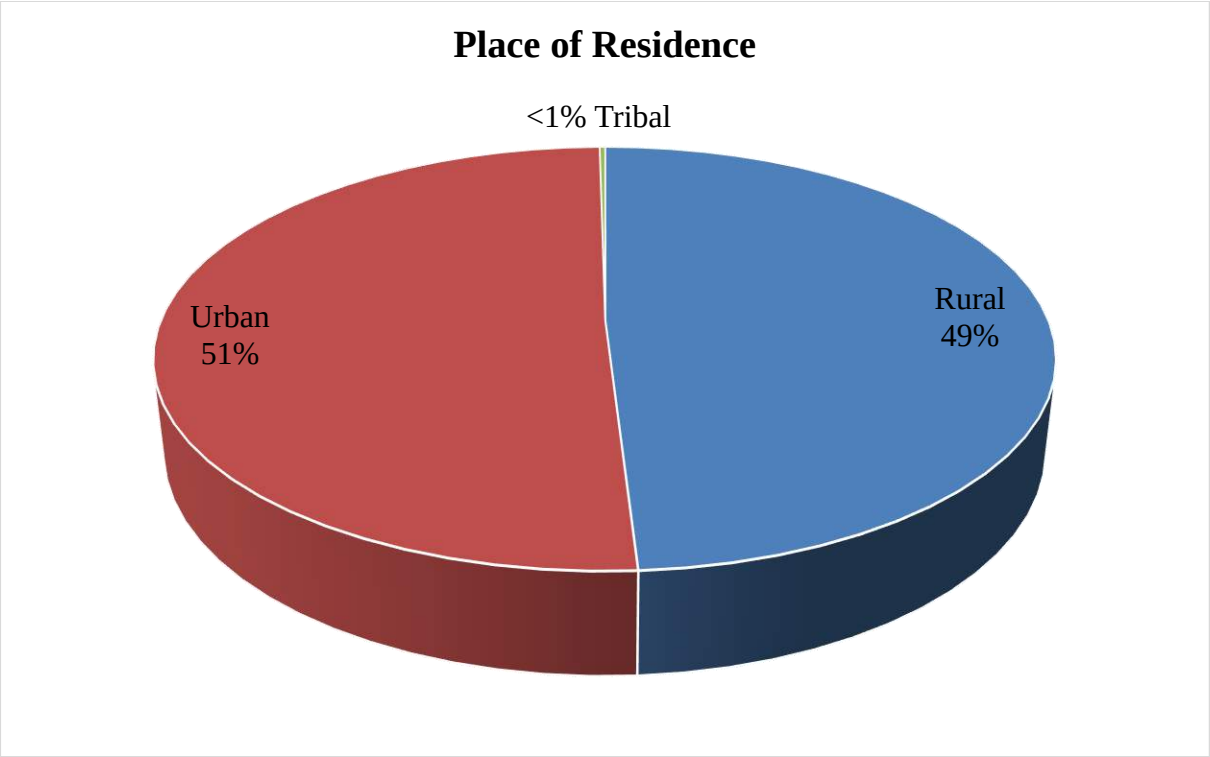


Figure 10: Place of Residence

Distance from Home to Healthcare Facilities:

The mean distances from the patient's current home address and the hospitals were calculated using Google Maps and rounded to the nearest 0.5 km. When the exact address was not able to be located using Google Maps, the nearest significant landmark was used for calculation. When the distances were less than 1 km, they were rounded to 1 km.

The mean distance from home to the **nearest healthcare facility** (the nearest General Practitioner doctor or private clinic or Primary Health centre - where they regularly go for check-ups) was 4.35 ± 4.15 km (range: 1 – 61 km), with 93% living within a 10 km radius from their nearest healthcare facility.

The **nearest specialty private hospital or Government Hospital** was located at a mean distance of 13.01 ± 9.5 km (range: 1 to 63 km), with more than 50% having a speciality hospital within a 10 km radius and more than 80% within a 20 km radius from their home.

The **nearest cancer centre** was located at a mean distance of 33.76 ± 22.32 km (range: 1- 99 km) with more than 75% of patients living within a 50 km radius and all (100%) within a 100 km radius of a cancer centre.

The mean distance from the **current treating hospital to home** was 45.5 km ± 44.51 km (range 1 to 533 km), with two-thirds (66.7%) choosing a cancer hospital within a 50 km radius and 95% of patients choosing a cancer hospital within 100 km radius from their home.

Although, the mean distance from nearest healthcare facility (**Nearest GP/PHC from home)** was equal between rural and urban areas (4.36 ± 3.61 Vs. 4.35 ± 4.63 km, p =0.51), cancer patients from rural areas had to travel significantly longer distances to get access to a speciality hospital (**Nearest Speciality Govt/ Private Hospital) (**14.65 ± 10.13 vs. 11.49 ± 8.53 km, p <0.001) **or** a cancer centre (**Nearest Cancer Centre)** (40.25 ± 22.05 km vs. 27.43 ± 20.46 km, p < 0.001) than people in urban areas. They also travelled more than urban area people to get cancer treatment (**Distance between home and current treating hospital) (**55.18 ± 49.29 km vs. 36.08 ± 37.04) (Tables 8 &9, Figures 11-14).

There was also a significant difference in the distance from the nearest cancer centre and home and Distance between home and current treating hospital amongst people of different religions with Christians being closer to cancer centres or choosing nearer cancer centres for treatments than people of other religions.

Table 8: Distance from Home to Healthcare Facilities

		Nearest GP/PHC from home (in km)	Nearest Speciality Govt/ Private Hospital (in km)	Nearest Cancer Centre (in km)	Distance between home and current treating hospital (in km)
Mean ± SD		4.35±4.16	13.04±9.48	33.76±22.23	45.49±44.51
Median		3.00	10.00	28.00	35.00
Mode		2.00	13.00	23.00	23.00
Range		1.00 - 61.00	1.00 - 63.00	1.00 -99.00	1.00 -533.00
Percentiles	**25**	2.00	6.00	15.00	18.00
	50	3.00	10.00	28.00	35.00
	75	5.00	17.38	49.00	58.00

Table 9: Nearest Healthcare Facility

Nearest GP/PHC from home (in Km)	No. of Patients (N)	Percent (%)
1-10 Km	1936	93.3
11-20 Km	118	5.7
21-30 Km	12	0.6
31-40 Km	4	0.2
41-50 Km	3	0.1
>51 Km	3	0.1
Total	**2076**	**100.0**

Table 10: Nearest Speciality Govt/ Private Hospital

Nearest Speciality Govt/ Private Hospital (in Km)	No. of Patients (N)	Percent (%)
1-10 Km	1084	52.2
11-20 Km	624	30.1
21-30 Km	244	11.8
31-40 Km	78	3.8
41-50 Km	26	1.3
51-75 Km	20	1.0
Total	**2076**	**100.0**

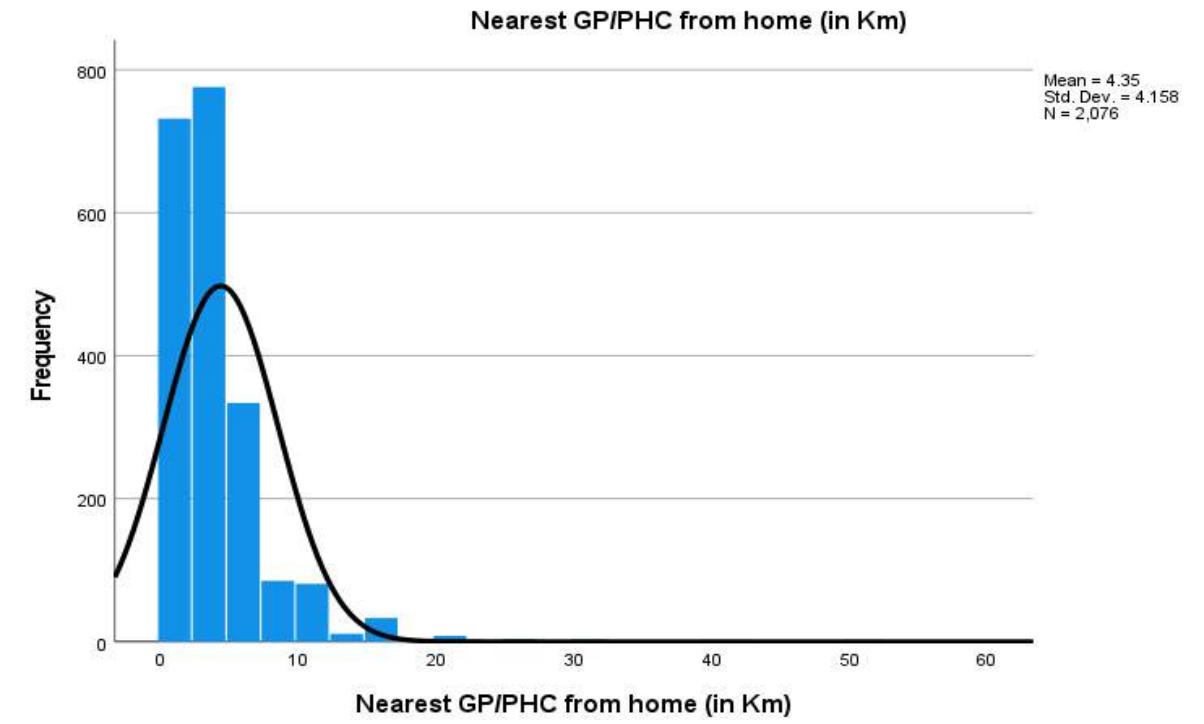


Figure 11:Nearest Healthcare Facility

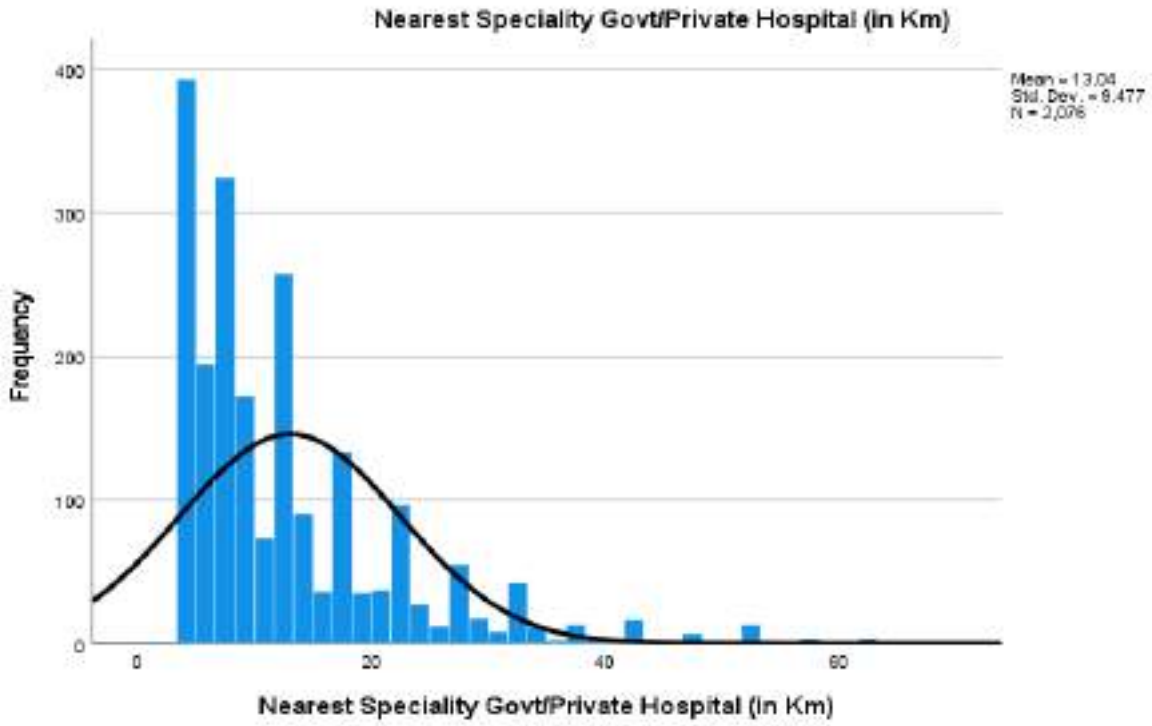


Figure 12:Nearest Speciality Govt/ Private Hospital

Table 11: Nearest Cancer Centre

Nearest Cancer Centre	No. of Patients (N)	Percent (%)
1-10 Km	323	15.6
11-20 Km	443	21.3
21-30 Km	321	15.5
31-40 Km	209	10.1
41-50 Km	277	13.3
51-75 Km	402	19.3
76 -100 Km	101	4.9
Total	**2076**	**100.0**

Table 12: Distance from Current Treating Hospital

Treating Hospital	No. of Patients (N)	Percent (%)
1-10 Km	231	11.1
11-20 Km	383	18.4
21-30 Km	302	14.5
31-40 Km	205	9.9
41-50 Km	268	12.8
51-75 Km	409	19.7
76 -100 Km	145	7.0
101-150 Km	78	3.8
151-200 Km	29	1.4
201-300 Km	12	0.6
301-400 Km	10	0.5
401-500 Km	3	0.1
More Than 500 Kms	1	0.0
Total	**2076**	**100.0**

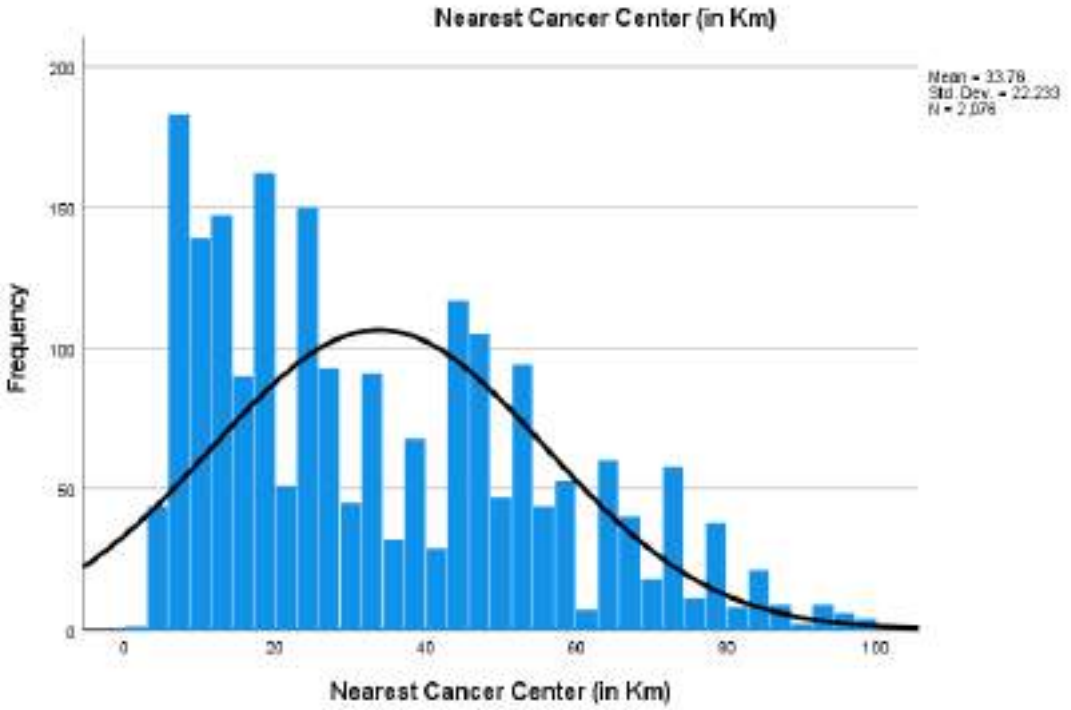


Figure 13:Nearest Cancer Centre

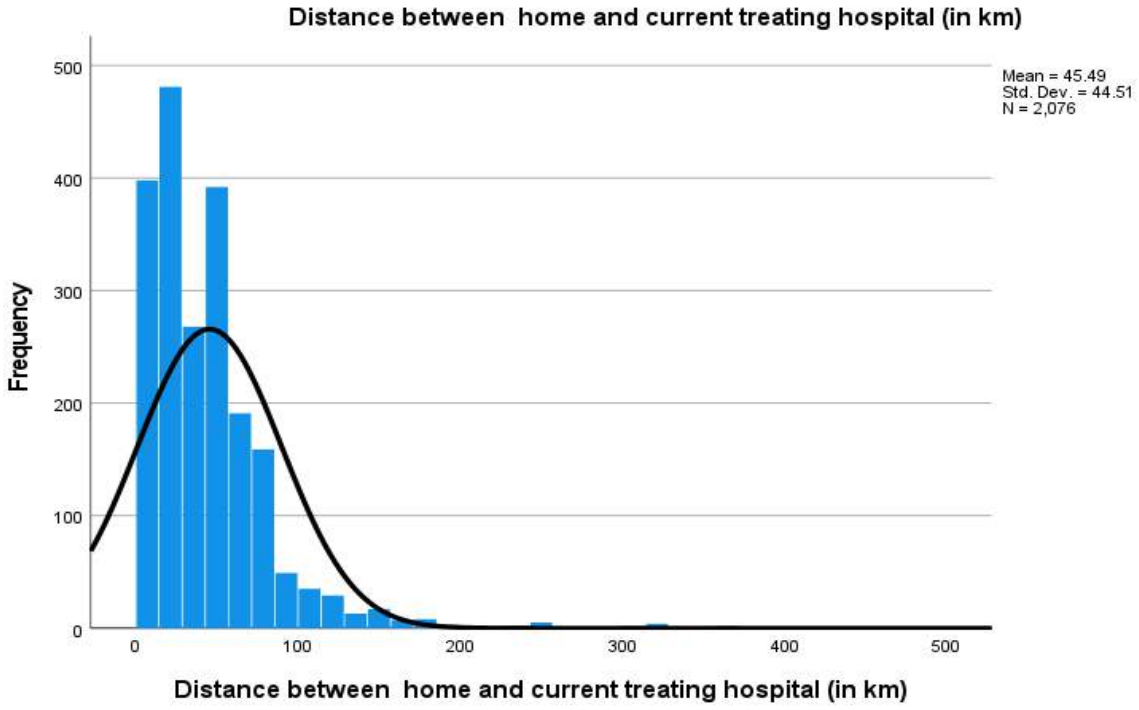


Figure 14:Distance from Current Treating Hospital

Table 13: Distances from Healthcare Facilities in Urban and Rural Areas

Place of residence		**Nearest GP/PHC from home (in Km)**	**Nearest Speciality Govt/ Private Hospital (in Km)**	**Nearest Cancer Centre (in Km)**	**Distance between home and current treating hospital (in km)**
Rural	**Mean ± SD**	4.36 ± 3.61	14.65 ± 10.13	40.25 ± 22.05	55.18 ± 49.29
Tribal	**Mean ± SD**	2.20 ± 0.45	10.40 ± 8.14	45.60 ± 35.83	55.60 ± 43.04
Urban	**Mean ± SD**	4.35 ± 4.63	11.49 ± 8.53	27.43 ± 20.46	36.08 ± 37.04
P value		0.05 (NS)	**<0.001**	**<0.001**	**<0.001**

NS = Non-Significant

Table 14: Distance from Healthcare Facilities Vs. Religious Affiliations

Religion		**Nearest GP/PHC from home (in Km)**	**Nearest Speciality Govt/ Private Hospital (in Km)**	**Nearest Cancer Centre (in Km)**	**Distance between home and current treating hospital (in km)**
Christian	**Mean ± SD**	4.09±3.32	12.15±8.82	28.92±20.90	31.81±24.63
Hindu	**Mean ± SD**	4.41±4.29	13.21±9.58	34.34±22.40	46.82±45.92
Muslim	**Mean ± SD**	3.61±2.62	11.35±8.38	30.94±20.21	42.97±39.26
P Value		**0.12**	**0.07**	**0.005**	**<0.001**

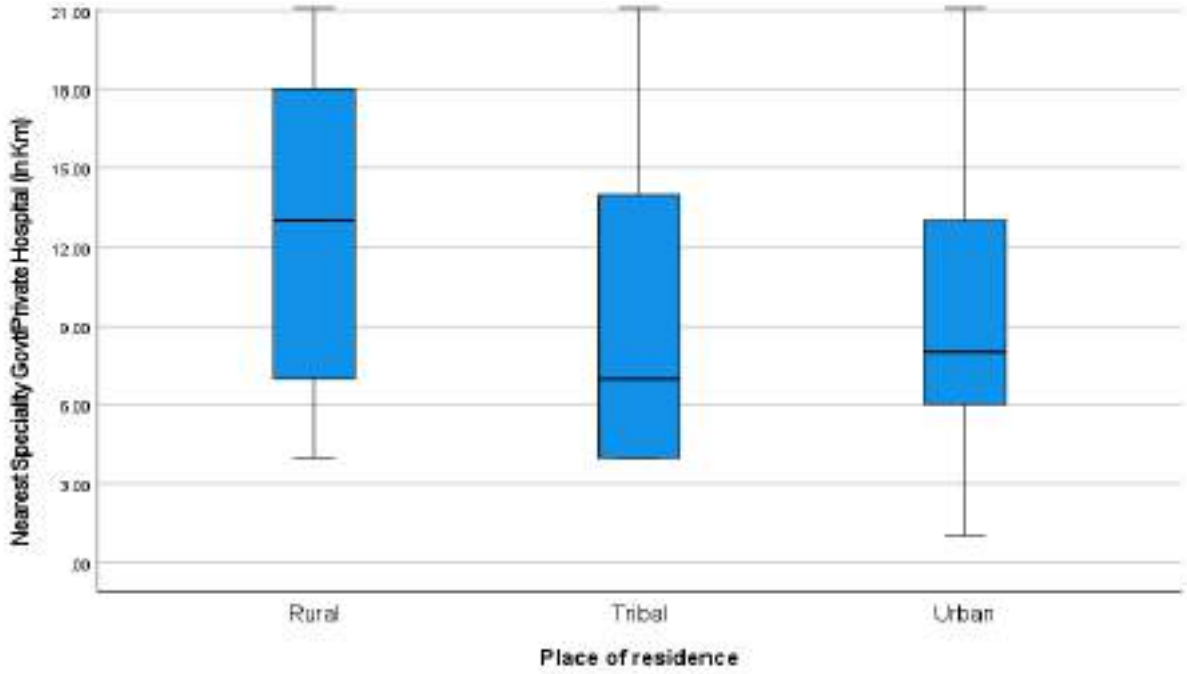


Figure 15: Nearest Speciality Hospital: Rural Vs. Urban

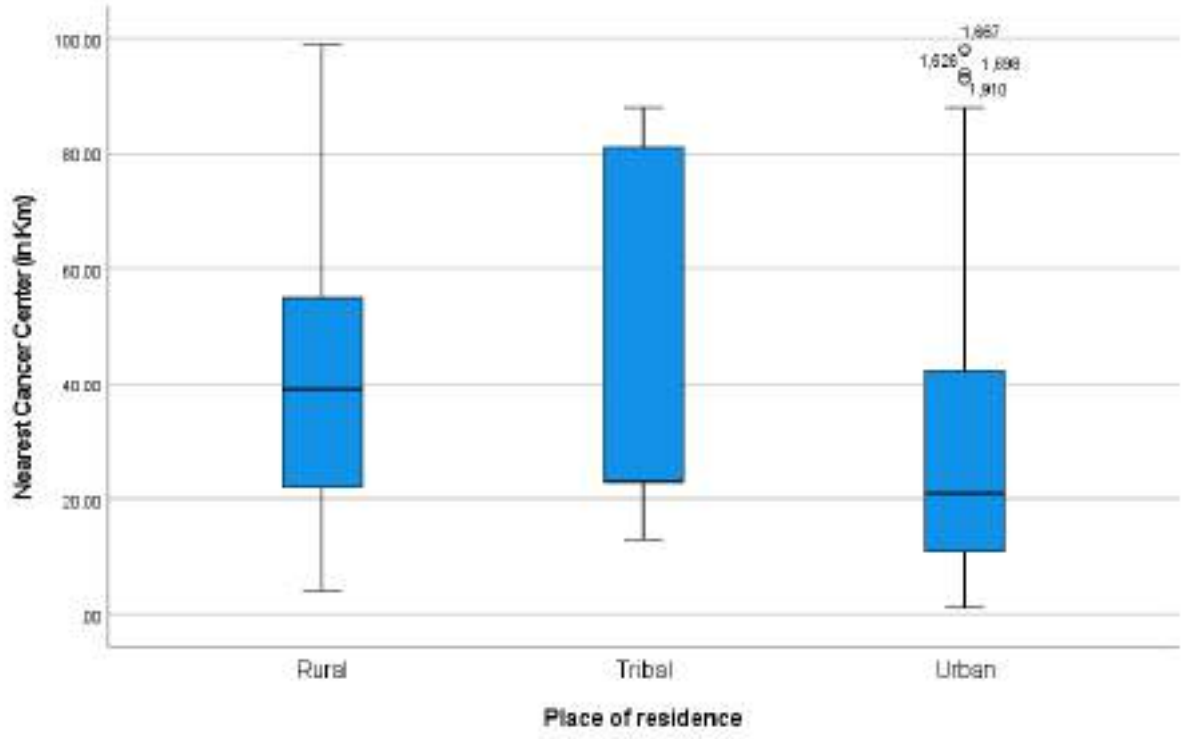


Figure 16:Nearest Cancer Centre: Rural Vs. Urban

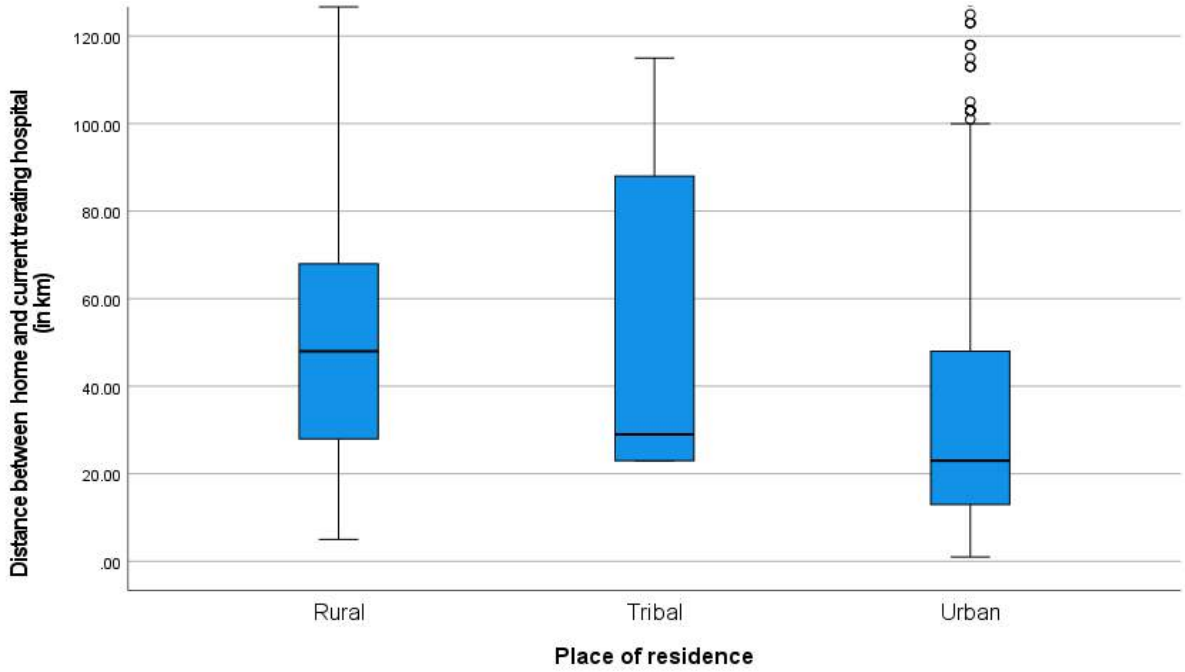


Figure 17:Current Treating Hospital: Rural Vs. Urban

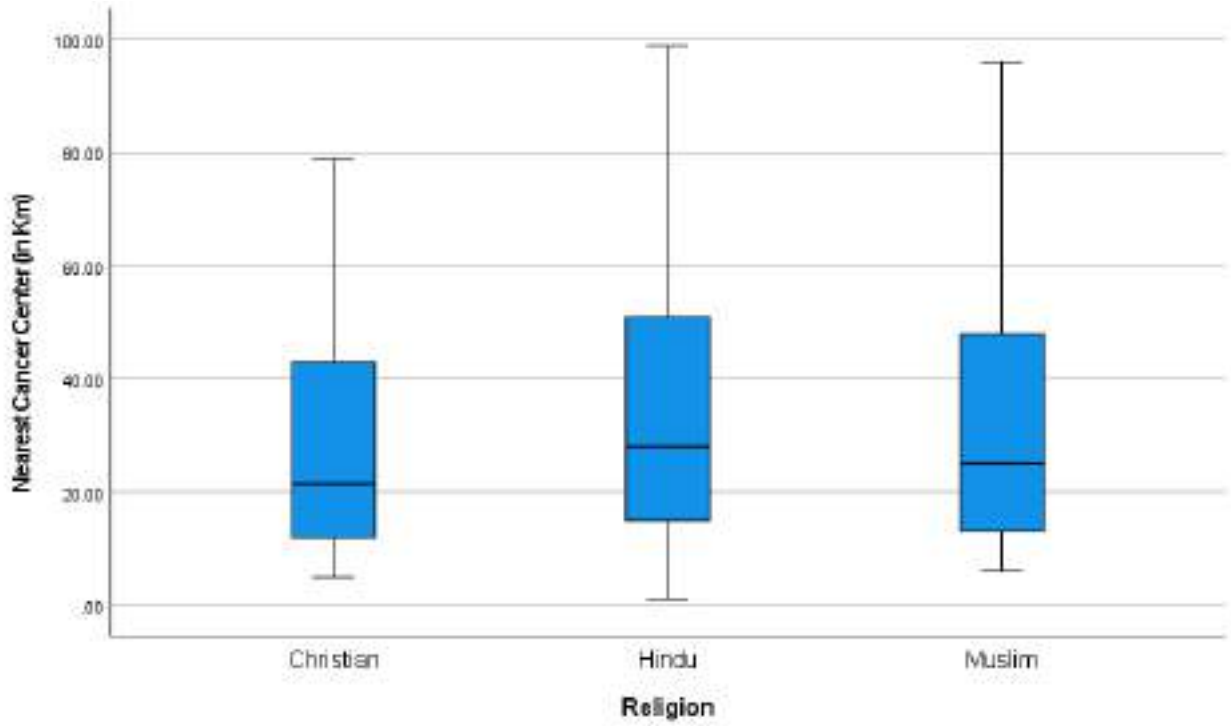


Figure 18: Nearest Cancer Centre Vs. Religion

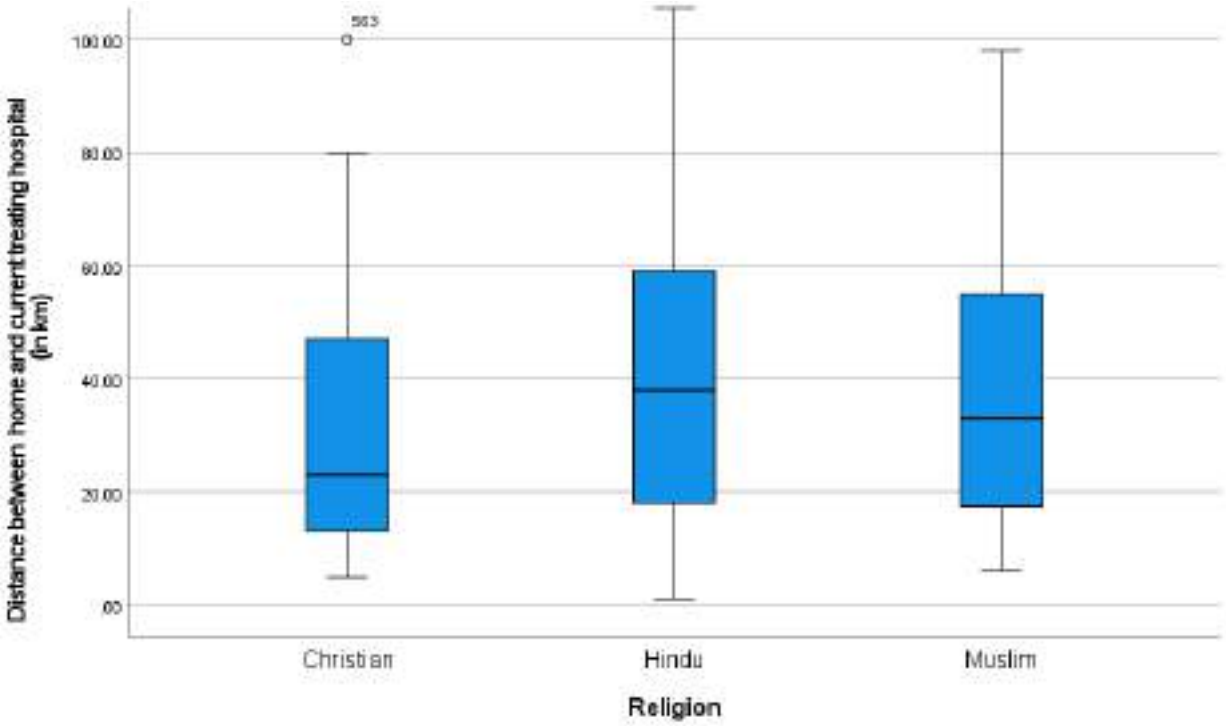


Figure 19: Current Treating Hospital Vs. Religion

Patient Demographics – Socioeconomic Factors:

The patient's religions affiliations were reflective of the population of Tamil Nadu with 87.4% Hindus (Table 10). 87.3% of patients were married and 78.5% of patients were from nuclear families with mean family strength of 4 (range 1 to 15 family members), which was equally divided between the religions and place of residence (Tables 12-14).

Table 15: Religious Affiliations

Religion	**Patients (N)**	**Percent (%)**
Hindu	1815	87.4
Christian	158	7.6
Muslim	103	5.0
Total	**2076**	**100.0**

Table 16: Marital Status

Marital Status	Patients (N)	Percent (%)
Unmarried	44	2.1
Married	1813	87.3
Divorced	5	0.2
Separated	22	1.1
Widow(er)	192	9.2
Total	**2076**	**100.0**

Table 17:Type of Family

Type of Family	Patients (N)	Percent (%)
Single	6	0.3
Nuclear	1629	78.5
Joint	268	12.9
Extended	173	8.3
Total	**2076**	**100.0**

Table 18: Number of Family members Vs. Religious Affiliation

Religion	No. of Family Members (Mean ± SD)	No. of Patients
Christian	3.69±1.56	158
Hindu	4.01±1.72	1815
Muslim	4.51±2.74	103
Total	**4.01±1.77**	**2076**

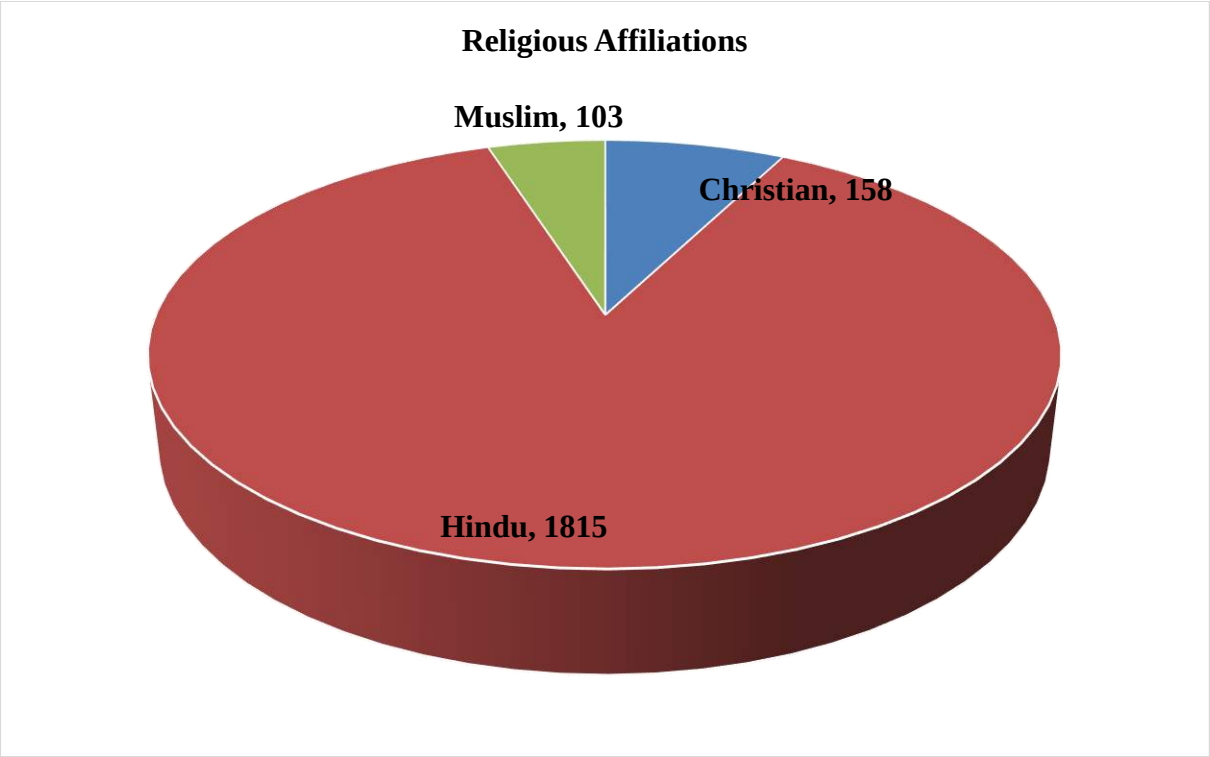


Figure 20:Religious Affiliations

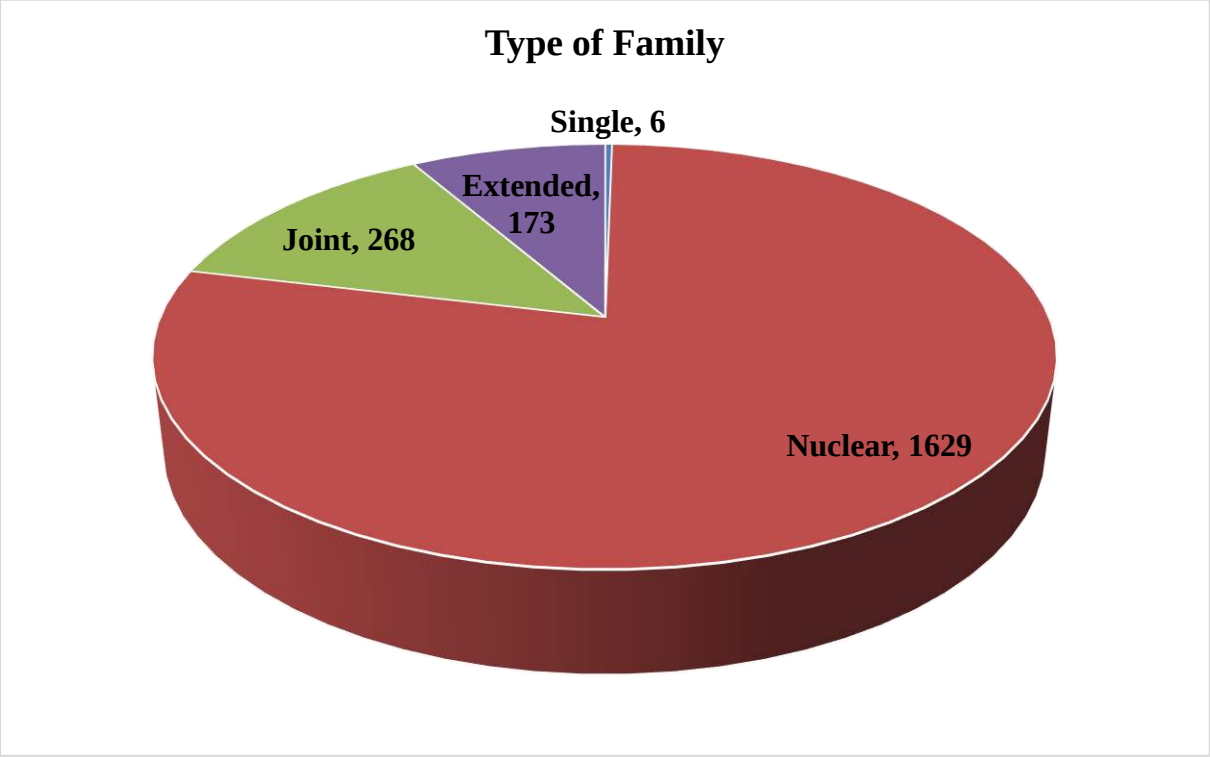


Figure 21:Type of Family

Table 19: Number of Family Members Vs Urban/Rural Divide

Place of residence	No. of Family Members (Mean ± SD)	No. of Patients
Rural	3.98±1.79	1018
Tribal	4.20±0.84	5
Urban	4.04±1.76	1053
Total	4.01±1.77	2076

Relationship of Primary Caregiver:

The spouse was the primary care giver for 59.1% (n=1226) patients, which was reflective of the marital status of the patient and the family structure.

Table 20:Relationship of primary care giver

Relationship of primary care giver	Patients (N)	Percent (%)
Husband	267	12.9
Wife	959	46.2
Son	326	15.7
Daughter	256	12.3
Father	34	1.6
Mother	48	2.3
Grandparent	6	0.3
Other Relative	173	8.3
Not known	7	0.3
Total	**2076**	**100.0**

Educational Status of Patient and Relatives:

Majority (>90%) of our patients were either illiterate or had only school level of education (Table 15). When we looked at the highest educational status within the family (primary caregiver or the head of the family, if not the patient), more than 40 percent were either a graduate or had a professional degree.

Table 21: Educational Status of the Patient

Highest level of education of the Patient	Patients (N)	Percent (%)
Illiterate	602	29.0
Primary school	472	22.7
Middle school	358	17.2
High school	306	14.7
Higher secondary	144	6.9
Graduate	158	7.6
Professional degree	36	1.7
Total	**2076**	**100.0**

Table 22:Highest Educational status Primary Care Giver/ Head of Family

Highest Educational status Primary Care Giver/ Head of Family	Patients (N)	Percent (%)
Illiterate	145	7.0
Primary school	207	10.0
Middle school	275	13.2
High school	304	14.6
Higher secondary	285	13.7
Graduate	709	34.2
Professional degree	151	7.3
Total	**2076**	**100.0**

Table 23: Educational Status of the Patient Vs Urban/Rural Residence

Highest level of education of the Patient	Place of Residence			Total	Pearson Chi-Square P Value
	Rural	Tribal	Urban		
Illiterate	352	2	248	602	
Primary school	230	0	242	472	
Middle school	169	0	189	358	
High school	148	2	156	306	**<0.001**
Higher secondary	59	1	84	144	
Graduate	49	0	109	158	
Professional degree	11	0	25	36	
Total	**1018**	**5**	**1053**	**2076**	

Table 24:Highest Educational status Primary Care Giver/ Head of Family Vs. Place of Residence

Highest Educational status Primary Care Giver/ Head of Family	Place of residence			Total	Pearson Chi-Square P Value
	Rural	Tribal	Urban		
Illiterate	81	0	64	**145**	
Primary school	107	0	100	**207**	
Middle school	141	1	133	**275**	
High school	161	0	143	**304**	**<0.001**
Higher secondary	151	3	131	**285**	
Graduate	328	1	380	**709**	
Professional degree	49	0	102	**151**	
Total	**1018**	**5**	**1053**	**2076**	

Table 25: Educational Status of the Patient Vs. Gender

Highest level of education of the Patient	Gender		Total	Pearson Chi-Square P Value
	Female	Male		
Illiterate	290	312	602	
Primary school	147	325	472	
Middle school	93	265	358	
High school	78	228	306	**<0.001**
Higher secondary	44	100	144	
Graduate	45	113	158	
Professional degree	11	25	36	
Total	**708**	**1368**	**2076**	

Table 26:Highest Educational status Primary Care Giver/ Head of Family Vs. Gender

Highest Educational status Primary Care Giver/ Head of Family	Gender		Total	Pearson Chi-Square P Value
	Female	Male		
Illiterate	38	107	145	
Primary school	80	127	207	
Middle school	91	184	275	
High school	108	196	304	0.18 (NS)
Higher secondary	106	179	285	
Graduate	230	479	709	
Professional degree	55	96	151	
Total	**708**	**1368**	**2076**	

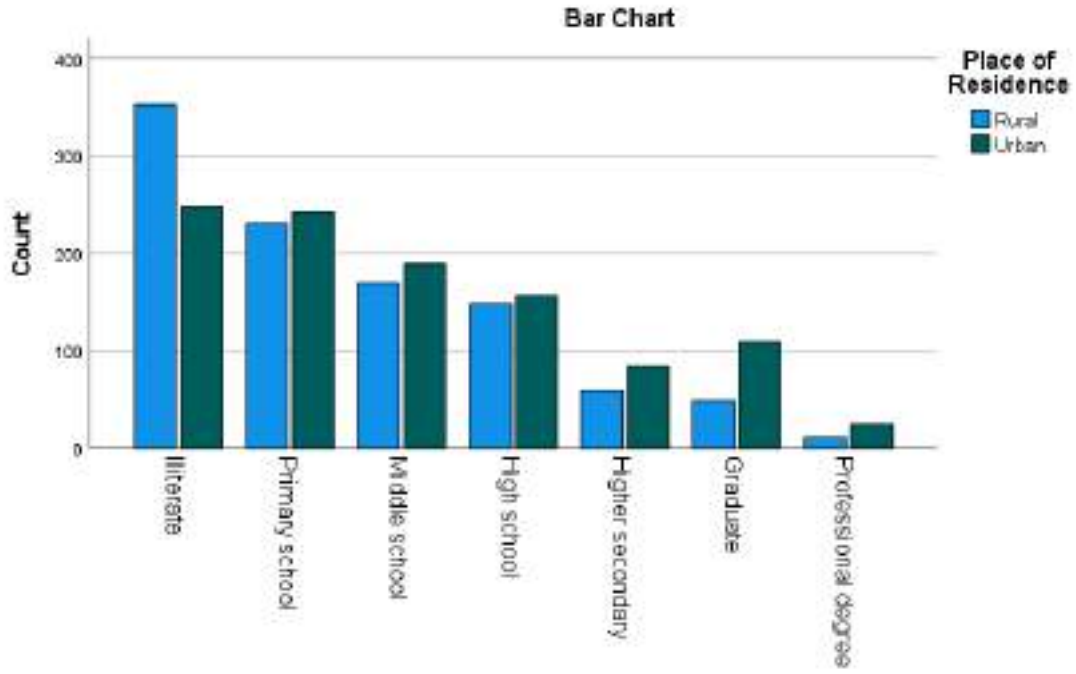


Figure 22: Educational Status of the Patient Vs. Rural/Urban Residence

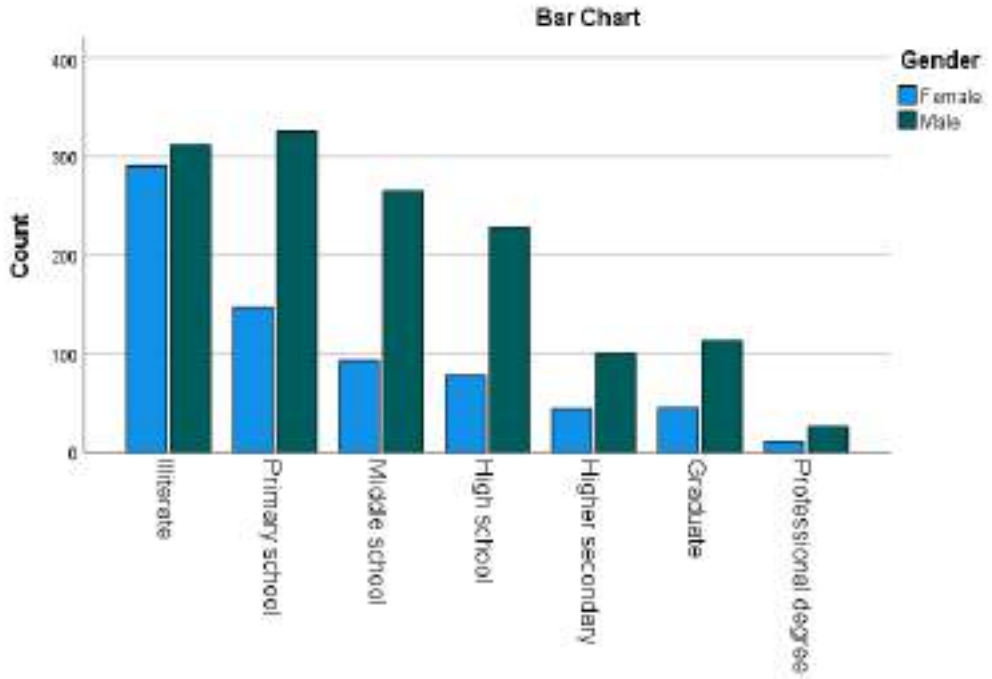


Figure 23:Educational Status of the Patient Vs. Gender

Table 27: Educational Status of the Patient Vs. Religious Affiliations

Highest level of education of the Patient	Religion			Total	P Value
	Christian	Hindu	Muslim		
Illiterate	36	542	24	602	0.07
Primary school	38	414	20	472	
Middle school	25	311	22	358	
High school	26	260	20	306	
Higher secondary	9	130	5	144	
Graduate	20	126	12	158	
Professional degree	4	32	0	36	
Total	**158**	**1815**	**103**	2076	

Table 28: Educational status of patient Vs. Age Groups

Highest level of education of the Patient	Age Groups					Total	P Value
	Children	Elderly	Middle Age	Old Adults	Young Adults		
Illiterate	1	254	64	278	5	602	
Primary school	1	194	63	210	4	472	
Middle school	1	139	56	155	7	358	
High school	2	104	72	123	5	306	**<0.001**
Higher secondary	2	46	28	63	5	144	
Graduate	0*	55	36	55	12	158	
Professional degree	0*	19	6	9	2	36	
Total	**7**	**811**	**325**	**893**	**40**	**2076**	

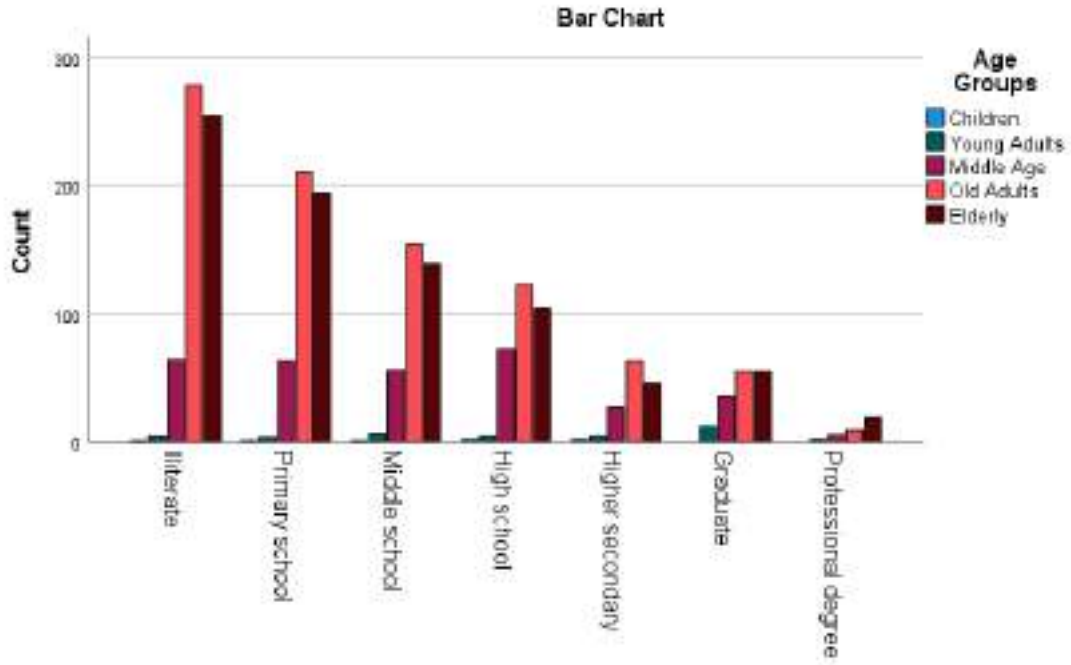


Figure 24: Educational Status of Patient Vs. Age Groups

There was a significant difference in the educational status of the patients and Highest Educational status Primary Care Giver/ Head of Family between Rural Vs Urban Population (P < 0.001, Urban patients and relatives were more educated). There was a significant difference in the educational status of the patients between male vs. female patients (P < 0.001, males were more educated) but not in the Highest Educational status Primary Care Giver/ Head of Family. and by age groups (p<0.00, elderly had less education) but no significant difference between the Hindus, Muslims or Christians (p= 0.07) (Tables 16 -19, Figures 15 & 16).

Socioeconomic Status:

The mean family income of the patient was Rs. 14928.66 ± 22163.62 per month (range Rs. 900 – Rs. 500000) with a mean per capita family income of Rs. 4046.85 ± 5568.63. We used the Modified BG Prasad Classification (October 2023) to classify the patients into 5 social classes. Lower Middle Class (34.8%), Middle Class (21.4%) and upper middle class (17.1%) formed the majority of our patients.

Table 1: Modified BG Prasad classification for October 2023 (Rupees/ month)

Social Class		Original BG Prasad classification of 1961 (Rs. / month)	Modified BG Prasad classification for Oct 2023 (Rs. / month)
I	Upper class	100 and above	9098 and above
II	Upper middle class	50 – 99	4549 - 9097
III	Middle class	30 – 49	2729 – 4550
IV	Lower middle class	15 – 29	1365 – 2728
V	Lower class	Below 15	Below 1365

Figure 25: Modified BG Prasad Classification for Socioeconomic status

Table 29: Socioeconomic Status

Socioeconomic Status (BG Prasad October 2023 Scale)	Patients (N)	Percent (%)
I Upper Class	158	7.6
II Upper Middle Class	354	17.1
III Middle Class	445	21.4
IV Lower Middle Class	722	34.8
V Lower Class	397	19.1
Total	**2076**	**100.0**

Occupation of Patient and Primary Caregiver:

We looked at the occupation of the patient and the primary caregiver or Head of family (highest level) and classified them into 7 categories based on the Kuppusamy Socioeconomic scale classification. More than 50% of patients were either unskilled or semiskilled workers with 25.4% being unemployed. Professionals and semi-professionals formed less than 8% of the population. The occupation of the primary care giver or the head of the family (highest) was similar: unskilled or semiskilled workers forming 49.1%, unemployed being 15.8% and professional/semi-professionals around 10%.

Table 30: Occupation of Patient:

Occupation of Patient	Patients (N)	Percent (%)
1.Professional	82	3.9
2.Semi-Professional	83	4.0
3.Clerical	56	2.7
4.Skilled	251	12.1
5.Semi-Skilled	424	20.4
6.Unskilled	653	31.5
7.Unemployed	527	25.4
Total	**2076**	**100.0**

Table 31:Occupation of Primary Care Giver/ Head of Family

Occupation of Primary Care Giver/ Head of Family	Patients (N)	Percent (%)
1.Professional	17	0.8
2.Semi-Professional	191	9.2
3.Clerical	390	18.8
4.Skilled	128	6.2
5.Semi-Skilled	474	22.8
6.Unskilled	547	26.3
7.Unemployed	329	15.8
Total	**2076**	**100.0**

Patient Demographics – Type of Cancer and Stage:

Oral cancers were the most common cancers among our patient population (34.2%, n=710), followed by lung cancer (13.3%, n=276), rectal cancer (11.4%, n= 237) and stomach cancer (10.9%, n=227). Majority of the patients had more advanced stage at presentation, Stage III – 55.1% and Stage IV -19.6%.

Table 32:Site of Cancer

Site of Cancer		Patients (N)	Percent (%)
Gastrointestinal Tract Cancers	**Anal Canal**	21	1.0
	Appendix	6	0.3
	Bile ducts	7	0.3
	Colon	132	6.4
	Oesophagus	206	9.9
	Gall bladder	21	1.0
	Liver	23	1.1
	Pancreas	34	1.6
	Stomach	227	10.9
	Rectum	237	11.4
	Small Intestine	7	0.3
Head and Neck Cancers	**Oral**	710	34.2
	Pharynx	82	4.0
	Larynx	84	4.0
Lung Cancers		276	13.3
Not Known		3	0.1
Total		2076	100.0

Table 33:Cancer Stage

Cancer Stage	Patients (N)	Percent (%)
1	54	2.6
2	471	22.7
3	1143	55.1
4	405	19.6
Not Known	3	0.1
Total	**2076**	**100.0**

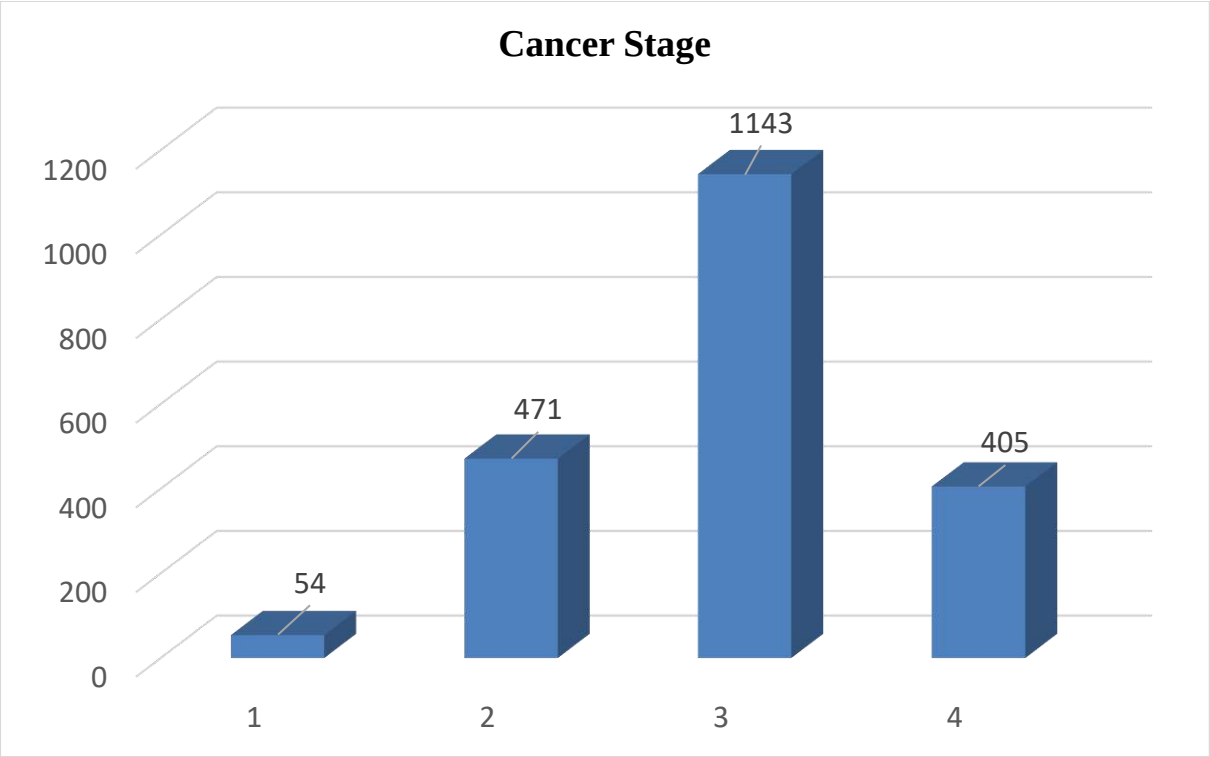


Figure 26:Cancer Stage

Presenting Symptoms:

The most common presenting symptoms were persistent abdominal discomfort (21.2%), altered bowel habits – constipation (20%) and mouth pain (17.7%).

Table 34:Presenting Symptom

Presenting Symptom	Patients (N)	Percent (%)
Persistent Abdominal Discomfort	441	21.2
Constipation	416	20
Mouth Pain	367	17.7
Difficulty in Swallowing/Opening mouth or chewing	326	15.7
Growth in mouth	237	11.4
Mouth ulcer	226	10.9
Weight Loss	149	7.2
Blood in Stool	186	9
Lip ulcer	125	6

Diarrhoea	123	5.9
Abdominal Lump	108	5.2
Chest Pain	112	5.4
Persistent Cough	89	4.3
Weakness or Fatigue	62	3
Shortness of Breath	70	3.4
Ear Pain	37	1.8
Blood in Sputum	35	1.7
Jaundice	12	0.6
Others	447	21.5

Comorbidities:

The most common comorbidities were Diabetes and Hypertension. The other co-morbidities are listed in table below.

Table 35:Comorbidities

Comorbidities	**Patients (N)**	**Percent (%)**
Diabetes	261	12.5
Hypertension	239	11.6
Others	88	4.3
Ischemic Heart Disease	67	4.2
Tuberculosis	23	1.1
Stroke	21	1.0
Chronic Kidney Disease	18	0.8
HIV/AIDS	7	0.3
Organ Transplant	3	0.1

Cancer Diagnosis and Treatment

Most patients (83.3%) presented to a hospital within their same district for their symptoms, private hospitals were preferred more than government hospitals for their first presentation (79% vs 21%). For 59.4% of patient's caner was suspected or diagnosed (without biopsy proof) at the hospital of their first presentation and were referred earlier to a higher centre for treatment. Again, for cancer diagnosis, patients preferred private specialty or tertiary level hospitals over government specialty/ tertiary hospitals (59% vs 41%).

Table 36:District - First presented

District - First presented	Patients (N)	Percent (%)
Same district	1730	83.3
Different district	346	16.7
Total	**2076**	**100.0**

Table 37:Type of Hospital

Type of Hospital	Yes	No
Cancer suspected/diagnosed at First Presentation	1234 (59.4%)	842 (40.6%)
Was an Oncologist available at the Hospital where Cancer was Diagnosed	1631 (78.6%)	445 (21.4%)
Was an Oncologist available at the Hospital where cancer treatment was started	2043 (98.4%)	33 (1.6%)

Table 38:Type of Hospital

Type of Hospital	First Presented with symptoms	Cancer Diagnosed	Received Cancer Treatment
Alternative medicine	2 (0.1%)	1(0.1%)	0
Govt. PHC/CHC	136 (6.6%)	48 (2.3%)	0
Private Clinic/ Nursing Home	277 (13.3%)	3 (0.1%)	0
Govt. Specialty Hospital	274 (13.2%)	339 (16.3%)	35 (1.7%)
Private Speciality Hospital	1064 (51.3%)	710 (34.2%)	69 (3.3%)
Govt. Tertiary Hospital	23 (1.1%)	461 (22.2%)	850 (40.9%)

Private Tertiary Hospital	360 (14.4%)	514 (24.8%)	1122 (54.0)
Total	**2076**	**2076**	**2076**

Table 39:Type of hospital/s where patients received treatment

Type of hospital/s where patients received treatment	**Patients (N)**	**Percent (%)**
Only Government	627	30.2
Only Private	956	46.1
Both	493	23.7
Total	**2076**	**100.0**

In 78.6% of cases an oncologist was available in the hospital where the cancer was diagnosed. For cancer treatment also, the patients preferred private hospitals over government hospitals (55.7% Vs. 44.2%). In 98.4% of cases, there was an oncologist available at the hospital where cancer treatment was started.

A majority (77.2%) of patients (n=1603) visited at least 2 doctors/hospitals and 20.3% (n=421) visited 3 doctors for diagnosis of cancer. The median number of Hospitals visited by the patient before start of treatment for cancer for its diagnosis was 2 hospitals/doctors (range 1 to 5). Once cancer was diagnosed almost all patients (94.5%) stuck to a single hospital, with less than 6% of patients changing hospitals.

Table 40:Number of doctors/ hospitals visited

Number of doctors/hospitals visited	**Before Cancer Diagnosis N (%)**	**After Cancer Diagnosis (For cancer treatment) N (%)**	**Total Number of doctors/hospitals visited N (%)**
1	19 (0.9%)	1961 (94.5%)	
2	1603 (77.2%)	106 (5.1%)	18(0.9%)
3	421 (20.3%)	9 (0.4%)	1549 (74.6%)
4	32 (1.5%)		419(20.2%)
5	1		79 (3.8%)
6			10 (0.5%)
7			1
	2076	**2076**	**2076**

The median number of hospitals visited for cancer treatment was 1 hospital (range 1 to 3) adding to total of 3 hospitals (range 2 to 7) for cancer diagnosis and treatment. The most common reason for choosing a particular hospital for treatment was its **popularity for cancer treatment (32.7%) and a referral from another hospital/doctor (26.4%).**

Table 41:Reason for Choosing the current treating Hospital

S. No	Reason for Choosing the current treating Hospital	Frequency (in %)
1	Hospital/Doctor known for cancer Treatment	32.7
2.	Referred to this hospital	26.4
3.	Known Doctor/Hospital	24.4
5	The hospital was nearer to home	13.1
6	Financial Reasons	11.3
7	Suggested by Friend/Relative	12
4	Facilities not available in the referred hospital	11.4
8	Alternate medicine	0.3
9	Others	6.3

Type of Treatments received

Surgery (62.2%), chemotherapy (79%) and radiotherapy (58.6%) formed the bulk of the treatment options. Forty patients (1.9%) opted for alternate medicine (AYUSH).

Table 42:Type of Cancer treatment

Type of Cancer treatment	Patients (N)	Percent (%)
Surgery	1292	62.2
Chemotherapy	1640	79
Radiotherapy	1216	58.6
Hormonal Therapy	6	0.3
Immunotherapy	7	0.3
Alternate Medicine (AYUSH)	40	1.9

Intent of treatment:

The intent of treatment was curative in 74.6% of patients and 86.1% of patients completed the planned treatment.

Table 43:Intent of treatment

Intent of treatment	Patients (N)	Percent (%)
Curative	1549	74.6
Palliative	471	22.7
Palliative/Symptomatic	45	2.2
No treatment	11	0.5
Total	**2076**	**100.0**

Status of Cancer Treatment:

Once treatment was started, 86.1% of patients completed the treatment.

Table 44:Status of Cancer Treatment

Status of treatment	Patients (N)	Percent (%)
Completed	1788	86.1
On treatment	189	9.1
Incomplete	45	2.2
Modified/Delayed	39	1.8
No Treatment	15	0.7
Total	**2076**	**100.0**

Reasons for Incomplete treatment:

The most common reason for incomplete treatment was financial reasons (15.1%).

Table 45:Reasons for Incomplete treatment

S.No	Reasons for Incomplete treatment (as given by the patient)	Frequency (in %)
1	Financial reasons	15.6
2.	Advised treatment elsewhere	14.2
3.	There was no one to take me to the hospital	12.3

5	Social Reasons	10.4
6	Unable to tolerate treatment	8.2
7	The hospital was far from home	7.4
4	Patient decided to take treatment elsewhere/other treatment	6.5
8	Death during treatment	0.3
9	Other reasons	3.7

Cost of Cancer Treatment:

The cost of treatment was covered by CMCHIS in 72.4% of patients and 31.1% percent of patients paid out of pocket for their treatment.

Table 46: Treatment Cost Coverage

Cost of Treatment Covered by	**Patients (N)**	**Percent (%) ***
CMCHIS	1503	72.4
Self	645	31.1
Private Health Insurance	95	4.6
ABPMJAY	15	0.7
ESI	36	1.7
CGHS/EHS	13	0.6
Others	17	0.8

*Total not equal to 100% as one patient would have used more than one way to cover his/her cost of treatment

Status of Patient at Last Follow up:

The median follow-up was 246 days or around 8 months (IQR 185 – 385 days). At the last follow up, 40.9% were without disease, 33.5% had disease progression or recurrence and there were 48 deaths. The status of the patient was not known in 18.8% of patients. Since the median follow-up was less than 1 year, no meaningful cancer survival analysis could be derived.

Table 47:Disease status at last Follow up

Disease status at last Follow up	Patients (N)	Percent (%)
No disease	849	40.9
Progression/Recurrence	696	33.5
Not Known	391	18.8
New cancer/Second primary	87	4.2
Dead	48	2.3
Too advanced/cachexia	5	.2
Total	**2076**	**100.0**

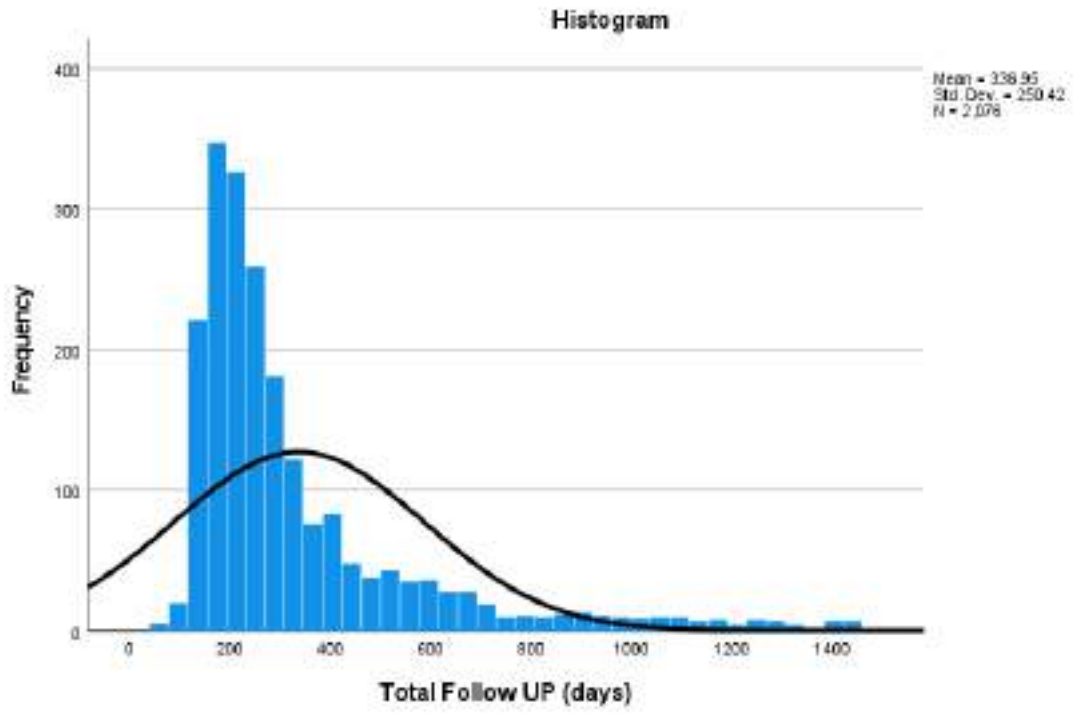


Figure 27: Total Follow Up Duration

Quality of Life Assessment at Last Follow up:

Quality of Life (QOL) assessment was done in 1672 patients at the time of last follow-up. The baseline Quality of Life (QOL) assessment was based on patient/family member recollection of the QOL at the time of cancer diagnosis and is prone to recall bias and selection bias. The QOL assessment at follow-up was done by the field investigators and is prone to

investigator bias. QOL assessment was done using Katz Index for activities of daily life where 1 point is given for each activity if done with no supervision or assistance and 0 points if supervision or assistance is required.

Number of patients with 1 point on the Katz Index for activities of daily life (QOL scores) for Toileting, transferring, continence and feeding improved at follow-up when compared to the baseline scores, whereas, scores for Bathing and dressing where the same or decreased. **Mean Daily Life activities score (Katz index of independence) improved at Followup.**

We also used the EORTC QLQC30 questionnaire which categorised the difficulties in daily activities into 4 classes (not at all, a little, very much, quite a bit) and overall health during the past week and overall quality of life over the past week into a 7-point Likert scale (really bad to really good). The mean total score was 60.36 ± 10.99(range 32 to 103) with a median or 63 (IQR: 53 -67).

Table 48: Quality of Life Assessment at Last Follow up:

Activities able to do without supervision or assistance (N=1672)	**At diagnosis N (% of total population)**	**At Follow-up) N (% of total population)**
Bathing	1566(75.4)	1476 (71.1)
Dressing	1574(75.8)	1514 (72.9)
Toileting	1259(60.6)	1495(72)
Transferring	1267(61)	1494(72)
Continence	1301(62.7)	1536 (74)
Feeding	1217(58.6%)	1404(80.5)
Daily Life activities score (Katz index of independence) Mean ± SD	4.92±1.77	5.37 ± 1.52
EORTC QLQ30 Score Mean ± SD	NA	60.36 ± 10.99

Total Population = 2076

RESULTS - CANCER DELAYS

Primary Delay:

The mean **primary delay or patient delay or presentation delay** was 49.61± 75.35 days ranging from 1 to 1064 days (almost 3 years) with a median of 30 days (Inter quartile range IQR: 12 to 61 days). The data was non-parametric and skewed to the right. In our patients, 13.8% had less than 1 week of primary delay but 54.6% had a **significant primary delay** (more than 28 days or 4 weeks) of more than 28 days.

Table 49: Cancer Delays

Cancer Delays		Primary Delay (days)	Referral Delay (Days)	Secondary Delay (days)	Tertiary Delay (days)	Total Delay from first presentation to treatment	Total Delay from symptom to treatment (days)	Total Follow UP (days)
Mean ± SD		49.61± 75.35	25.83 ± 38.74	38.21 ± 43.11	13.29 ± 17.16	51.50 ± 46.34	101.10 ± 88.62	336.95 ± 250.42
Median		30	11	26	8	37	77	246.50
Mode		31	0	10	3	31	61	214
Minimum		1	0	0	0	2	8	63
Maximum		1064	390	433	197	440	1108	1470
Percentiles	**25**	12	4	13	4	23	49	185
	50	30	11	26	8	37	77	246.50
	75	61	30	44	16	63	126	384.75

Table 50:Primary Delay

Primary Delay	Patients (N)	Percent (%)
1 Week (1- 7 days)	286	13.8
2 Weeks (8-14 days)	353	17.0
3 Weeks (15-21 days)	191	9.2
4 Weeks (22-28 days)	113	5.4
>4 Weeks (>28 days)	1133	54.6
Total	**2076**	**100.0**

Table 51: Significant Primary Delay

Primary Delay	Patients (N)	Percent (%)
Acceptable Delay (≤ 28 days)	943	45.4
Significant Delay (> 28 days)	1133	54.6
Total	**2076**	**100.0**

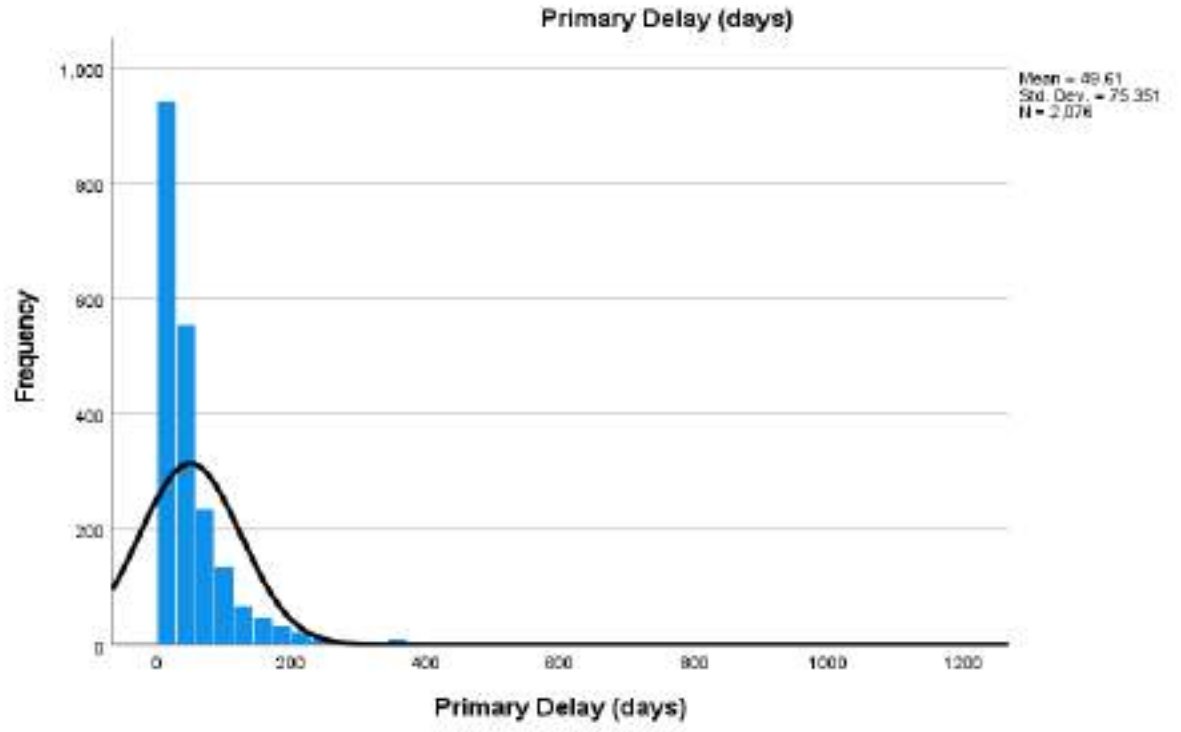


Figure 28: Primary Delays

Table 52:Reason for Primary delay:

S.No	Reason for Primary delay (as given by the patient)	Frequency (in %)
1.	I was not aware	48.6
2.	I didn't have knowledge or information	18.2
3.	I thought that symptoms will resolve spontaneously	17.8
4	Financial reasons	15.6
5	I didn't have time	1.7
6	There was a family problem during that time	0.9
7	There was no one to take me to the hospital	0.6
8	The hospital was far from home	0.4
9	Other reasons	3.1

The most common reason given by the patient for the primary delay was that they were not aware of the symptoms (48.6%). There was no significant difference in the primary delays between the cancer sites but there was a **significant difference in primary delays based on the cancer stages (higher the stage, longer the primary delay, in stage 3 and 4 cancers**).

There was no difference between rural or urban patients but Christian patients tended to have longer primary delays. **When the primary care giver was a relative other than the immediate family member, the delay was higher. Married people had more acceptable primary delays than widowed or single patients but the type of family did not affect primary delays**.

When tested linearly only BMI showed a significant correlation with primary delay (P value: 0.03, negative correlation: -0.05, 95% CI: -0.1 to -0.01).

Table 53: Primary Delay Vs. Patient Demographics

Patient Demographics		Primary Delay			Pearson Chi-square P Value
		Acceptable Delay	Significant Delay	Total	
Cancer Site	**GI Cancers**	428	493	921	0.21 (NS)
	Head & Neck Cancers	377	499	876	
	Lung Cancers	137	139	276	
	Not Known	1	2	3	
Cancer Site	**Anal Canal**	8	13	21	0.21 (NS)
	Appendix	3	3	6	
	Bile ducts	2	5	7	
	Colon	54	78	132	
	Esophagus	96	110	206	
	Gall bladder	14	7	21	
	Liver	15	8	23	
	Pancreas	16	18	34	
	Rectum	119	118	237	
	Small Intestine	4	3	7	
	Stomach	97	130	227	
	Oral	301	409	710	
	Pharynx/Larynx	76	90	166	
	Lung	137	139	276	
	Not Known	1	2	3	
Cancer Stage	**1**	27	27	54	**0.04**
	2	240	231	471	
	3	**495**	**648**	**1143**	
	4	**181**	**227**	**408**	
Gender	**Female**	330	378	708	0.43 (NS)
	Male	613	755	1368	
	Rural	461	557	1018	0.8 (NS)

Place of residence	**Tribal**	3	2	5	
	Urban	479	574	1053	
Religion	**Christian**	54	104	158	0.11
	Hindu	839	976	1815	
	Muslim	50	53	103	
Socioeconomic Status (BG Prasad 2023 Scale)	**I Upper Class**	62	96	158	0.28 (NS)
	II Upper Middle Class	162	192	354	
	III Middle Class	191	254	445	
	IV Lower Middle Class	343	379	722	
	V Lower Class	185	212	397	
BMI Groups (Asian Classification)	**1.Underweight**	187	269	456	0.15 (NS)
	2.Normal	392	476	868	
	3.Overweight	142	165	307	
	4.Obese 1	167	167	334	
	5.Obese 2	55	56	111	
Age Groups	**Children**	4	3	7	0.7 (NS)
	Elderly	369	442	811	
	Middle Age	150	175	325	
	Old Adults	398	495	893	
	Young Adults	22	18	40	
Relationship of primary care giver	**Husband**	140	127	267	**0.01**
	Wife	433	526	959	
	Father	19	15	34	
	Mother	20	28	48	
	Daughter	111	145	256	
	Son	147	179	326	
	Grandparent	6	0	6	
	Other Relative	**65**	**108**	**173**	
	Not known	2	5	7	
Marital status	**Never Married**	19	24	43	**0.02**
	Un Married	1	0	1	

	Married	838	975	1813	
	Divorced	5	0	5	
	Separated	**7**	**15**	**22**	
	Widow (er)	**73**	**119**	**192**	
Type of Family	**Single**	2	4	6	0.55 (NS)
	Nuclear	751	878	1629	
	Extended	78	95	173	
	Joint	112	156	268	
Patient's Educational Status	**Illiterate**	256	346	602	0.24 (NS)
	Primary school	211	261	472	
	Middle school	166	192	358	
	High school	151	155	306	
	Higher secondary	73	71	144	
	Graduate	74	84	158	
	Professional degree	12	24	36	
Highest education of relatives	**Illiterate**	73	72	145	0.12 (NS)
	High school	136	168	304	
	Middle school	131	144	275	
	Primary school	104	103	207	
	Higher secondary	138	147	285	
	Graduate	303	406	709	
	Professional degree	58	93	151	
Total		943	1133	2076	

Table 52a: Primary Delay Vs. Patient Demographics

Primary Delay:	**Age (years)**	**BMI**	**Total members**	**Total family monthly income (Rs)**	**Per Capita Monthly Income (Rs/ Person)**	**QOL EORTC QLQC30Total Score**

Acceptable Delay	**Mean**	56.48	22.25	4.00	14204.24	3851.25	60.44
	Median	57.00	21.64	4.00	10000.00	2500.00	64.00
	SD	12.27	4.79	1.73	18920.79	4924.72	10.84
Significant Delay	**Mean**	56.66	21.79	4.03	15531.60	4209.64	60.30
	Median	57.00	21.14	4.00	10000.00	2500.00	63.00
	SD	11.82	4.74	1.80	24530.13	6049.90	11.12
Total	**Mean**	56.58	22.00	4.01	14928.66	4046.85	60.36
	Median	57.00	21.40	4.00	10000.00	2500.00	63.00
	SD	12.02	4.77	1.77	22163.62	5568.63	10.99

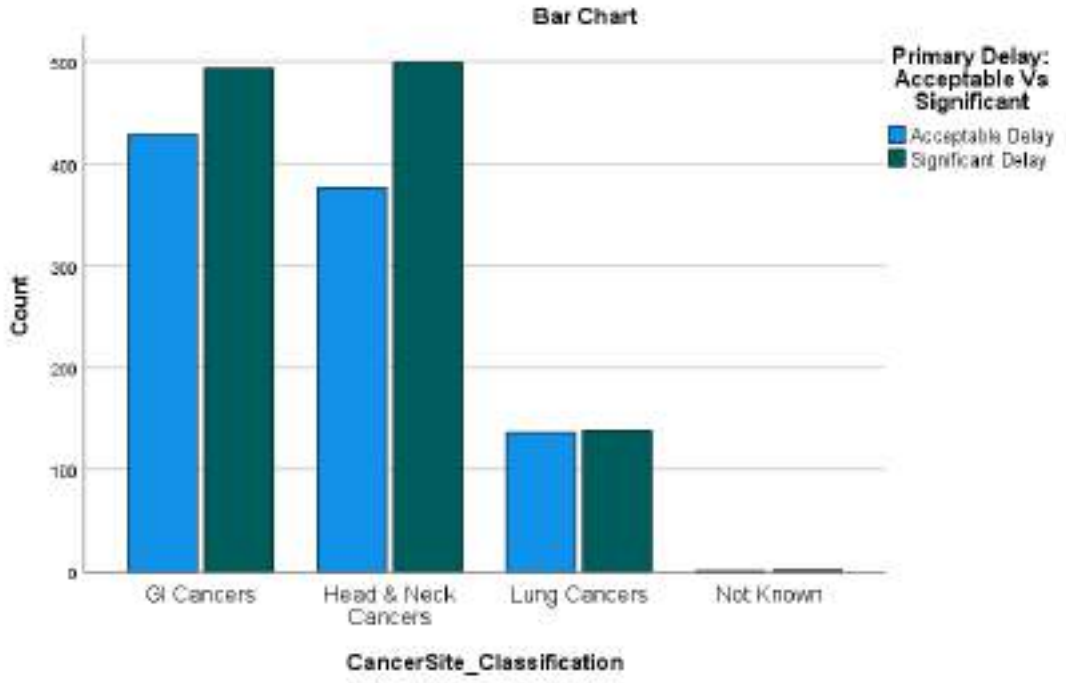


Figure 29: Primary Delay Vs Cancer Site

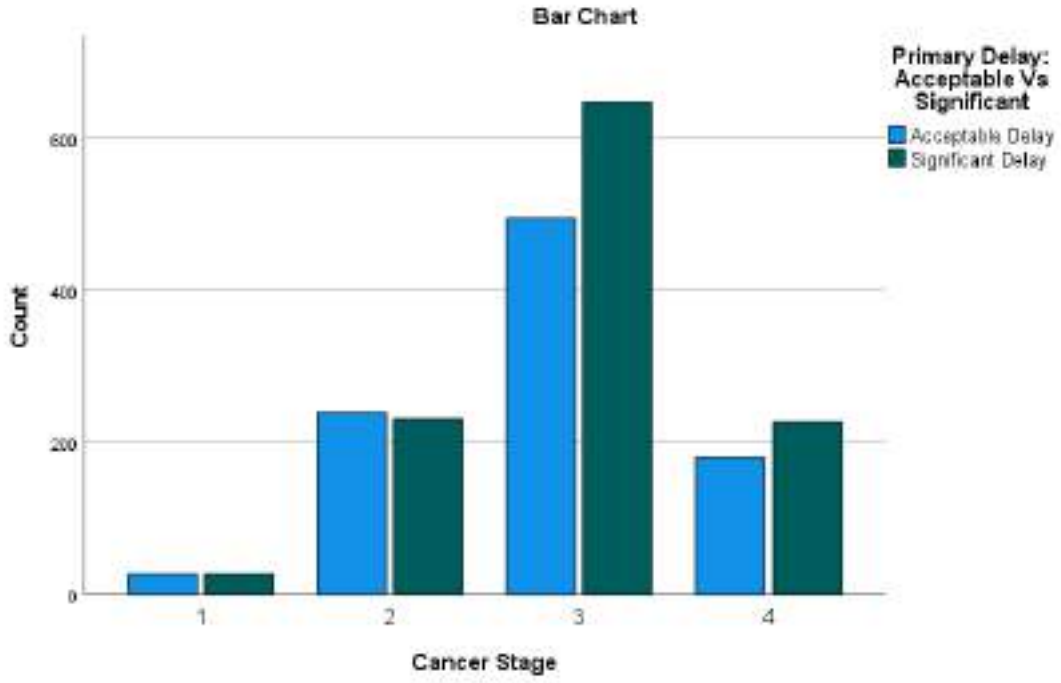


Figure 30: Primary Delay Vs Cancer Stage

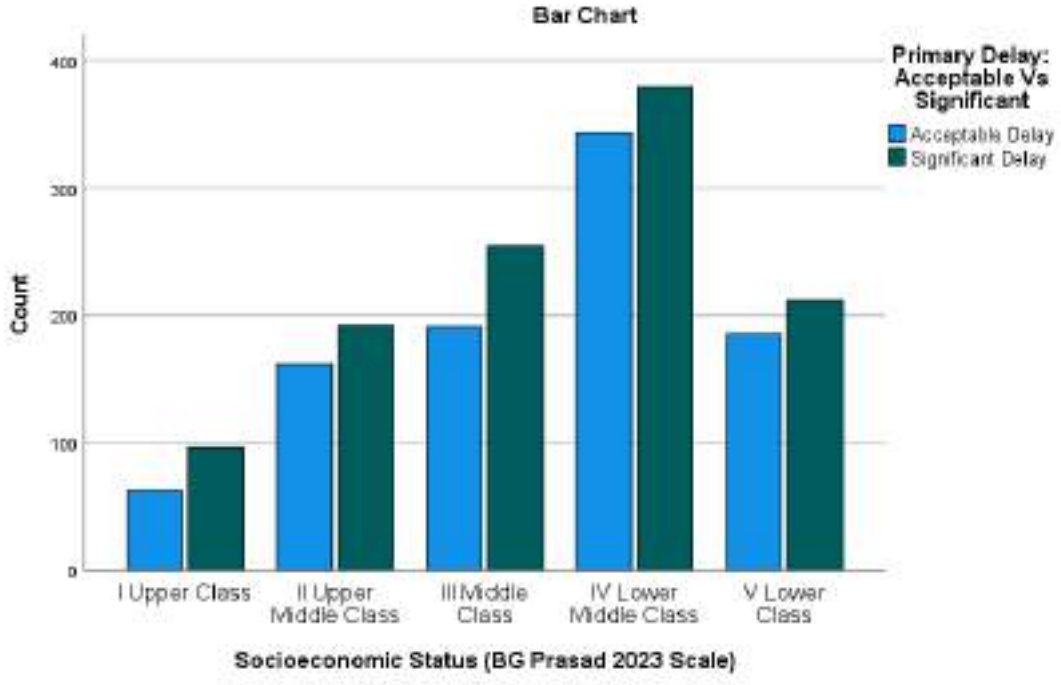


Figure 31: Primary Delay Vs SES

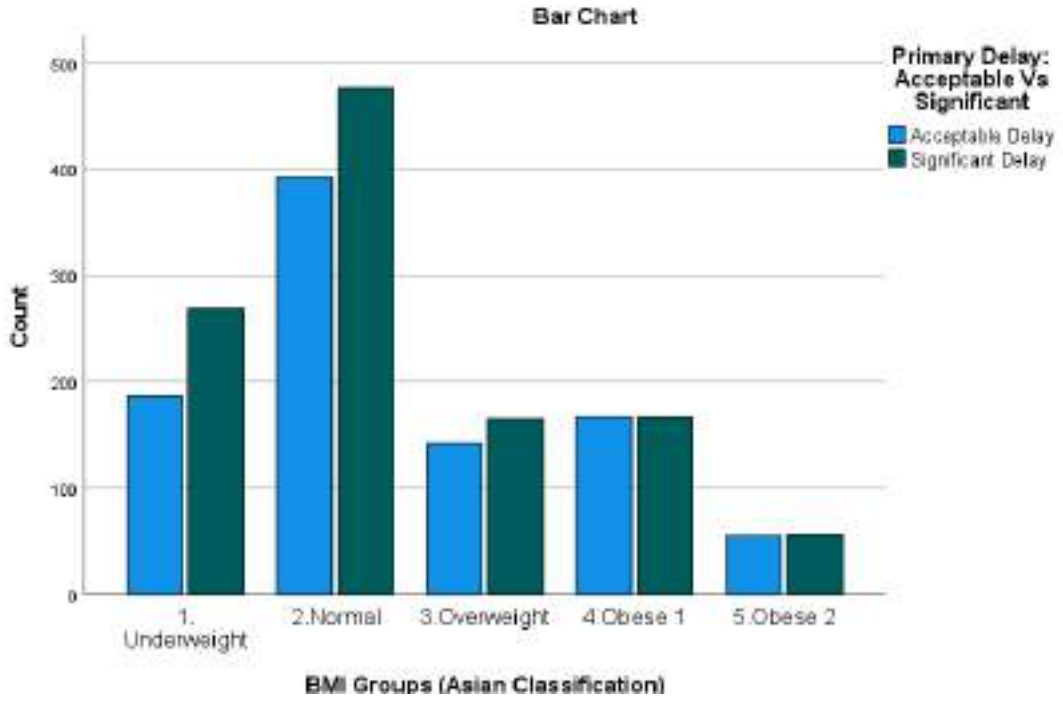


Figure 32:Primary Delay Vs BMI

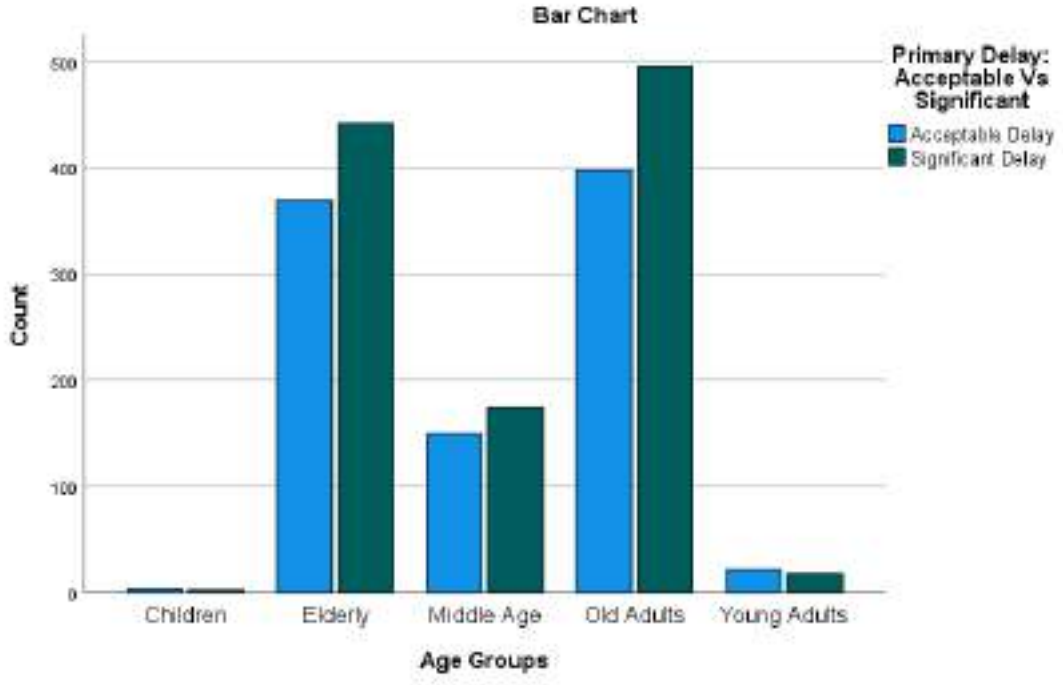


Figure 33:Primary Delay Vs Age

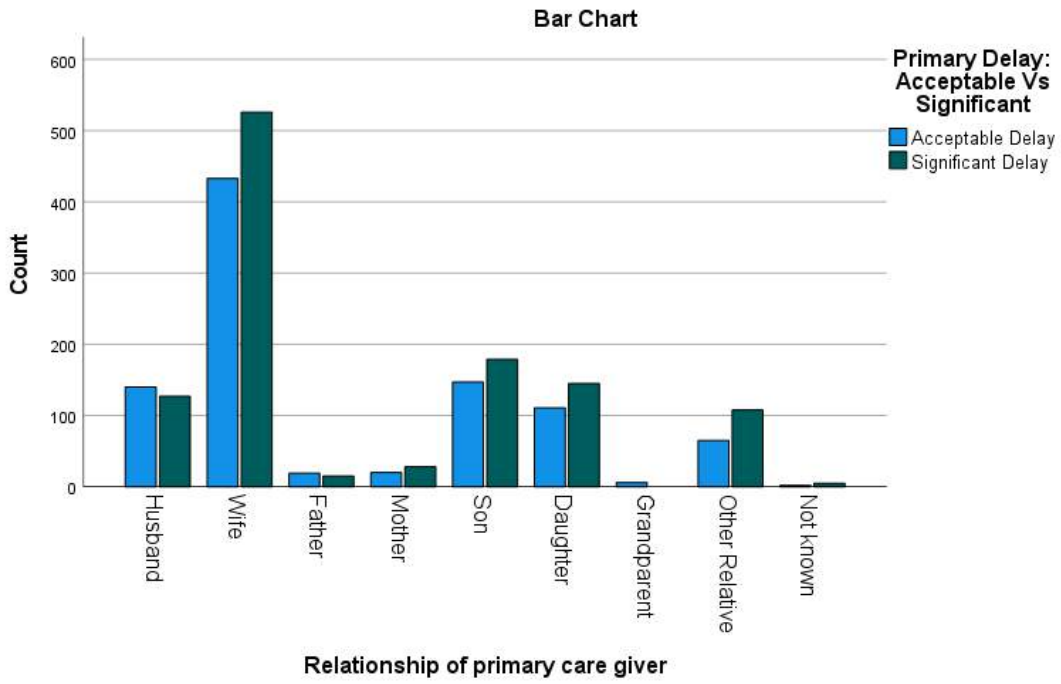


Figure 34:Primary Delay Vs Primary Care Giver

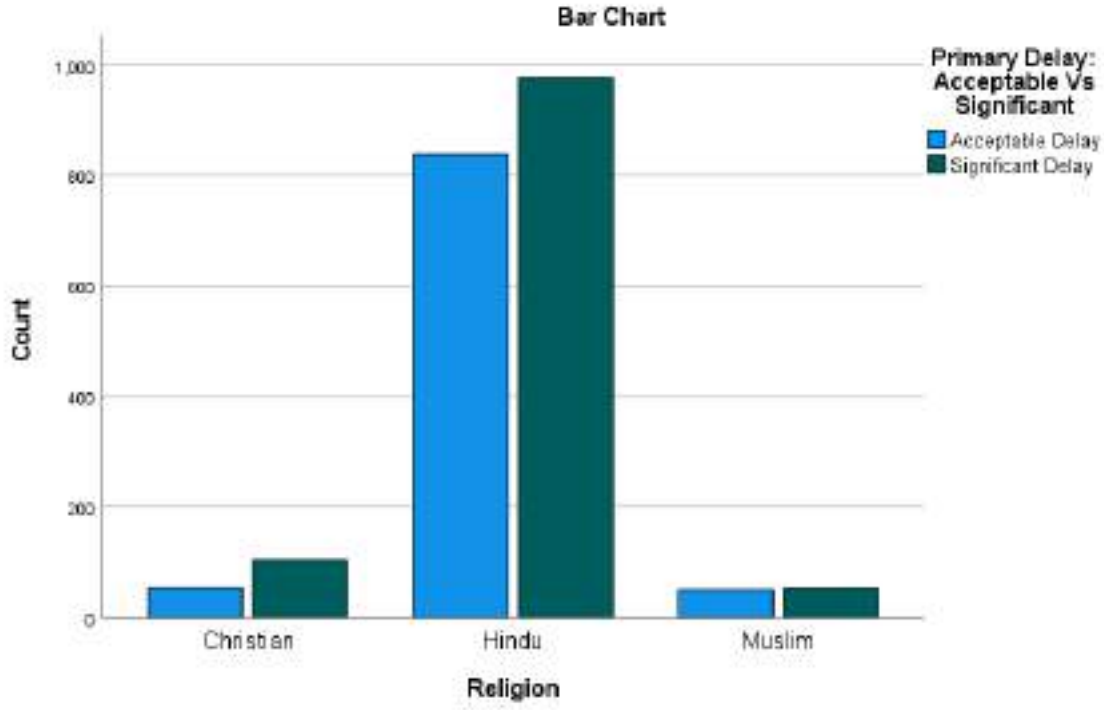


Figure 35:Primary Delay Vs Religion

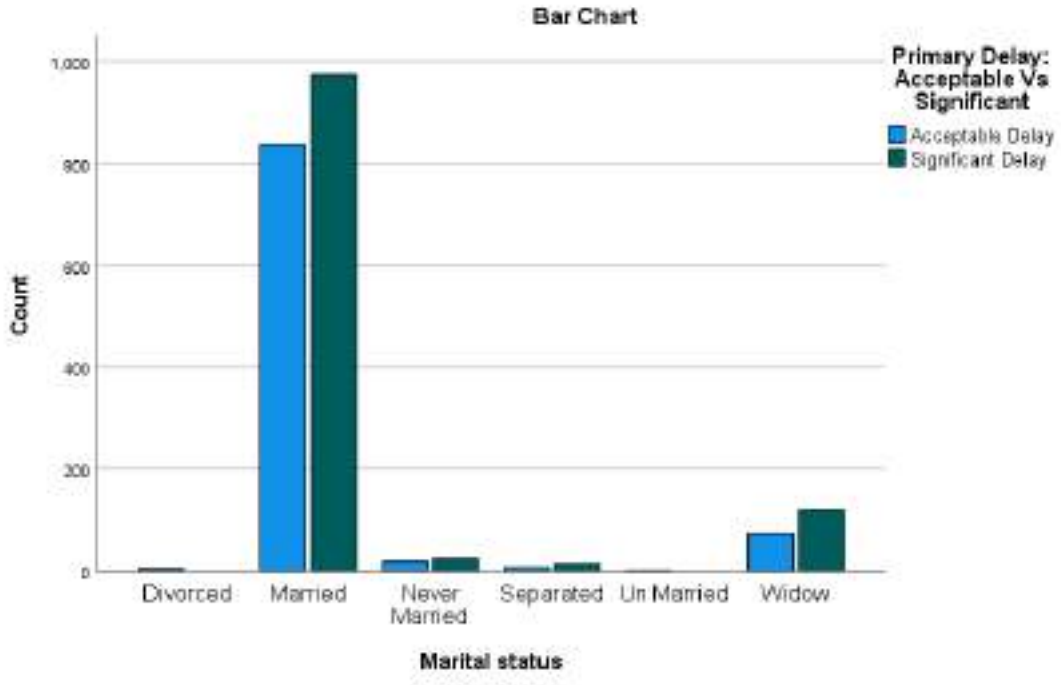


Figure 36: Primary Delay Vs Marital Status

Table 54:Primary Delay Vs. Distance from Health Facilities

Distance from Health Facilities		**Primary Delay**		**Total**	**Pearson Chi-square P Value**
		Acceptable Delay	**Significant Delay**		
Nearest GP/PHC	**1-10 Km**	874	1062	1936	0.23 (NS)
	11-20 Km	56	62	118	
	21-30 Km	8	4	12	
	31-40 Km	1	3	4	
	41-50 Km	1	2	3	
	>50 Km	3	0	3	
Nearest Speciality Hospital	**1-10 Km**	495	589	1084	0.06 (NS)
	11-20 Km	293	332	625	
	21-30 Km	110	133	243	
	31-40 Km	32	46	78	
	41-50 Km	4	22	26	

	51-75 Km	9	11	20	
Nearest Cancer Centre	**1-10 Km**	148	175	323	0.42 (NS)
	11-20 Km	200	243	443	
	21-30 Km	148	173	321	
	31-40 Km	87	122	209	
	41-50 Km	122	155	277	
	51-75 Km	181	220	401	
	76 -100 Km	57	45	102	
Current Treating Hospital	**1-10 Km**	107	124	231	0.15 (NS)
	11-20 Km	176	207	383	
	21-30 Km	136	166	302	
	31-40 Km	80	125	205	
	41-50 Km	121	146	267	
	51-75 Km	181	228	409	
	76 -100 Km	78	68	146	
	101-150 Km	34	44	78	
	151-200 Km	12	17	29	
	201-300 Km	10	2	12	
	301-400 Km	6	4	10	
	401-500 Km	2	1	3	
	> 500 Kms	0	1	1	
Total		**943**	**1133**	**2076**	

Table 55: Primary Delay Vs. Distance from Healthcare Facilities

Primary Delay:		**Nearest GP/PHC from home (in Km)**	**Nearest Speciality Govt/Private Hospital (in Km)**	**Nearest Cancer Centre (in Km)**	**Distance between home and current treating hospital (in km)**
Acceptable Delay	**Mean**	4.40	12.63	34.16	47.15
	Median	3.00	10.00	28.00	35.00

	SD	4.64	8.90	22.97	48.32
Significant Delay	**Mean**	4.31	13.38	33.43	44.11
	Median	3.00	10.00	28.00	35.00
	SD	3.71	9.92	21.60	41.05
Total	**Mean**	4.35	13.04	33.76	45.49
	Median	3.00	10.00	28.00	35.00
	SD	4.16	9.48	22.23	44.51

The distance from the patients' home and the nearest health care facility or speciality hospital or cancer centre or the current treating hospital did not lead to any significant difference in primary delays. However, **patients living in certain districts (Ariyalur, Chennai, Erode, Kanyakumari, Karur, Nagapattinam, Perambalur, Pudukottai, Thanjavur, Thirunelveli, Thiruvarur, Thiruvannamalai and Trichy) had significantly high primary delays**. Whereas, patients from districts like Chengalpattu, Coimbatore, Dharmapuri,Madurai, Namakkal, Sivagangai, Theni, and Vellore did not have much primary delays.

Table 56: Primary Delay Vs. Home District

District	**Primary Delay**		**Total**	**Pearson Chi-square P Value**
	Acceptable Delay	**Significant Delay**		
Ariyalur	9	19	28	**<0.001**
Chengalpattu	9	6	15	
Chennai	89	128	217	
Coimbatore	94	65	159	
Cuddalore	18	21	39	
Dharmapuri	8	5	13	
Dindigul	20	25	45	
Erode	44	63	107	
Kallakurichi	2	1	3	
Kancheepuram	13	15	28	
Kanniyakumari	34	71	105	
Karur	11	20	31	

Krishnagiri	7	8	15	
Madurai	69	47	116	
Mayiladuthurai	6	10	16	
Nagapattinam	8	19	27	
Namakkal	36	33	69	
Perambalur	3	12	15	
Pudukottai	19	31	50	
Ramanathapuram	14	17	31	
Ranipet	6	8	14	
Salem	30	34	64	
Sivagangai	24	19	43	
Tenkasi	7	9	16	
Thanjavur	43	71	114	
The Nilgiris	8	7	15	
Theni	25	15	40	
Thirunelveli	31	42	73	
Thiruvallur	26	26	52	
Thiruvarur	15	25	40	
Thoothukudi	15	15	30	
Tirupathur	5	7	12	
Tiruppur	39	40	79	
Tiruvannamalai	14	25	39	
Trichirappalli	38	103	141	
Vellore	58	23	81	
Viluppuram	14	15	29	
Virudhunagar	32	33	65	
Total	**943**	**1133**	**2076**	

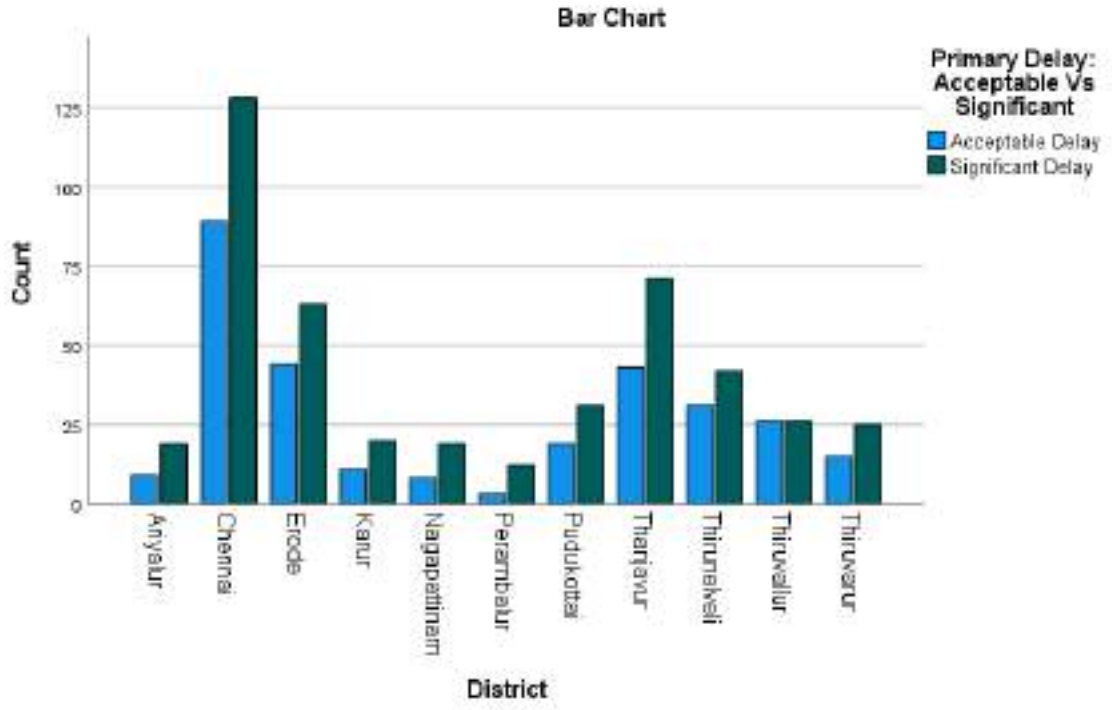


Figure 37:Primary Delay Vs. Home District

Similarly, patients presenting to a hospital in a different district than home district for cancer treatment had a significantly higher risk of having primary delays (RR:1.13, 95% CI: 1.03-1.25).

Table 57: Primary Delay Vs. District First Presented

District - First presented	Primary Delay		Total	Pearson Chi-square P Value	Relative Risk (95% Confidence Interval
	Acceptable Delay	Significant Delay			
Different district	137	209	346	**0.02**	**1.13 (1.03-1.25)**
Same district	806	924	1730		
Total	943	1133	2076		

The type of hospital where the patient presented did not affects the primary delays. However, when the patient's cancer was diagnosed in a **tertiary Government** hospital, the chance of having a significant primary delay was higher, when compared to a private hospital of smaller government hospitals (P=0.03) Also, **if the hospital where the cancer was diagnosed had an oncology department or specialist, the chance of primary delay was low**

(RR 1.17 (1.07-1.28) for absence of an oncologist and significant primary delay). The Number of doctors/hospitals visited before start of cancer treatment, Number of hospitals visited for cancer treatment or Total Number of doctors/ hospitals visited were not different when there was a significant primary delay.

Table 58:Primary Delay Vs. Hospital where cancer was diagnosed

Hospital where cancer was diagnosed had an oncology department/ specialist	Primary Delay		Total	Pearson Chi-square P Value	Relative Risk (95% Confidence Interval
	Acceptable Delay	Significant Delay			
Yes	772	859	1631	**<0.001**	**1.17 (1.07-1.28)**
No	171	274	445		
Total	**943**	**1133**	**2076**		

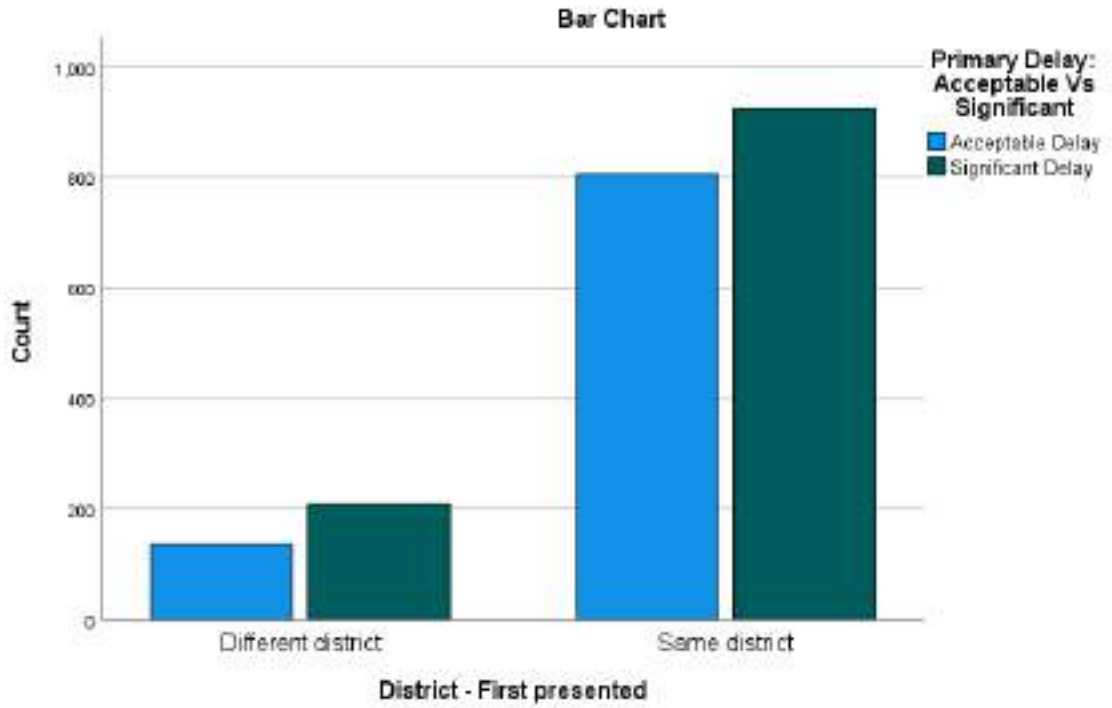


Figure 38:Primary Delay Vs. District First Presented

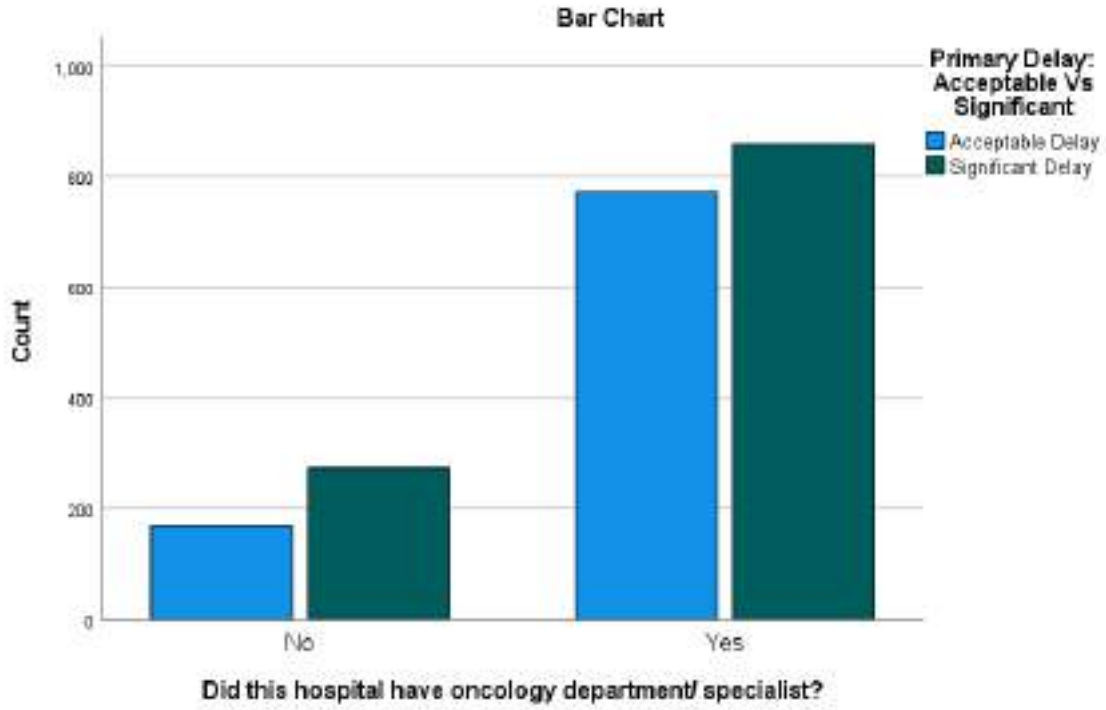


Figure 39:Primary Delay Vs. Presence of Oncologist

Table 59: Primary Delay Vs. Type of Hospital

Type of Hospital		**Primary Delay**			**Pearson Chi-square P Value**
		Acceptable Delay	**Significant Delay**	**Total**	
Type of Hospital cancer was diagnosed	**Alternative medicine**	0	1	1	**0.03**
	Govt. CHC/ Specialty Hospital	175	164	339	
	Govt. PHC	**15**	**33**	**48**	
	Govt. Tertiary Hospital	**193**	**268**	**461**	
	Private Clinic	1	2	3	
	Private Hospital	**559**	**665**	**1224**	
Type of Hospital presented with symptoms	**Alternative medicine**	0	2	2	0.06 (NS)
	Govt. CHC/ Specialty Hospital	135	142	277	
	Govt. PHC	67	69	136	

	Govt. Tertiary Hospital	107	167	274	
	Private Clinic	7	16	23	
	Private Hospital	627	737	1364	
	Govt. Tertiary Hospital	266	342	608	
	Private Hospital	499	623	1122	
Total		**943**	**1133**	**2076**	

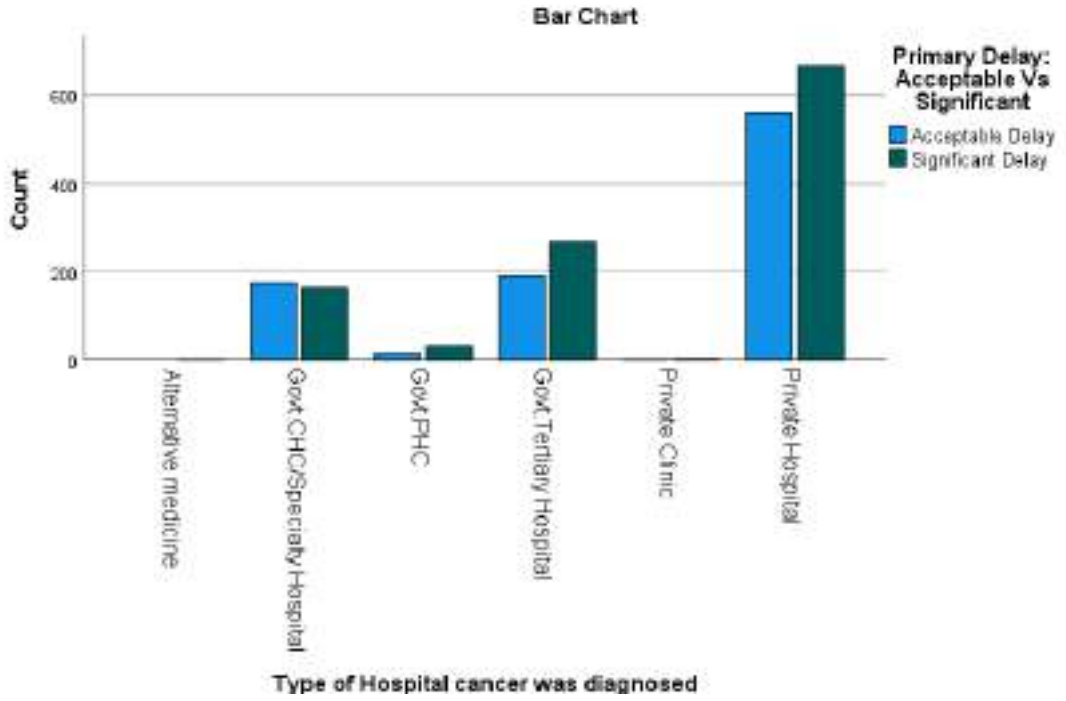


Figure 40: Primary Delay Vs. Type of Hospital cancer was diagnosed

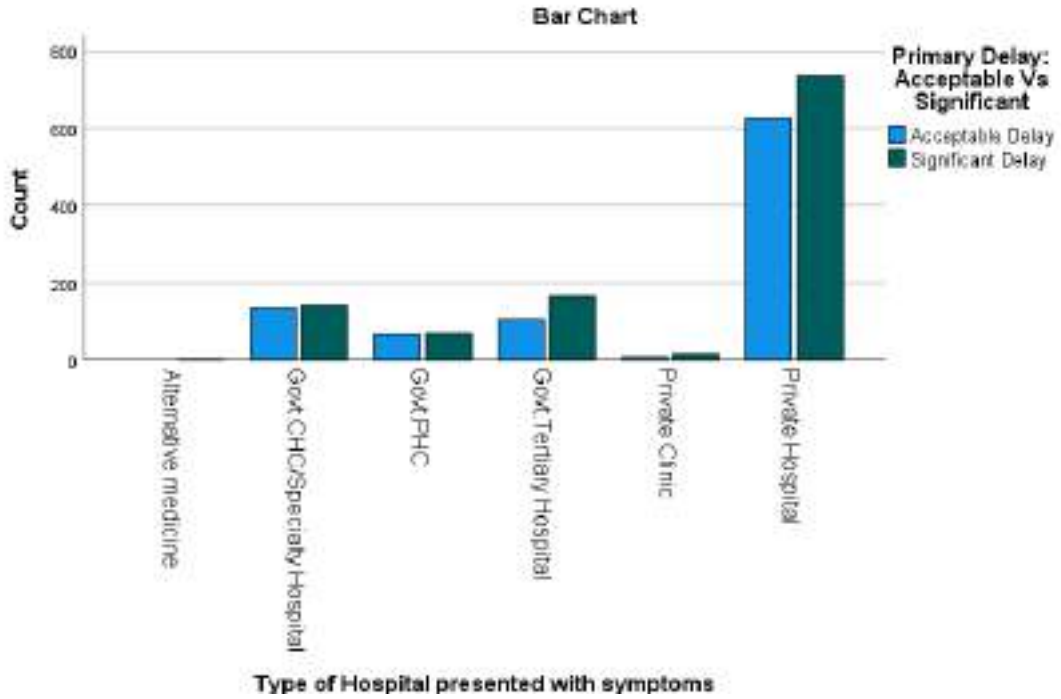


Figure 41: Primary Delay Vs. Type of Hospital presented with symptoms

Table 60: Primary Delay Vs. type of Hospital

Primary Delay:		**Number of doctors/ hospitals visited before start of cancer treatment**	**Number of hospitals visited for cancer treatment**	**Total Number of doctors/ hospitals visited**
Acceptable Delay	**Mean**	2.21	1.05	3.26
	Median	2.00	1.00	3.00
	SD	0.47	0.23	0.56
Significant Delay	**Mean**	2.24	1.07	3.30
	Median	2.00	1.00	3.00
	SD	0.48	0.27	0.59
Total	**Mean**	2.23	1.06	3.29
	Median	2.00	1.00	3.00
	SD	0.48	0.25	0.58

Referral Delay:

The mean **Referral Delay** was 25.83 ± 38.74 days ranging from 0 to 390 days (more than one year) with a median of 11 days (IQR: 4 to 30 days). This data was again non-parametric and skewed to the right. One hundred and fifty-six patients (7.5%) were referred to a higher centre on the same day of first presentation by their first healthcare contact and experienced no **Referral Delay**. **Significant referral delays (**more than 28 days or 4 weeks) from primary healthcare practitioners to a higher centre was seen only in 26.1% of patients.

Referral Delays were significantly higher in lung cancer patients but there was no difference in referral delays based on the cancer stage. None of the other socioeconomic factors studied affected the referral delay significantly.

Table 61:Referral Delay

Referral Delay	**Patients (N)**	**Percent (%)**
No Delay (0 days)	156	7.5
1 Week (1- 7 days)	616	29.7
2 Weeks (8-14 days)	393	18.9
3 Weeks (15-21 days)	215	10.4
4 Weeks (22-28 days)	154	7.4
>4 Weeks (>28 days)	542	26.1
Total	**2076**	**100.0**

Table 62: Significant Referral Delay

Referral Delay	**Patients (N)**	**Percent (%)**
Acceptable Delay (≤ 28 days)	1534	73.9
Significant Delay (> 28 days)	542	26.1
Total	**2076**	**100.0**

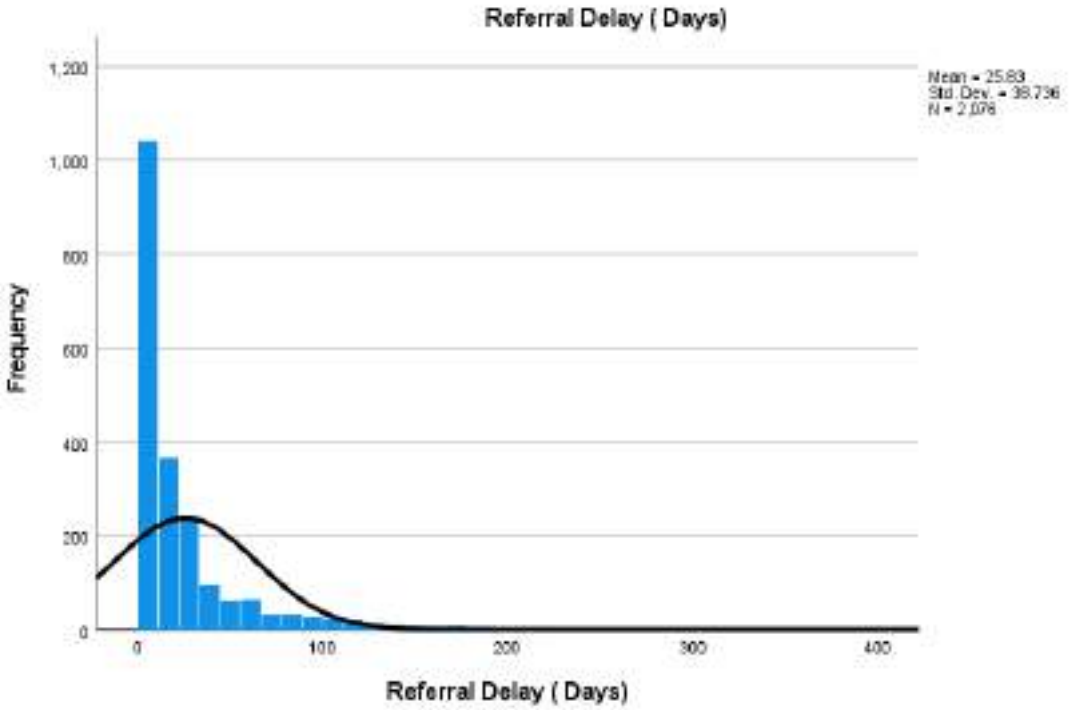


Figure 42:Referral Delay

Table 63: Referral Delay Vs. Patient Demographics

Patient Demographics		**Referral Delay**			**Pearson Chi-square P Value**
		Acceptable Delay	**Significant Delay**	**Total**	
Cancer Site	**GI Cancers**	670	251	921	0.21 (NS)
	Head & Neck Cancers	675	201	876	
	Lung Cancers	187	89	276	
	Not Known	2	1	3	
Cancer Site	**Anal Canal**	13	8	21	0.07 (NS)
	Appendix	3	3	6	
	Bile ducts	7	0	7	
	Colon	97	35	132	
	Esophagus	153	53	206	
	Gall bladder	16	5	21	
	Liver	19	4	23	

	Pancreas	28	6	34	
	Rectum	169	68	237	
	Small Intestine	4	3	7	
	Stomach	161	66	227	
	Oral	553	157	710	
	Pharynx/Larynx	122	44	166	
	Lung	187	89	276	
	Not Known	2	1	3	
Cancer Stage	**1**	43	11	54	0.5 (NS)
	2	356	115	471	
	3	832	311	1143	
	4	303	105	408	
Gender	**Female**	514	194	708	0.33 (NS)
	Male	1020	348	1368	
Place of residence	**Rural**	748	270	1018	0.88 (NS)
	Tribal	4	1	5	
	Urban	782	271	1053	
Religion	**Christian**	119	39	158	0.6 (NS)
	Hindu	1343	472	1815	
	Muslim	72	31	103	
Socioeconomic Status (BG Prasad 2023 Scale)	**I Upper Class**	131	27	158	0.08 (NS)
	II Upper Middle Class	259	95	354	
	III Middle Class	319	126	445	
	IV Lower Middle Class	528	194	722	
	V Lower Class	297	100	397	
BMI Groups (Asian Classification)	**1.Underweight**	332	124	456	0.75 (NS)
	2.Normal	648	220	868	
	3.Overweight	233	74	307	
	4.Obese 1	240	94	334	
	5.Obese 2	81	30	111	
Age Groups	**Children**	6	1	7	0.95 (NS)

	Elderly	596	215	811	
	Middle Age	243	82	325	
	Old Adults	660	233	893	
	Young Adults	29	11	40	
Relationship of primary care giver	**Husband**	199	68	267	0.65 (NS)
	Wife	703	256	959	
	Father	27	7	34	
	Mother	33	15	48	
	Son	239	87	326	
	Daughter	197	59	256	
	Grandparent	6	0	6	
	Other Relative	126	47	173	
	Not known	4	3	7	
Marital status	**Never Married**	30	13	43	0.67 (NS)
	Un Married	1	0	1	
	Married	1350	463	1813	
	Divorced	3	2	5	
	Separated	15	7	22	
	Widow (er)	135	57	192	
Type of Family	**Single**	3	3	6	0.46 (NS)
	Nuclear	1208	421	1629	
	Extended	123	50	173	
	Joint	200	68	268	
Patient's Educational Status	**Illiterate**	439	163	602	0.87 (NS)
	Primary school	349	123	472	
	Middle school	272	86	358	
	High school	221	85	306	
	Higher secondary	107	37	144	
	Graduate	121	37	158	
	Professional degree	25	11	36	
	Illiterate	99	46	145	0.73 (NS)

Highest education of relatives	**High school**	153	54	207	
	Middle school	205	70	275	
	Primary school	228	76	304	
	Higher secondary	205	80	285	
	Graduate	531	178	709	
	Professional degree	113	38	151	
Total		**1534**	**542**	**2076**	

Table 64:Referral Delay Vs. Patient Demographics

Referral Delay		**Age (years)**	**BMI**	**Total members**	**Total family monthly income (Rs)**	**Per Capita Monthly Income (Rs/Person)**	**EORTCQLQC30_Total_Score**
Acceptable Delay	**Mean**	56.62	21.98	4.01	15451.56	4166.94	60.36
	Median	57.00	21.38	4.00	10000.00	2500.00	64.00
	SD	12.14	4.75	1.78	24429.44	5953.75	10.99
Significant Delay	**Mean**	56.46	22.05	4.01	13448.71	3706.94	60.39
	Median	57.00	21.45	4.00	10000.00	2500.00	63.00
	SD	11.70	4.83	1.73	13784.50	4282.04	11.00
Total	**Mean**	56.58	22.00	4.01	14928.66	4046.85	60.36
	Median	57.00	21.40	4.00	10000.00	2500.00	63.00
	SD	12.02	4.77	1.77	22163.62	5568.63	10.99

Referral delay also **did not vary significantly between the districts**, did not vary depending on whether the patient presented to a hospital within the same district or not, whether the hospital had an oncology department or not, or the type of hospital where the patient presented, was diagnosed or treated.

Table 65: Referral Delay Vs. Home District

District	Referral Delay		Total	Pearson Chi-square P Value
	Acceptable Delay	Significant Delay		
Ariyalur	19	9	28	0.49
Chengalpattu	10	5	15	
Chennai	157	60	217	
Coimbatore	121	38	159	
Cuddalore	29	10	39	
Dharmapuri	7	6	13	
Dindigul	33	12	45	
Erode	77	30	107	
Kallakurichi	1	2	3	
Kancheepuram	22	6	28	
Kanniyakumari	75	30	105	
Karur	24	7	31	
Krishnagiri	13	2	15	
Madurai	81	35	116	
Mayiladuthurai	16	0	16	
Nagapattinam	22	5	27	
Namakkal	56	13	69	
Perambalur	11	4	15	
Pudukottai	38	12	50	
Ramanathapuram	25	6	31	
Ranipet	10	4	14	
Salem	51	13	64	
Sivagangai	32	11	43	
Tenkasi	10	6	16	
Thanjavur	93	21	114	
The Nilgiris	8	7	15	
Theni	30	10	40	
Thirunelveli	51	22	73	

Thiruvallur	39	13	52	
Thiruvarur	33	7	40	
Thoothukudi	24	6	30	
Tirupathur	6	6	12	
Tiruppur	55	24	79	
Tiruvannamalai	29	10	39	
Trichirappalli	100	41	141	
Vellore	59	22	81	
Viluppuram	21	8	29	
Virudhunagar	46	19	65	
Total	1534	542	2076	

Table 66: Referral Delay Vs. District - First presented

District - First presented	**Referral Delay**		**Total**	**Pearson Chi-square P Value**	**Relative Risk (95% Confidence Interval**
	Acceptable Delay	**Significant Delay**			
Different district	252	94	346	0.62	1.05 (0.81-1.27)
Same district	1282	448	1730		
Total	1534	542	2076		

However, **significant referral delays were associated with a higher number of doctors/hospitals visited before start of cancer treatment (P<0.001), Number of hospitals visited for cancer treatment (P<0.001), and Total Number of doctors/ hospitals visited (P<0.001).**

Table 67:Referral Delay Vs No. of Hospitals

Referral Delay		Number of doctors/hospitals visited before start of cancer treatment	Number of hospitals visited for cancer treatment	Total Number of doctors/ hospitals visited
Acceptable Delay	**Mean**	2.10	1.04	3.15
	Median	2.00	1.00	3.00
	SD	0.36	0.21	0.45
Significant Delay	**Mean**	2.57	1.11	3.68
	Median	3.00	1.00	4.00
	SD	0.59	0.34	0.71
Total	**Mean**	2.23	1.06	3.29
	Median	2.00	1.00	3.00
	SD	0.48	0.25	0.58
P value		**<0.001**	**<0.001**	**<0.001**

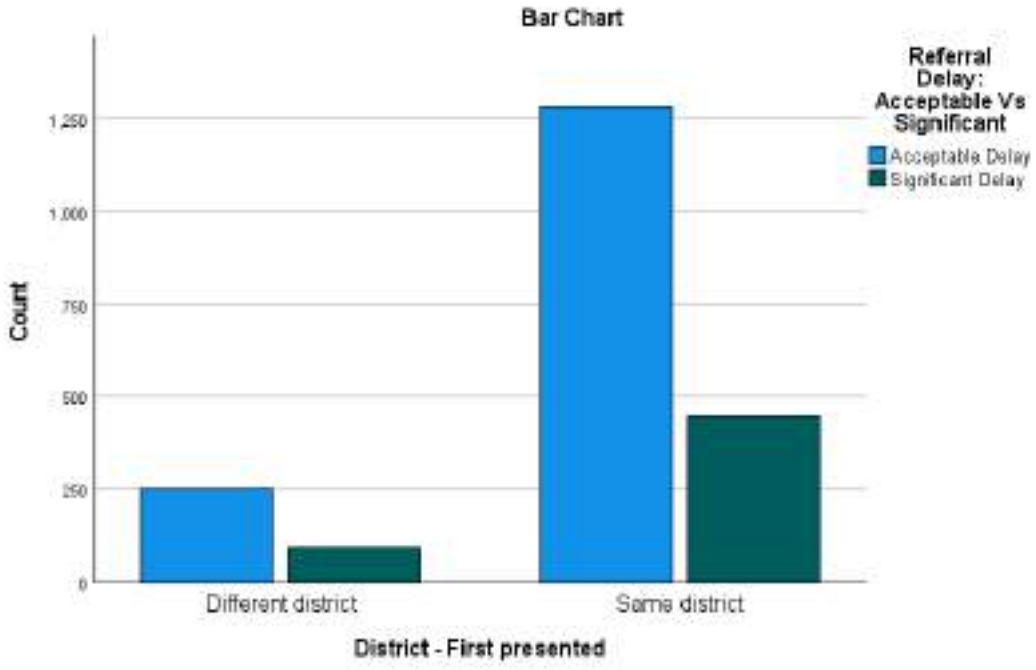


Figure 43:Referral Delay Vs. District - First presented

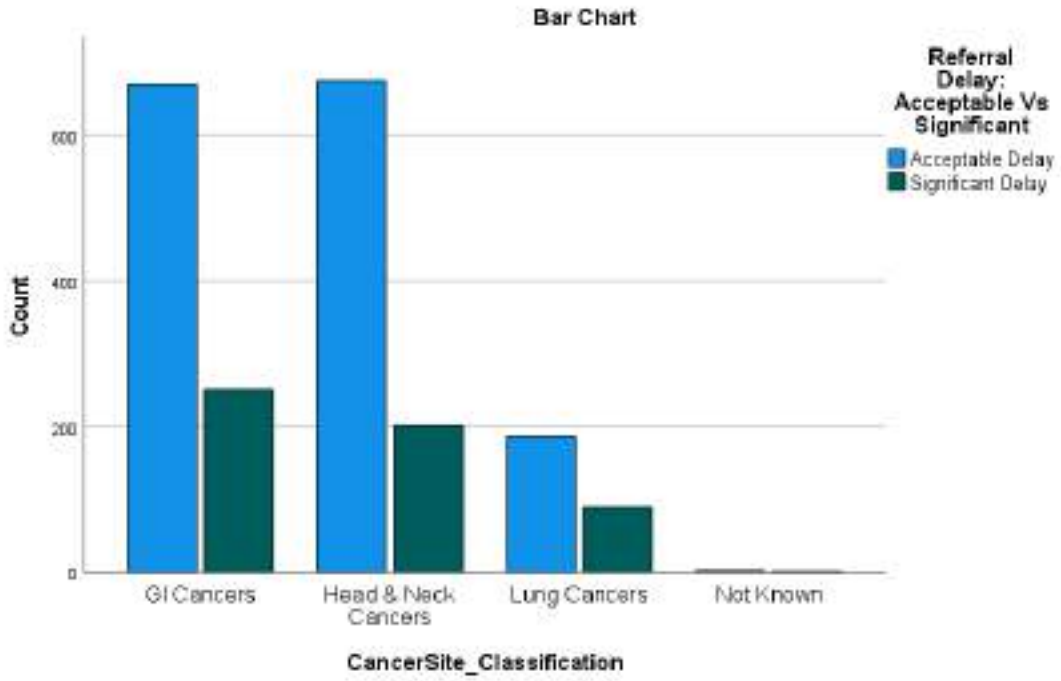


Figure 44:Referral Delay Vs. Cancer Site

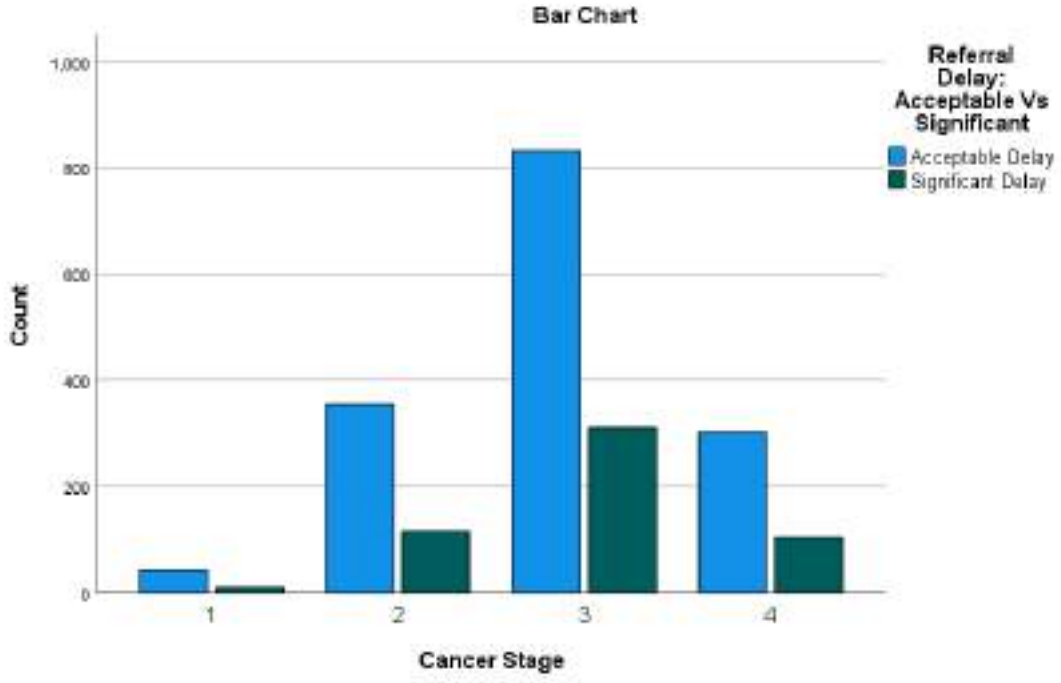


Figure 45:Referral Delay Vs. Cancer Stage

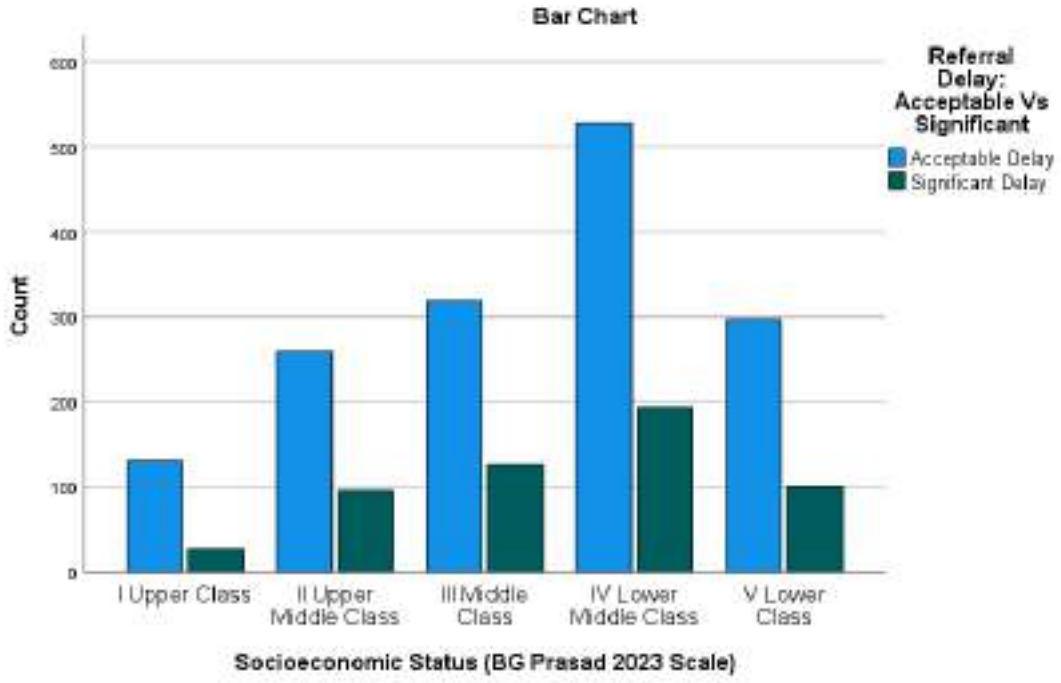


Figure 46:Referral Delay Vs. SES

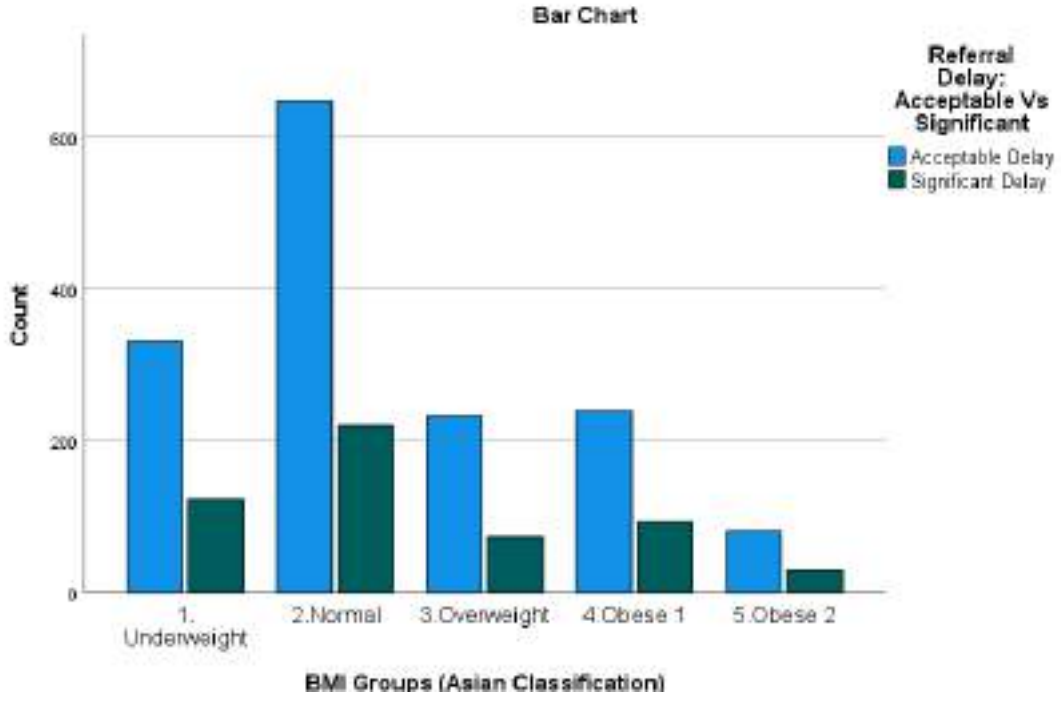


Figure 47:Referral Delay Vs. Cancer Site Vs SES

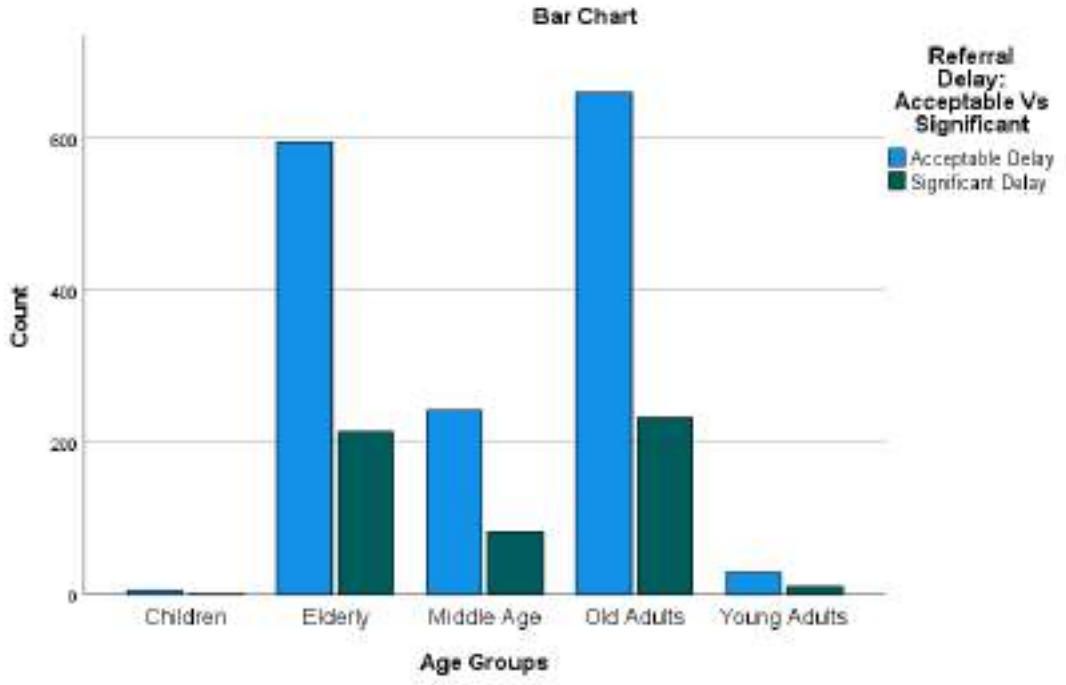


Figure 48:Referral Delay Vs. Cancer Site Vs. Age

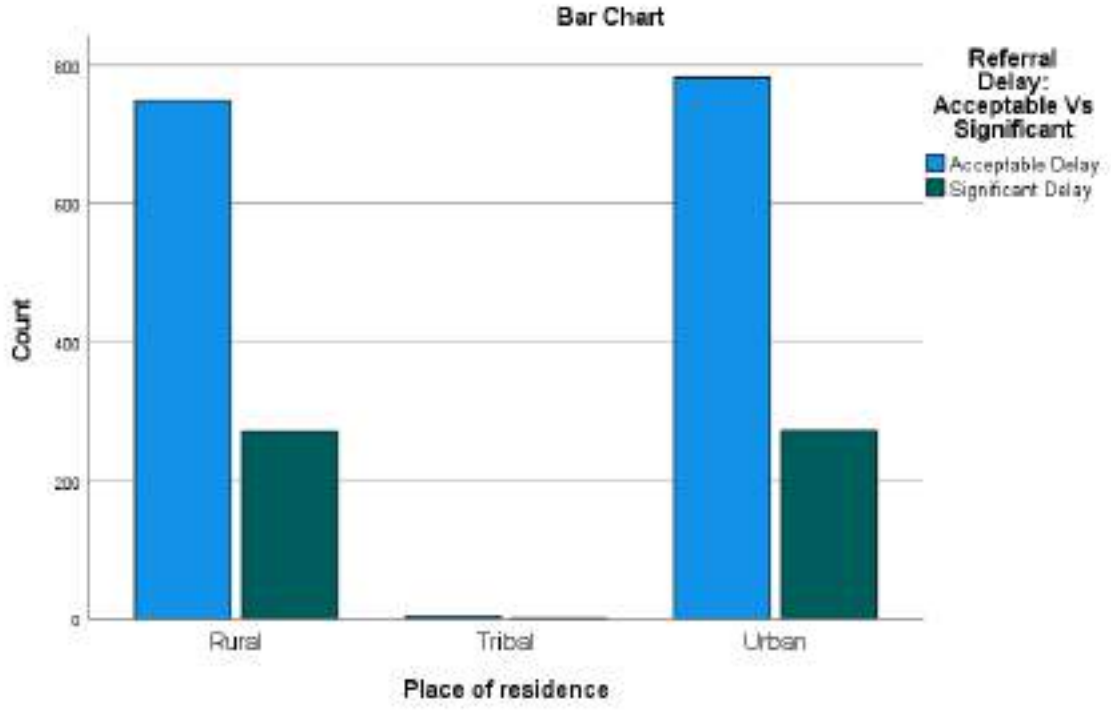


Figure 49:Referral Delay Vs. Place of Residence

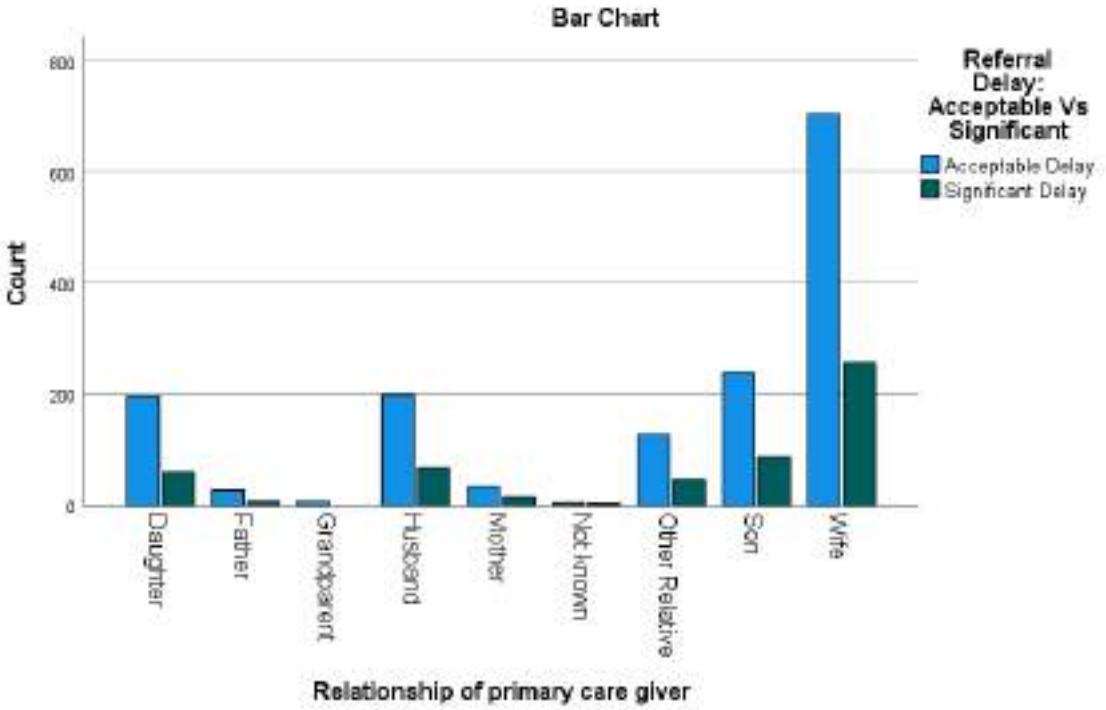


Figure 50:Referral Delay Vs. Primary Care giver

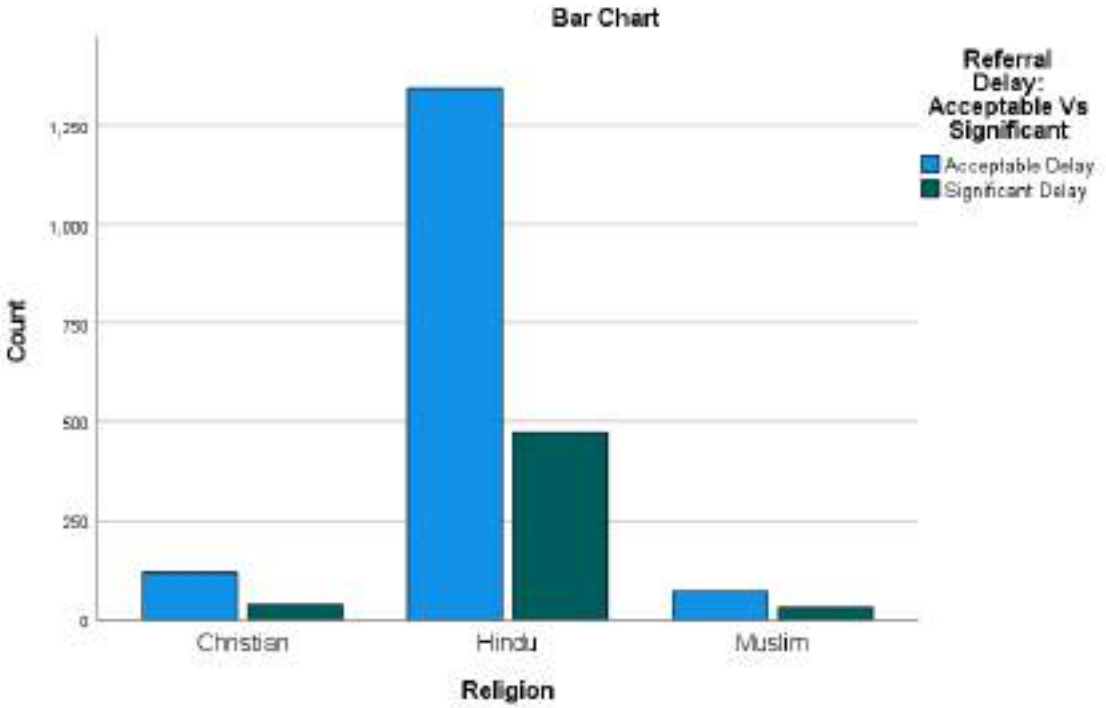


Figure 51:Referral Delay Vs. Religion

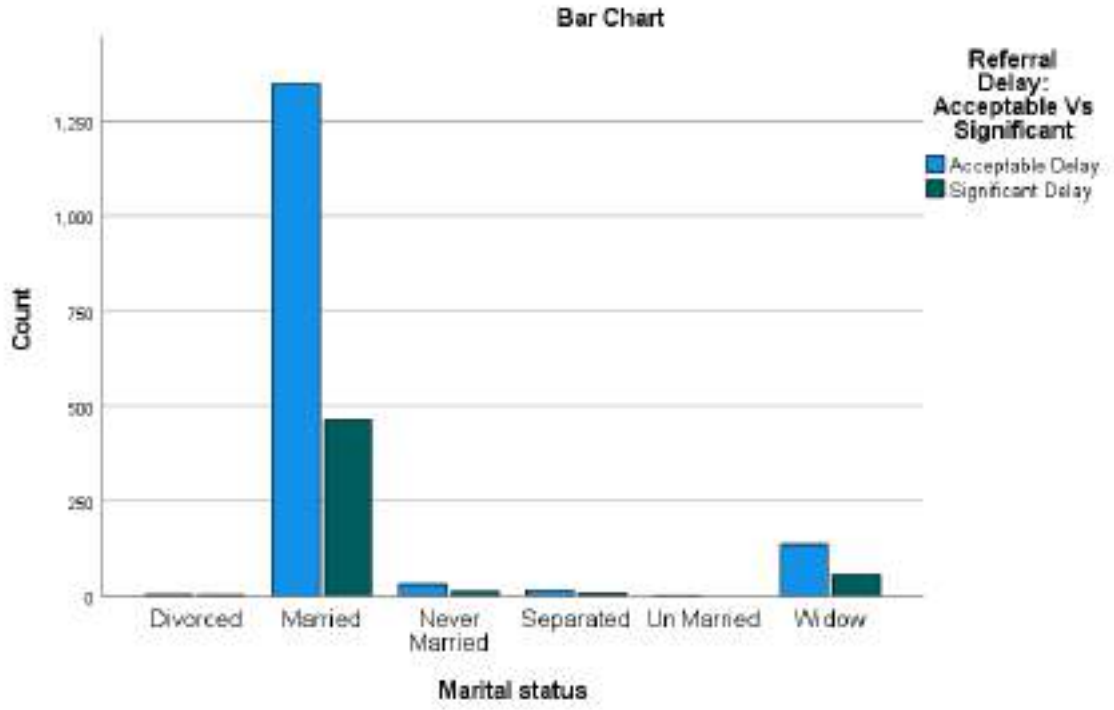


Figure 52:Referral Delay Vs. Marital Status

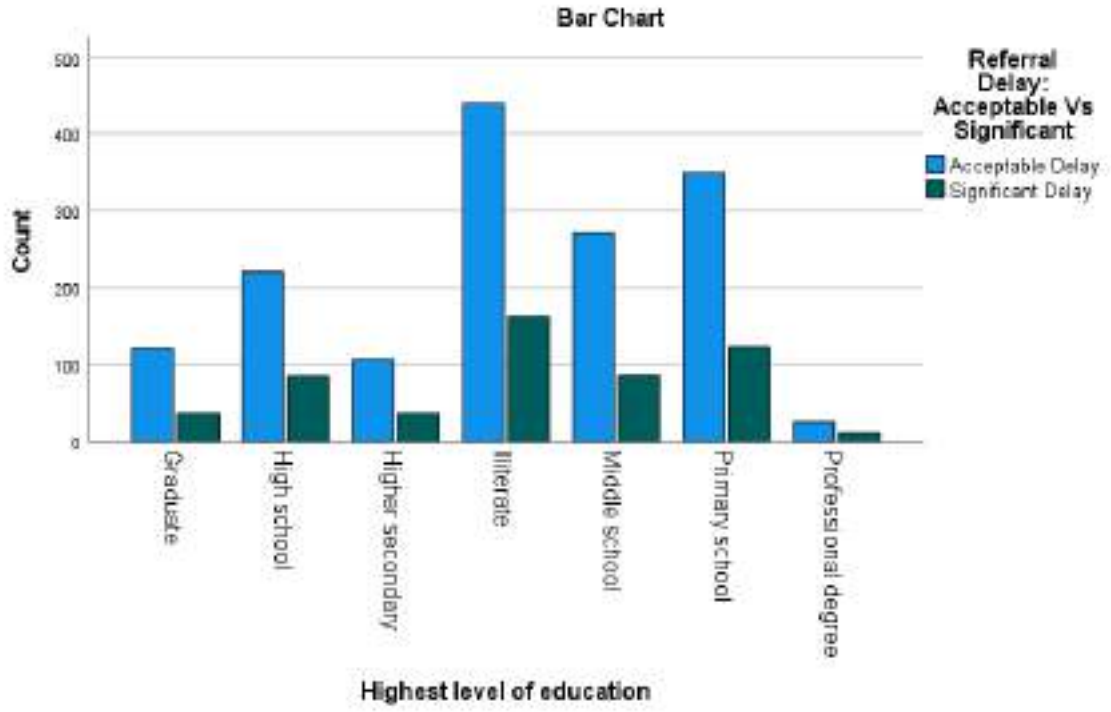


Figure 53:Referral Delay Vs. Patient's Education

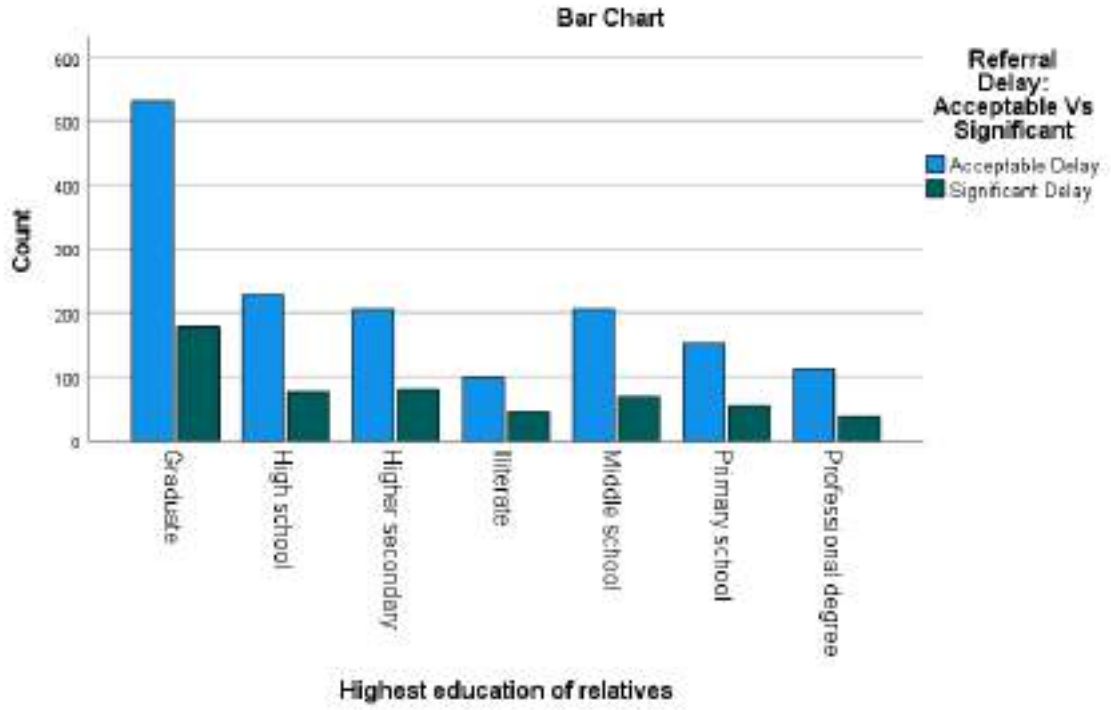


Figure 54:Referral Delay Vs. Highest Educational status in Family

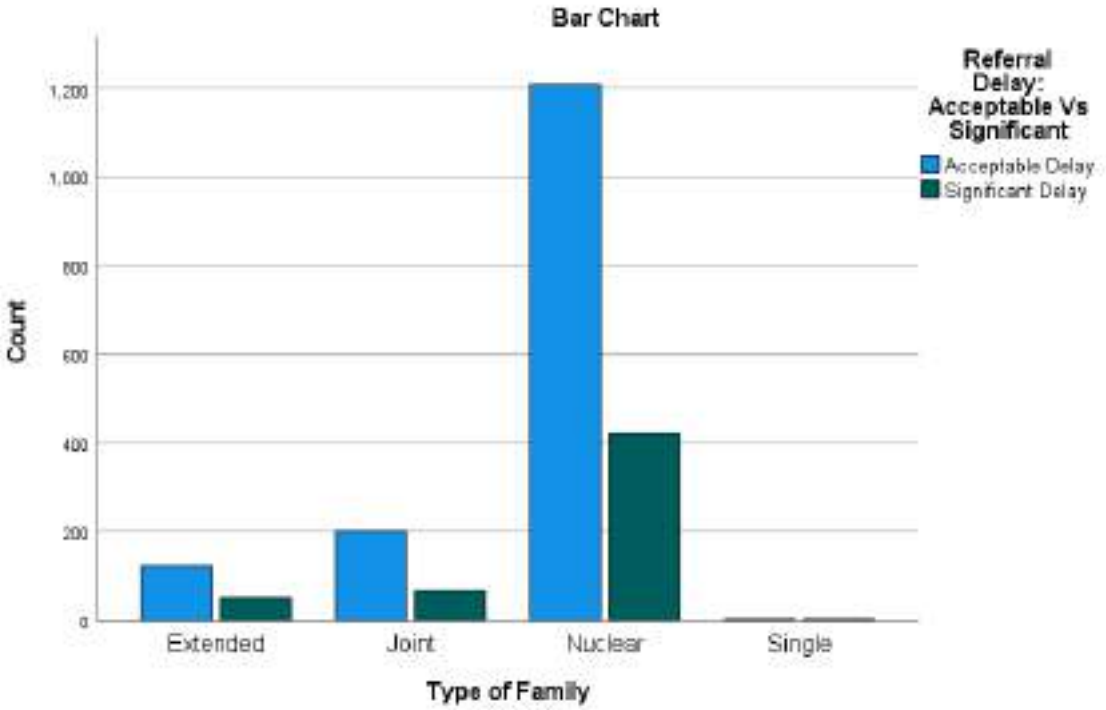


Figure 55:Referral Delay Vs. Type of Family

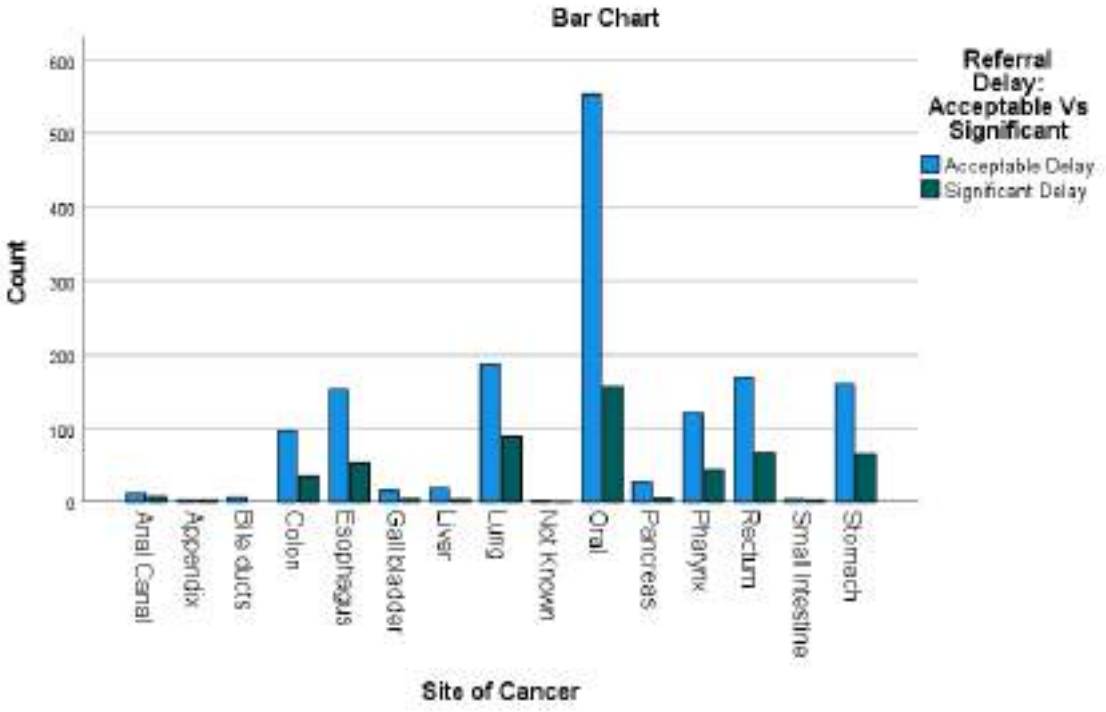


Figure 56:Referral Delay Vs. cancer site

Referral delay also **did not vary** significantly with the distance of home to healthcare facilities (Nearest GP/PHC, Nearest Speciality Hospital, Nearest Cancer Centre and Current Treating Hospital)

Table 68: Referral Delay Vs. Distance from Health Facilities

Distance from Health Facilities		**Referral Delay**			**Pearson Chi-square P Value**
		Acceptable Delay	**Significant Delay**	**Total**	
Nearest GP/PHC	**1-10 Km**	1428	508	1936	0.87 (NS)
	11-20 Km	90	28	118	
	21-30 Km	8	4	12	
	31-40 Km	3	1	4	
	41-50 Km	3	0	3	
	>50 Km	2	1	3	
Nearest Speciality Hospital	**1-10 Km**	802	282	1084	0.9 (NS)
	11-20 Km	458	167	625	
	21-30 Km	186	57	243	
	31-40 Km	55	23	78	
	41-50 Km	19	7	26	
	51-75 Km	14	6	20	
Nearest Cancer Centre	**1-10 Km**	234	89	323	0.81 (NS)
	11-20 Km	331	112	443	
	21-30 Km	233	88	321	
	31-40 Km	161	48	209	
	41-50 Km	207	70	277	
	51-75 Km	297	104	401	
	76 -100 Km	71	31	102	
Current Treating Hospital	**1-10 Km**	171	60	231	0.57 (NS)
	11-20 Km	280	103	383	
	21-30 Km	212	90	302	
	31-40 Km	155	50	205	

	41-50 Km	205	62	267	
	51-75 Km	303	106	409	
	76 -100 Km	107	39	146	
	101-150 Km	56	22	78	
	151-200 Km	25	4	29	
	201-300 Km	7	5	12	
	301-400 Km	9	1	10	
	401-500 Km	3	0	3	
	> 500 Kms	1	0	1	
Total		943	1133	2076	

Table 69:Referral Delay Vs. Distance from Health Facilities

Referral Delay		**Nearest GP/PHC from home (in Km)**	**Nearest Speciality Govt/Private Hospital (in Km)**	**Nearest Cancer Centre (in Km)**	**Distance between home and current treating hospital (in km)**
Acceptable Delay	**Mean**	4.38	12.99	33.72	46.07
	Median	3.00	10.00	28.00	37.90
	SD	4.20	9.44	21.97	46.21
Significant Delay	**Mean**	4.27	13.16	33.89	43.84
	Median	3.00	10.00	28.00	33.00
	SD	4.03	9.58	22.97	39.28
Total	**Mean**	4.35	13.04	33.76	45.49
	Median	3.00	10.00	28.00	35.00
	SD	4.16	9.48	22.23	44.51

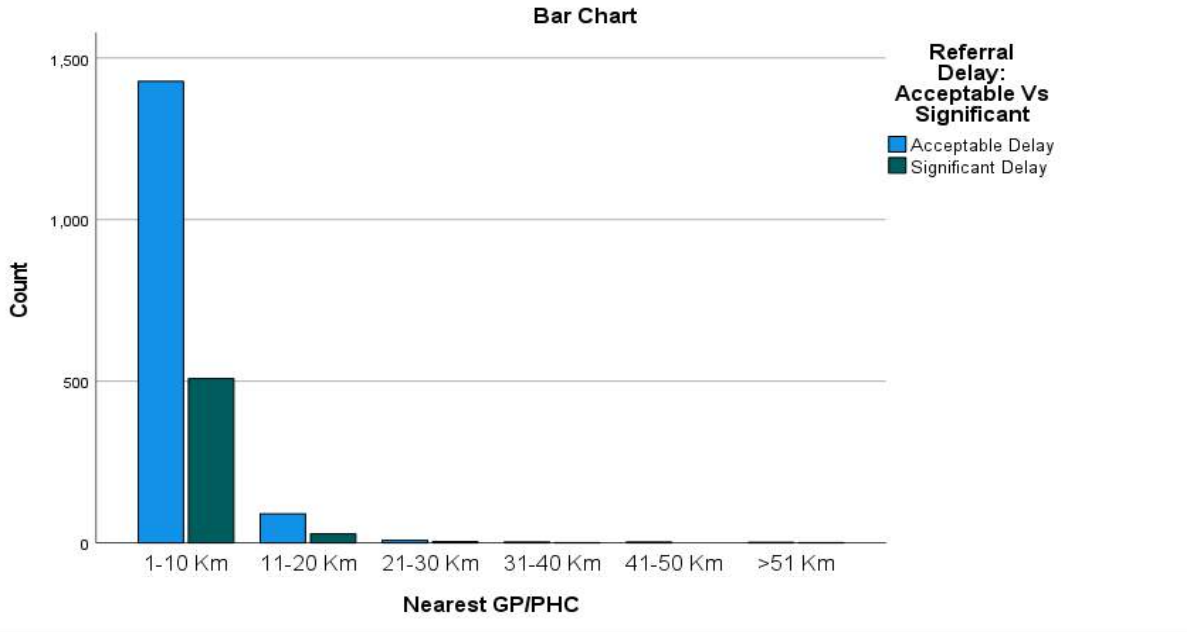


Figure 57: Referral Delay Vs. Distance from GP/PHC

Secondary Delay:

The mean **Secondary Delay or Diagnostic Delay** was 38.21 ± 43.11 days ranging from 0 to 433 days (more than 1 year) with a median of 26 days (IQR: 13 to 44 days). Three patients experienced no delays (0 days) for diagnosis of and 12.3% of patients were diagnosed within 1 week of presentation to the higher centre (speciality hospital or cancer centre). However, 45.2% of patients experience **significant secondary delays (**more than 28 days or 4 weeks). **The most common reason for secondary delays was that the patient obtained a second opinion (25%).**

Table 70: Secondary Delay

Secondary Delay	**Patients (N)**	**Percent (%)**
No Delay (0 days)	3	0.1
1 Week (1- 7 days)	255	12.3
2 Weeks (8-14 days)	362	17.4
3 Weeks (15-21 days)	291	14.0
4 Weeks (22-28 days)	227	10.9
>4 Weeks (>28 days)	938	45.2
Total	**2076**	**100.0**

Table 71: Significant Secondary Delay

Secondary Delay	**Patients (N)**	**Percent (%)**
Acceptable Delay (≤ 28 days)	1138	54.8
Significant Delay (> 28 days)	938	45.2
Total	**2076**	**100.0**

Table 72:Reason for Secondary delay

S.No	Reason for Secondary delay: (as given by the patient)	Frequency (in %)
1	I was not aware	29.8
2.	Second Opinion	25.3
3.	Financial reasons	16.7
4	I thought that symptoms will resolve spontaneously	10.5
5	I didn’t have knowledge or information	7.6
6	Alternate Treatments	4.5
7	I didn’t have time	1.4
8	There was a family problem during that time	1.7
9	There was no one to take me to the hospital	0.6
10	The hospital was far from home	0.6
11	Other reasons	5.7

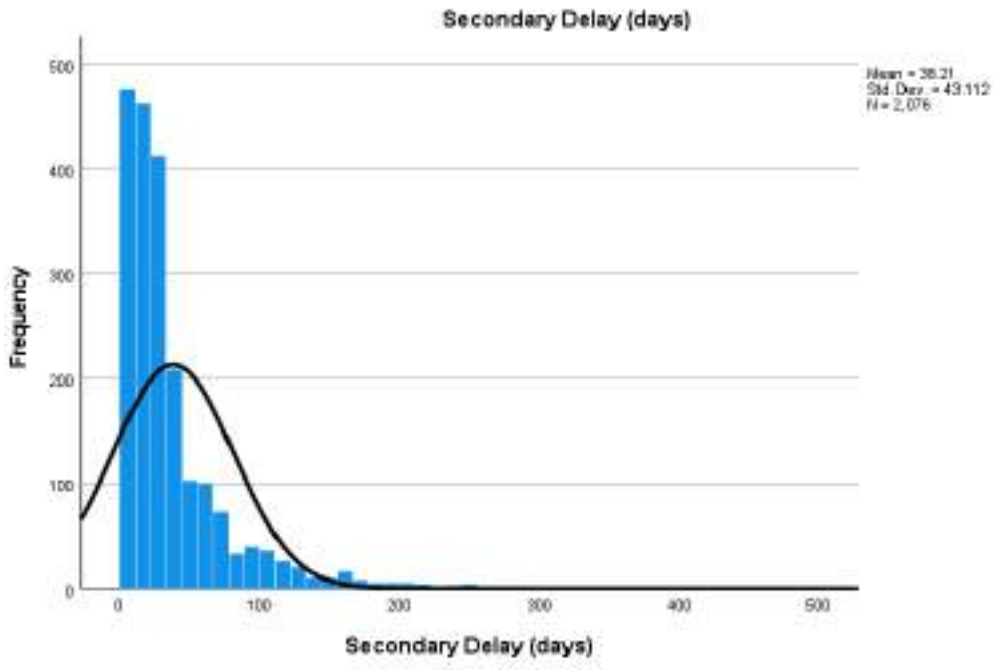


Figure 58: Secondary Delay

Table 73: Secondary Delay Vs. Patient Demographics

Patient Demographics		Secondary Delay			Pearson Chi-square P Value
		Acceptable Delay	Significant Delay	Total	
Cancer Site	**GI Cancers**	496	425	921	**<0.001**
	Head & Neck Cancers	523	353	876	
	Lung Cancers	**117**	**159**	**276**	
	Not Known	2	1	3	
Cancer Site	**Anal Canal**	11	10	21	**0.005**
	Appendix	2	4	6	
	Bile ducts	5	2	7	
	Colon	75	57	132	
	Esophagus	112	94	206	
	Gall bladder	12	9	21	
	Liver	14	9	23	
	Pancreas	20	14	34	
	Rectum	119	118	237	
	Small Intestine	3	4	7	
	Stomach	123	104	227	
	Oral	428	282	710	
	Pharynx/Larynx	95	71	166	
	Lung	**117**	**159**	**276**	
	Not Known	2	1	3	
Cancer Stage	**1**	38	16	54	0.11 (NS)
	2	249	222	471	
	3	627	516	1143	
	4	224	184	408	
Gender	**Female**	380	328	708	0.55 (NS)
	Male	758	610	1368	
Place of residence	**Rural**	558	460	1018	0.97 (NS)
	Tribal	3	2	5	

	Urban	577	476	1053	
Religion	**Christian**	86	72	158	0.99
	Hindu	996	819	1815	(NS)
	Muslim	56	47	103	
Socioeconomic Status (BG Prasad 2023 Scale)	**I Upper Class**	**110**	**48**	**158**	**0.002**
	II Upper Middle Class	180	174	354	
	III Middle Class	238	207	445	
	IV Lower Middle Class	397	325	722	
	V Lower Class	213	184	397	
BMI Groups (Asian Classification)	**1.Underweight**	260	196	456	0.35 (NS)
	2.Normal	469	399	868	
	3.Overweight	169	138	307	
	4.Obese 1	172	162	334	
	5.Obese 2	68	43	111	
Age Groups	**Children**	5	2	7	0.33 (NS)
	Elderly	458	353	811	
	Middle Age	183	142	325	
	Old Adults	474	419	893	
	Young Adults	18	22	40	
Relationship of primary care giver	**Husband**	141	126	267	0.76 (NS)
	Wife	516	443	959	
	Father	22	12	34	
	Mother	25	23	48	
	Daughter	145	111	256	
	Son	184	142	326	
	Grandparent	5	1	6	
	Other Relative	96	77	173	
	Not known	4	3	7	
Marital status	**Never Married**	20	23	43	0.44 (NS)
	Un Married	0	1	1	
	Married	1005	808	1813	

	Divorced	3	2	5	
	Separated	9	13	22	
	Widow (er)	101	91	192	
Type of Family	**Single**	2	4	6	0.09 (NS)
	Nuclear	873	756	1629	
	Extended	101	72	173	
	Joint	162	106	268	
Patient's Educational Status	**Illiterate**	328	274	602	0.94 (NS)
	Primary school	258	214	472	
	Middle school	206	152	358	
	High school	166	140	306	
	Higher secondary	79	65	144	
	Graduate	82	76	158	
	Professional degree	19	17	36	
Highest education of relatives	**Illiterate**	68	77	145	0.34 (NS)
	High school	105	102	207	
	Middle school	150	125	275	
	Primary school	170	134	304	
	Higher secondary	160	125	285	
	Graduate	396	313	709	
	Professional degree	89	62	151	
Total		**1138**	**938**	**2076**	

Higher Significant Secondary delays were seen in **Lung Cancer patients (P<0.005). Upper Class Patients had a significantly lower secondary delays (P= 0.002),** which was evident when analysed for total **family monthly income and per capita monthly income. Patients with significant secondary delays had lesser mean total family monthly income (Rs. 16,286 vs 12,282) and mean per capita monthly income (Rs. 4357 Vs 3,670). However, the levels of association were low (0.07 and 0.06 respectively).**

Table 74:Secondary Delay Vs. Patient Demographics

Secondary Delay		Age (years)	BMI	Total members	Total family monthly income (Rs)	Per Capita Monthly Income (Rs/Person)	EORTCQLQC30 Total Score
Acceptable Delay	**Mean**	56.95	22.01	4.05	16286.12	4356.95	60.23
	Median	58.00	21.34	4.00	10000.00	2500.00	63.00
	SD	12.14	4.94	1.79	27224.70	6524.42	10.90
Significant Delay	**Mean**	56.13	21.99	3.97	13281.77	3670.63	60.53
	Median	57.00	21.48	4.00	10000.00	2500.00	64.00
	SD	11.87	4.55	1.74	13545.72	4093.74	11.10
Total	**Mean**	56.58	22.00	4.01	14928.66	4046.85	60.36
	Median	57.00	21.40	4.00	10000.00	2500.00	63.00
	SD	12.02	4.77	1.77	22163.62	5568.63	10.99
P value		0.12	0.91	0.34	**0.002**	**0.005**	0.57
Eta					**0.07**	**0.06**	
Eta squared					**0.005**	**0.004**	

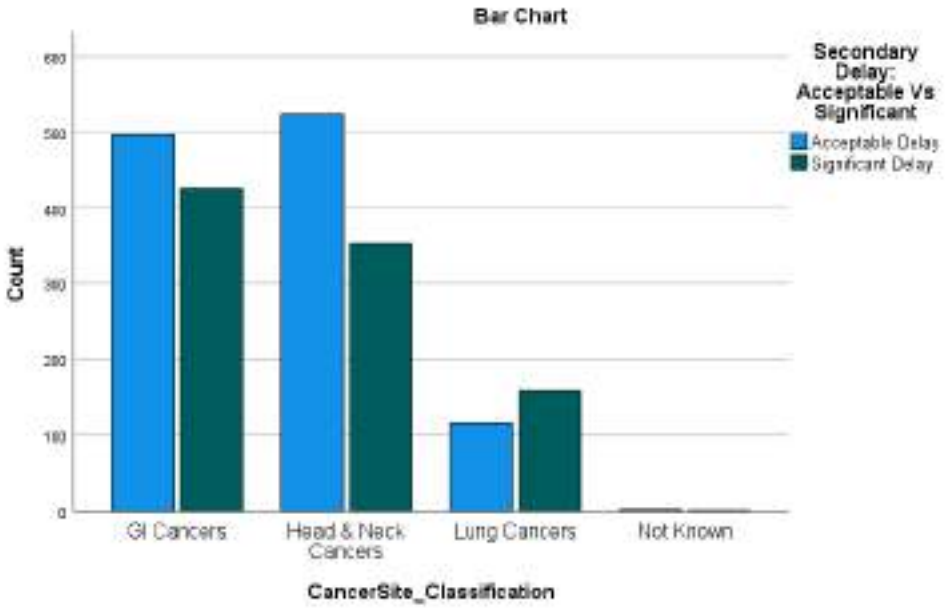


Figure 59:: Secondary Delay Vs Cancer Site

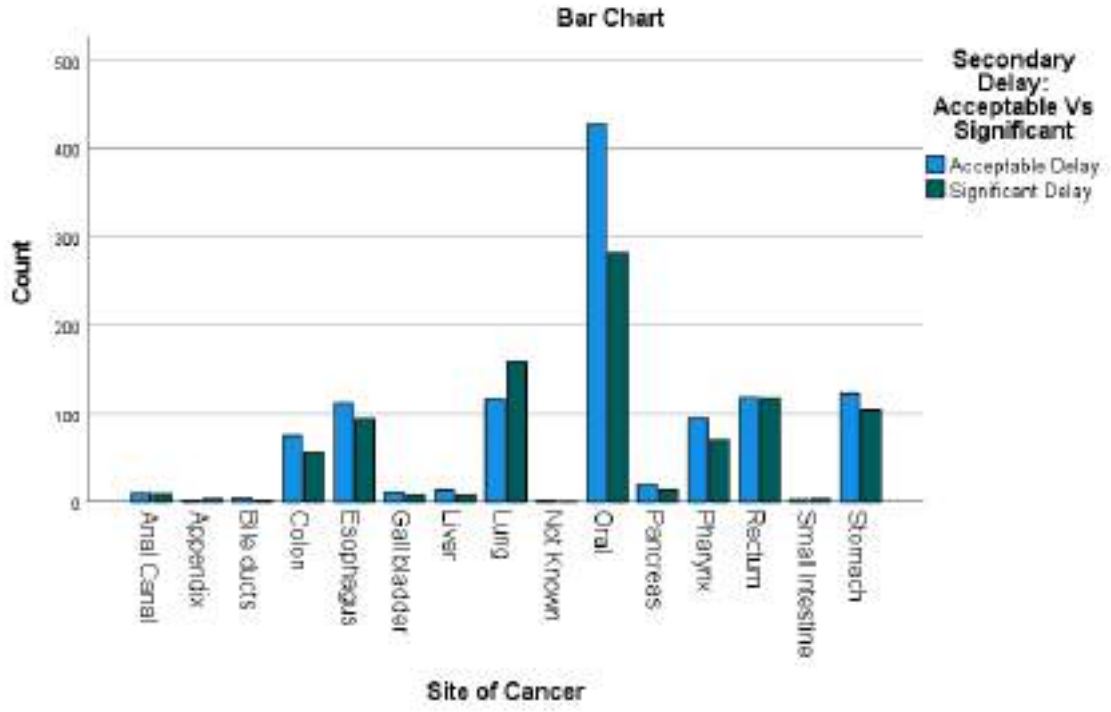


Figure 60: Secondary Delay Vs Cancer Site

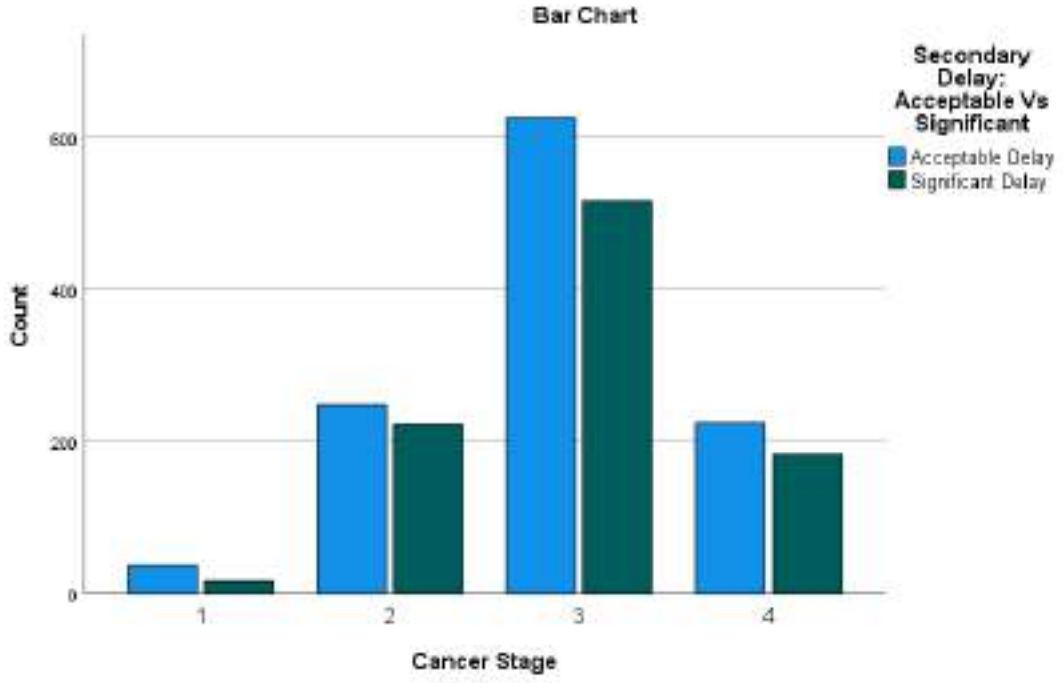


Figure 61:Secondary Delay Vs Cancer Stage

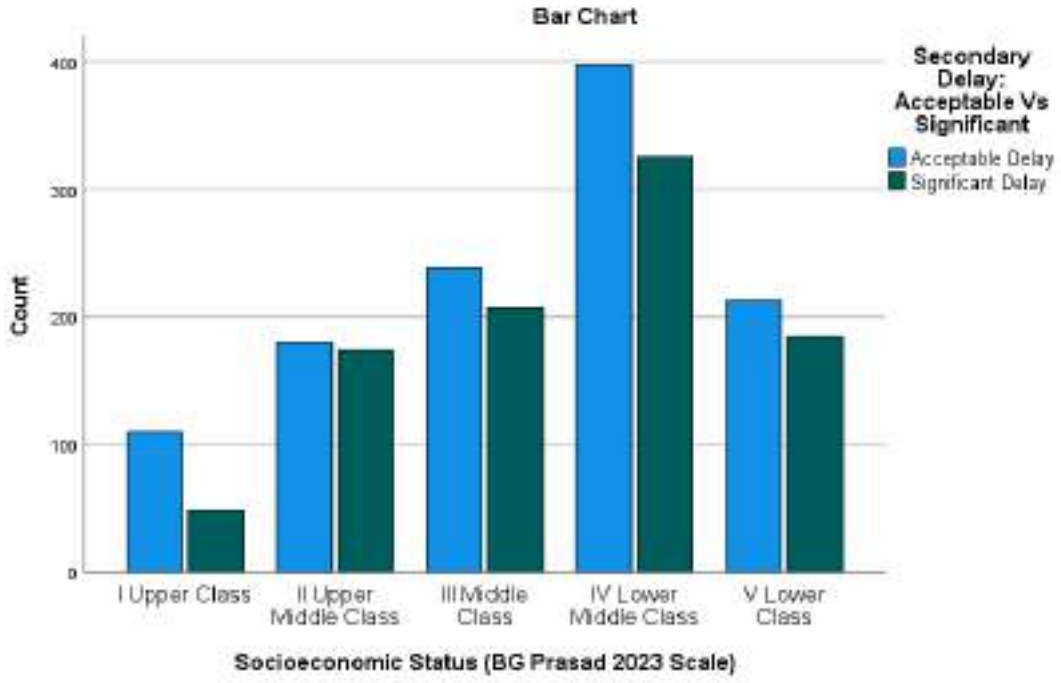


Figure 62:Secondary Delay Vs SES

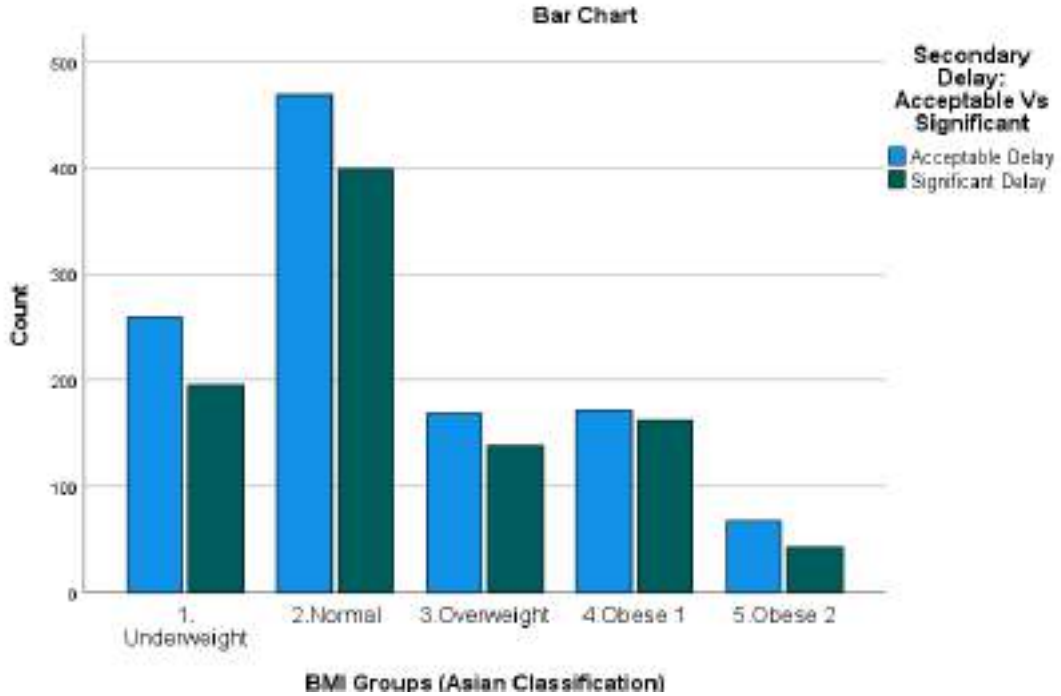


Figure 63:Secondary Delay Vs BMI

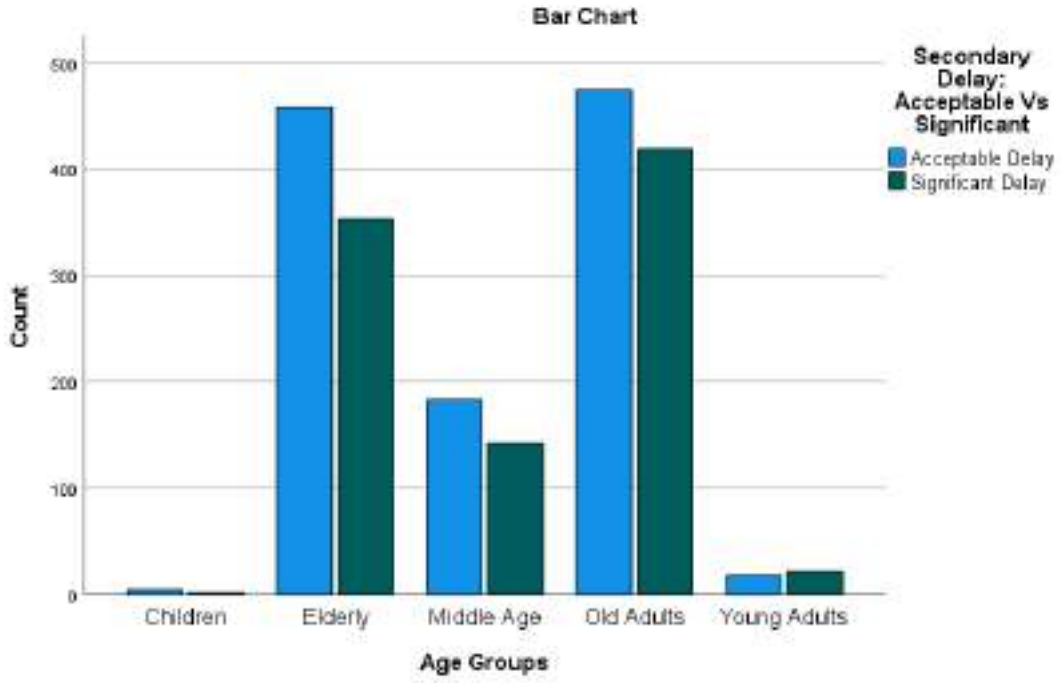
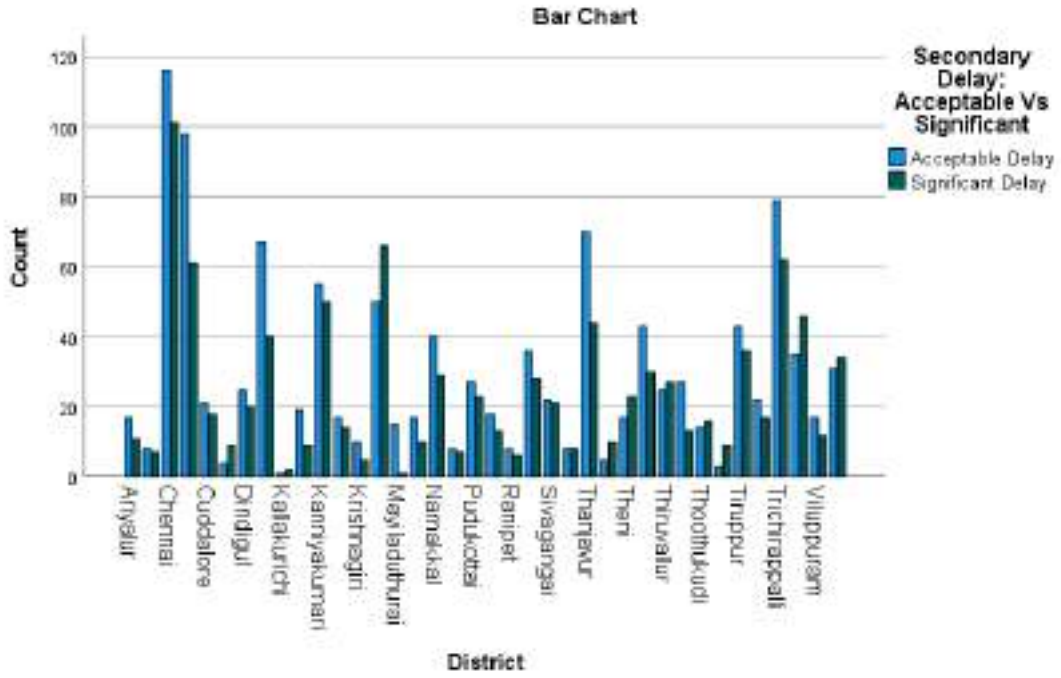


Figure 64:Secondary Delay Vs Age

Table 75: Secondary Delay Vs. Home District

District	Secondary Delay		Total	Pearson Chi-square P Value
	Acceptable Delay	Significant Delay		
Ariyalur	17	11	28	
Chengalpattu	8	7	15	
Chennai	116	101	217	
Coimbatore	98	61	159	
Cuddalore	21	18	39	
Dharmapuri	**4**	**9**	**13**	
Dindigul	25	20	45	**0.04**
Erode	67	40	107	
Kallakurichi	**1**	**2**	**3**	
Kancheepuram	19	9	28	
Kanniyakumari	55	50	105	
Karur	17	14	31	
Krishnagiri	10	5	15	

Madurai	**50**	**66**	**116**	
Mayiladuthurai	15	1	16	
Nagapattinam	17	10	27	
Namakkal	40	29	69	
Perambalur	8	7	15	
Pudukottai	27	23	50	
Ramanathapuram	18	13	31	
Ranipet	8	6	14	
Salem	36	28	64	
Sivagangai	22	21	43	
Tenkasi	**8**	**8**	**16**	
Thanjavur	70	44	114	
The Nilgiris	**5**	**10**	**15**	
Theni	**17**	**23**	**40**	
Thirunelveli	43	30	73	
Thiruvallur	**25**	**27**	**52**	
Thiruvarur	27	13	40	
Thoothukudi	**14**	**16**	**30**	
Tirupathur	3	9	12	
Tiruppur	43	36	79	
Tiruvannamalai	22	17	39	
Trichirappalli	79	62	141	
Vellore	**35**	**46**	**81**	
Viluppuram	17	12	29	
Virudhunagar	**31**	**34**	**65**	
Total	1138	938	2076	



Patients from certain districts (**Dharmapuri, Kallakurichi, Madurai, The Nilgiris, Tenkasi, Theni, Thiruvallur, Thoothukudi, Tirupathur, Vellore and Virudhunagar)** had higher secondary delays when compared to other districts. Certain districts like Ariyalur, Chennai, Coimbatore, Erode, Kancheepuram, Krishnagiri, Mayiladuthurai, Namakkal, Ramnathapuram, Thanjavur, Thirunelveli, Tirupur, Trichy and Villupuram performed better with lower secondary delays.

Table 76: Secondary Delay Vs. Number of Hospitals

Secondary Delay		Number of doctors/hospitals visited before start of cancer treatment	Number of hospitals visited for cancer treatment	Total Number of doctors/ hospitals visited	Primary Delay	Referral Delay
Acceptable Delay	**Mean**	2.07	1.04	3.11	51.12	7.59
	Median	2.00	1.00	3.00	31.00	6.00
	SD	.32	.21	.42	74.98	8.47
Significant Delay	**Mean**	2.42	1.08	3.50	47.78	47.96
	Median	2.00	1.00	3.00	30.00	31.00

	SD	.55	.30	.66	75.80	48.39
Total	**Mean**	2.23	1.06	3.29	49.61	25.83
	Median	2.00	1.00	3.00	30.00	11.00
	SD	.48	.25	.58	75.35	38.74
P value		**<0.001**	**<0.001**	**<0.001**	**0.3**	**<0.001**
Eta		**0.37**	**0.09**	**0.34**		**0.52**
Eta Squared		**0.14**	**0.008**	**0.12**		**0.27**

Significant Secondary Delays was associated with Number of doctors/hospitals visited before start of cancer treatment (P<0.001, strength of association: moderate, 14%), Number of hospitals visited for cancer treatment (P<0.001, strength of association weak) and Total Number of doctors/ hospitals visited ((P<0.001, strength of association medium, 12%).

Secondary delay was also significantly associated with referral delays (higher the referral delay, higher the secondary delay, P<0.001, strength of association moderate, 27%, Higher Significant primary delays also led to higher significant secondary delays (RR: 1.12(1.02-1.23). Higher Significant referral delays also led to significant secondary delays: RR 36(20.15-65.02). Presentation to a hospital within the same district or presence/absence of an oncology department in the hospital did not affect secondary delays.

Table 77: Secondary Delay Vs. District - First presented

District - First presented	**Secondary Delay**		**Total**	**Pearson Chi-square P Value**	**Relative Risk (95% Confidence Interval**
	Acceptable Delay	**Significant Delay**			
Different district	201	145	346	0.18	0.91 (0.8-1.05)
Same district	937	793	1730		
Total	**1138**	**938**	**2076**		

The presence or absence of an oncologist/oncology department in the hospital where cancer was diagnosed had positive association with secondary delay, though this was non-significant (P=0.05), RR 1.1 (1-1.2). When there was a **significant primary delay (P= 0.02,**

RR: 1.12(1.02-1.23) or a referral delay P<0.001 RR: 36(20.15-65.02), there was a significant increase in the probability of having a significant secondary delay. **The important finding here was the relative risk of having a secondary delay if there was a referral delay: There was 36 times more risk of having a secondary delay if there was a referral delay.**

Table 78: Secondary Delay Vs. Hospital where cancer was diagnosed had an oncology department/ specialist

Hospital where cancer was diagnosed had an oncology department/ specialist	Secondary Delay		Total	Pearson Chi-square P Value	Relative Risk (95% Confidence Interval
	Acceptable Delay	Significant Delay			
Yes	876	755	1631	**0.05**	**1.1 (1.0-1.2)**
No	262	183	445		
Total	1138	938	2076		

Table 79: Primary Delay Vs. Secondary Delay

Primary Delay	Secondary Delay		Total	Pearson Chi-square P Value	Relative Risk (95% Confidence Interval)
	Acceptable Delay	Significant Delay			
Acceptable Delay	491	452	943	**0.02**	**1.12(1.02-1.23)**
Significant Delay	647	486	1133		
Total	**1138**	**938**	**2076**		

Table 80:Referral Delay Vs. Secondary Delay

Referral Delay	Secondary Delay		Total	Pearson Chi-square P Value	Relative Risk (95% Confidence Interval)
	Acceptable Delay	Significant Delay			
Acceptable Delay	1127	407	1534	**<0.001**	**36(20.15-65.02)**
Significant Delay	11	531	542		
Total	**1138**	**938**	**2076**		

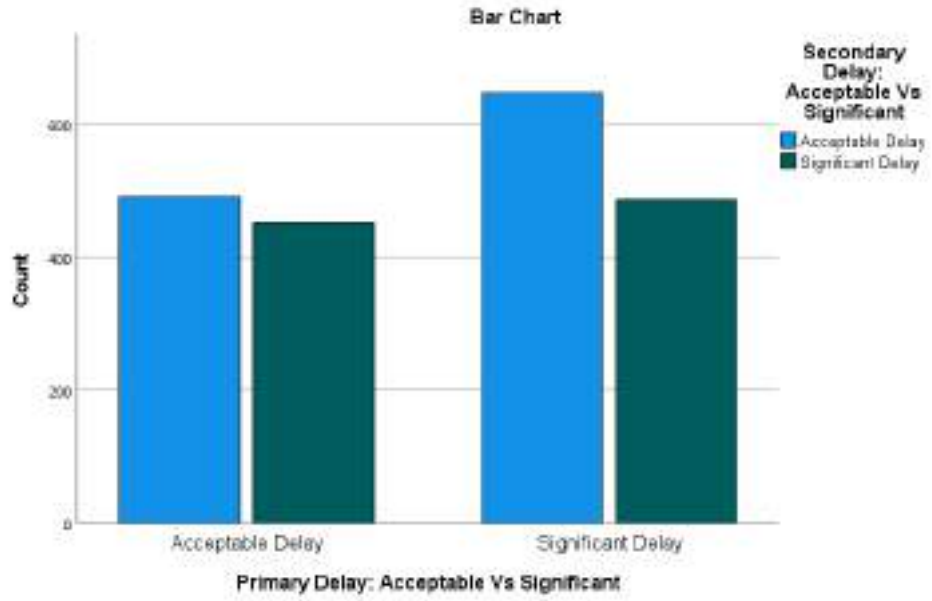


Figure 65:Primary Delay Vs. Secondary Delay

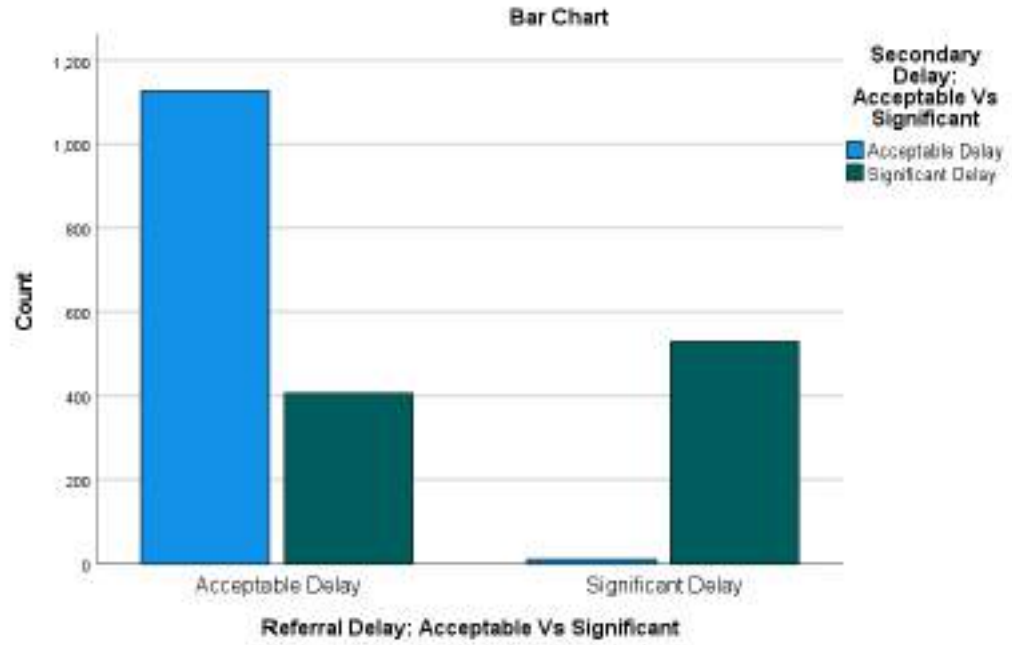


Figure 66:Referral Delay Vs. Secondary Delay

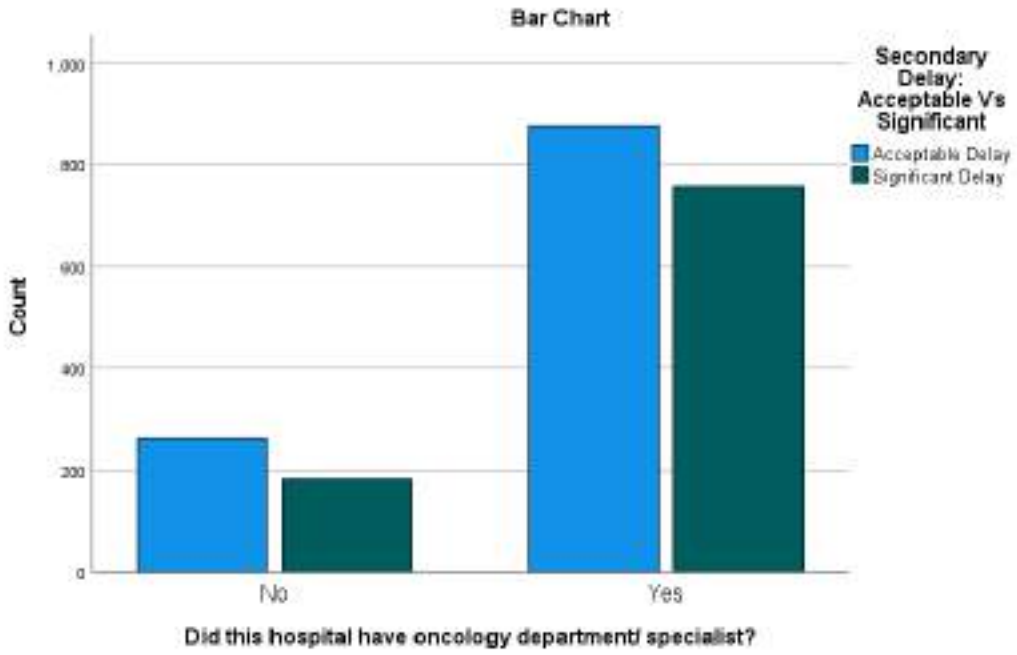


Figure 67:Secondary Delay Vs. Hospital where cancer was diagnosed had an oncology department/ specialist

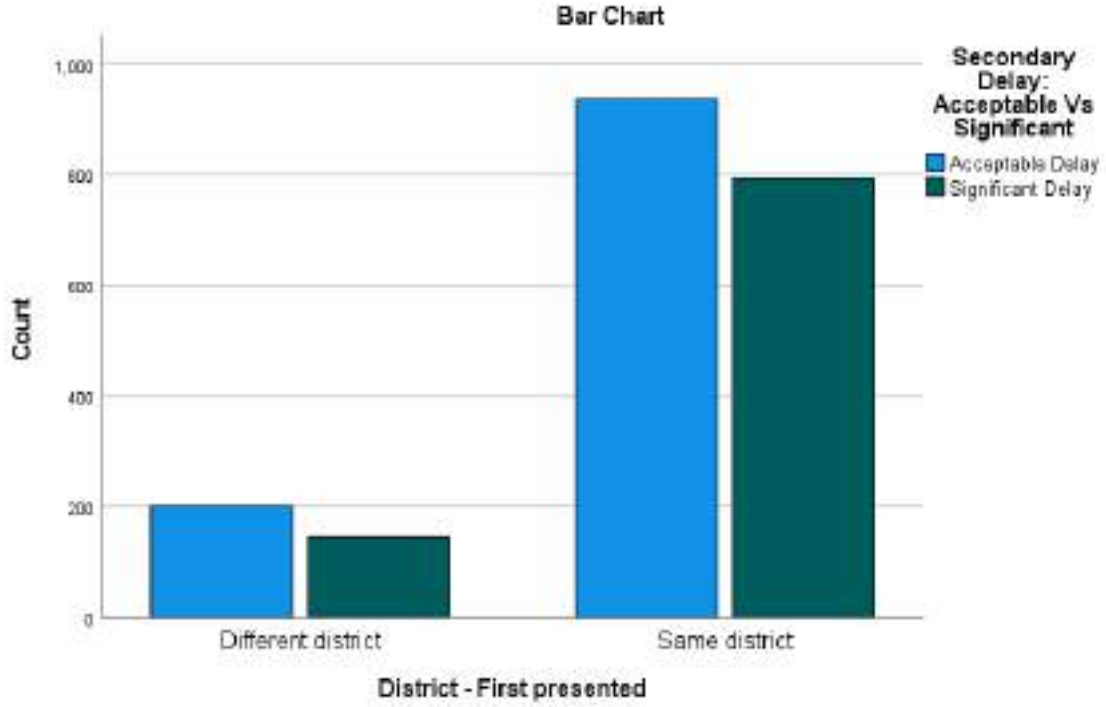


Figure 68:Secondary Delay Vs. District - First presented

Distance from home to healthcare facilities (Nearest GP/PHC from home (in Km), Nearest Speciality Govt/Private Hospital (in Km), Nearest Cancer Center (in Km) and Distance between home and current treating hospital (in km)) did not significantly affect secondary delays.

Table 81:Secondary Delay Vs. Distance to Health care facilities

Distance from Health Facilities		**Secondary Delay**			
		Acceptable Delay	**Significant Delay**	**Total**	**Pearson Chi-square P Value**
Nearest GP/PHC	**1-10 Km**	1	2	3	0.43 (NS)
	11-20 Km	1065	871	1936	
	21-30 Km	62	56	118	
	31-40 Km	6	6	12	
	41-50 Km	1	3	4	
	>50 Km	3	0	3	
Nearest Speciality Hospital	**1-10 Km**	598	486	1084	0.33 (NS)
	11-20 Km	344	281	625	
	21-30 Km	129	114	243	
	31-40 Km	48	30	78	
	41-50 Km	12	14	26	
	51-75 Km	7	13	20	
Nearest Cancer Centre	**1-10 Km**	162	161	323	0.05
	11-20 Km	259	184	443	
	21-30 Km	168	153	321	
	31-40 Km	132	77	209	
	41-50 Km	148	129	277	
	51-75 Km	216	185	401	
	76 -100 Km	53	49	102	
Current Treating Hospital	**1-10 Km**	118	113	231	0.7 (NS)
	11-20 Km	217	166	383	
	21-30 Km	151	151	302	

	31-40 Km	121	84	205	
	41-50 Km	149	118	267	
	51-75 Km	225	184	409	
	76 -100 Km	80	66	146	
	101-150 Km	45	33	78	
	151-200 Km	17	12	29	
	201-300 Km	6	6	12	
	301-400 Km	7	3	10	
	401-500 Km	1	2	3	
	More Than 500 Kms	1	0	1	
Total		**1138**	**938**	**2076**	

Table 82: Secondary Delay Vs. Distance to Health care facilities

Secondary Delay		**Nearest GP/PHC from home (in Km)**	**Nearest Speciality Govt/Private Hospital (in Km)**	**Nearest Cancer Center (in Km)**	**Distance between home and current treating hospital (in km)**
Acceptable Delay	**Mean**	4.34	12.80	33.63	45.94
	Median	3.00	10.00	28.00	38.00
	SD	4.14	9.16	21.94	44.72
Significant Delay	**Mean**	4.36	13.33	33.92	44.94
	Median	3.00	10.00	28.00	33.00
	SD	4.19	9.84	22.59	44.27
Total	**Mean**	4.35	13.04	33.76	45.49
	Median	3.00	10.00	28.00	35.00
	SD	4.16	9.48	22.23	44.51
P value		0.93	0.21	0.78	0.11

Tertiary Delay:

The mean **Tertiary delay or Treatment delay (after diagnosis of cancer)** was 13.29 ± 17.16 days ranging from 0 to 197 days (more than 6 months) with a median of 8 days (IQR: 4 to 16 days). This data was again non-parametric and skewed to the right. Seventeen patients (0.8%) did not have any tertiary delay and 47.7% of patients were treated for cancer within 1 week of their diagnosis. However, 10% of patients (n=207) experienced **significant Tertiary delay or Treatment delay (after diagnosis of cancer) (**more than 28 days or 4 weeks).

The **most common reason for tertiary or treatment delays was financial reasons (23.8%)** followed by patient not being aware of the disease (19.9%) and time taken for second opinions (15.9%)

Table 83:Tertiary Delay

Tertiary Delay	**Patients (N)**	**Percent (%)**
No Delay (0 days)	17	0.8
1 Week (1- 7 days)	991	47.7
2 Weeks (8-14 days)	475	22.9
3 Weeks (15-21 days)	259	12.5
4 Weeks (22-28 days)	127	6.1
>4 Weeks (>28 days)	207	10.0
Total	**2076**	**100.0**

Table 84: Significant Tertiary Delay

Tertiary Delay	**Patients (N)**	**Percent (%)**
Acceptable Delay (≤ 28 days)	1869	90.0
Significant Delay (> 28 days)	207	10.0
Total	**2076**	**100.0**

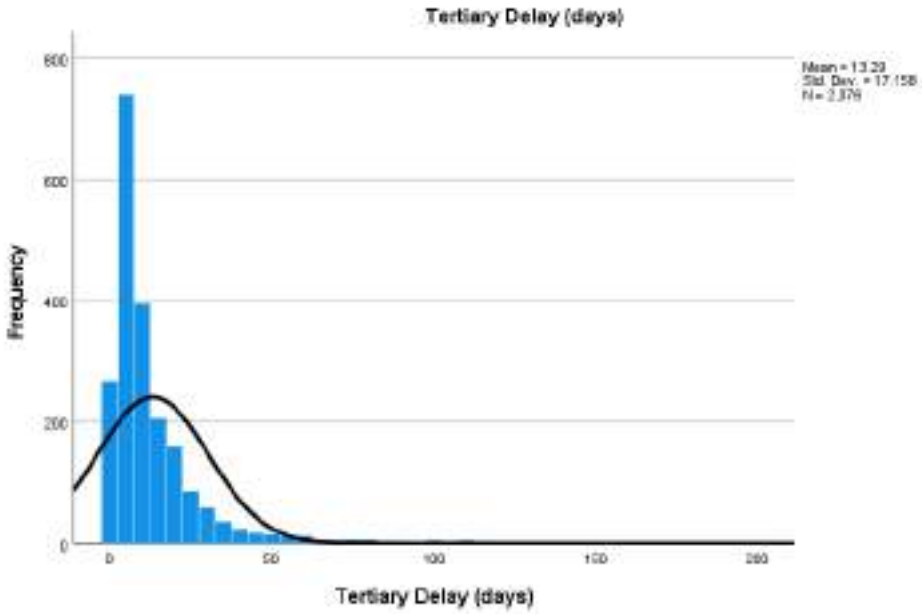


Figure 69:Tertiary Delay

Table 85:Reasons for Tertiary Delay

S.No	Reasons for Tertiary Delay	Frequency (in %)
1	Financial reasons	23.8
2.	I was not aware	19.9
3.	Second Opinion	15.9
4	Alternate treatments	7.5
5	I thought that symptoms will resolve spontaneously	9.4
6	Decided for no treatment	5.6
7	I didn’t have knowledge or information	4.5
8	I didn’t have time	1.3
9	There was a family problem during that time	1.7
10	There was no one to take me to the hospital	0.7
11	The hospital was far from home	0.9
12	Due to shortage of drugs	0.4
13	Other reasons	6.6

Table 86: Tertiary Delay Vs. Patient Demographics

Patient Demographics		Tertiary Delay		Total	Pearson Chi-square P Value
		Acceptable Delay	Significant Delay		
Cancer Site	**GI Cancers**	831	90	921	0.6 (NS)
	Head & Neck Cancers	788	88	876	
	Lung Cancers	248	28	276	
	Not Known	2	1	3	
Cancer Site	**Anal Canal**	21	0	21	0.22 (NS)
	Appendix	5	1	6	
	Bile ducts	5	2	7	
	Colon	119	13	132	
	Esophagus	181	25	206	
	Gall bladder	21	0	21	
	Liver	22	1	23	
	Pancreas	29	5	34	
	Rectum	209	28	237	
	Small Intestine	7	0	7	
	Stomach	212	15	227	
	Oral	642	68	710	
	Pharynx/Larynx	146	20	166	
	Lung	248	28	276	
	Not Known	2	1	3	
Cancer Stage	**1**	48	6	54	0.06 (NS)
	2	437	34	471	
	3	1028	115	1143	
	4	356	52	408	
Gender	**Female**	642	66	708	0.49 (NS)
	Male	1227	141	1368	
Place of residence	**Rural**	901	117	1018	0.06 (NS)
	Tribal	5	0	5	

	Urban	963	90	1053	
Religion	**Christian**	147	11	158	0.13 (NS)
	Hindu	1634	181	1815	
	Muslim	88	15	103	
Socioeconomic Status (BG Prasad 2023 Scale)	**I Upper Class**	137	21	158	0.15 (NS)
	II Upper Middle Class	323	31	354	
	III Middle Class	390	55	445	
	IV Lower Middle Class	658	64	722	
	V Lower Class	361	36	397	
BMI Groups (Asian Classification)	**1.Underweight**	401	55	456	0.1 (NS)
	2.Normal	775	93	868	
	3.Overweight	281	26	307	
	4.Obese 1	312	22	334	
	5.Obese 2	100	11	111	
Age Groups	**Children**	6	1	7	**0.005**
	Young Adults	34	6	40	
	Middle Age	306	19	325	
	Old Adults	**782**	**111**	**893**	
	Elderly	**741**	**70**	**811**	
Relationship of primary care giver	**Husband**	243	24	267	0.15 (NS)
	Wife	860	99	959	
	Father	34	0	34	
	Mother	42	6	48	
	Daughter	227	29	256	
	Son	298	28	326	
	Grandparent	4	2	6	
	Other Relative	156	17	173	
	Not known	5	2	7	
Marital status	**Never Married**	39	4	43	0.4 (NS)
	Un Married	1	0	1	
	Married	1636	177	1813	

	Divorced	4	1	5	
	Separated	22	0	22	
	Widow (er)	167	25	192	
Type of Family	**Single**	6	0	6	**0.03**
	Nuclear	1456	173	1629	
	Extended	**153**	**20**	**173**	
	Joint	254	14	268	
Patient's Educational Status	**Illiterate**	529	73	602	0.4 (NS)
	Primary school	434	38	472	
	Middle school	327	31	358	
	High school	276	30	306	
	Higher secondary	130	14	144	
	Graduate	140	18	158	
	Professional degree	33	3	36	
Highest education of relatives	**Illiterate**	130	15	145	0.9 (NS)
	High school	187	20	207	
	Middle school	253	22	275	
	Primary school	274	30	304	
	Higher secondary	253	32	285	
	Graduate	637	72	709	
	Professional degree	135	16	151	
Total		1869	207	2076	

Old Adults and Elderly patients had significantly high tertiary delays (P<0.005). Patients from joint families had significantly lessor tertiary delays (P=0.03), which was also evident when we analysed for mean number of family members (More the family members, lesser the tertiary delay. 4.04 vs 3.74)

Table 87:Tertiary Delay Vs. Patient Demographics

Tertiary Delay		Age (years)	BMI	Total members	Total family monthly income (Rs)	Per Capita Monthly Income (Rs/Person)	EORTCQLQC30_Total_Score
Acceptable Delay	**Mean**	56.60	22.07	4.04	14910.06	4017.00	60.08
	Median	57.00	21.48	4.00	10000.00	2500.00	63.00
	SD	12.06	4.76	1.78	22496.02	5551.33	10.99
Significant Delay	**Mean**	56.42	21.40	3.74	15096.62	4316.38	62.85
	Median	57.00	21.05	4.00	10000.00	3000.00	64.00
	SD	11.71	4.86	1.66	18946.47	5729.10	10.77
Total	**Mean**	56.58	22.00	4.01	14928.66	4046.85	60.36
	Median	57.00	21.40	4.00	10000.00	2500.00	63.00
	SD	12.02	4.77	1.77	22163.62	5568.63	10.99
P value		0.84	0.06	**0.02**	0.91	0.72	0.002

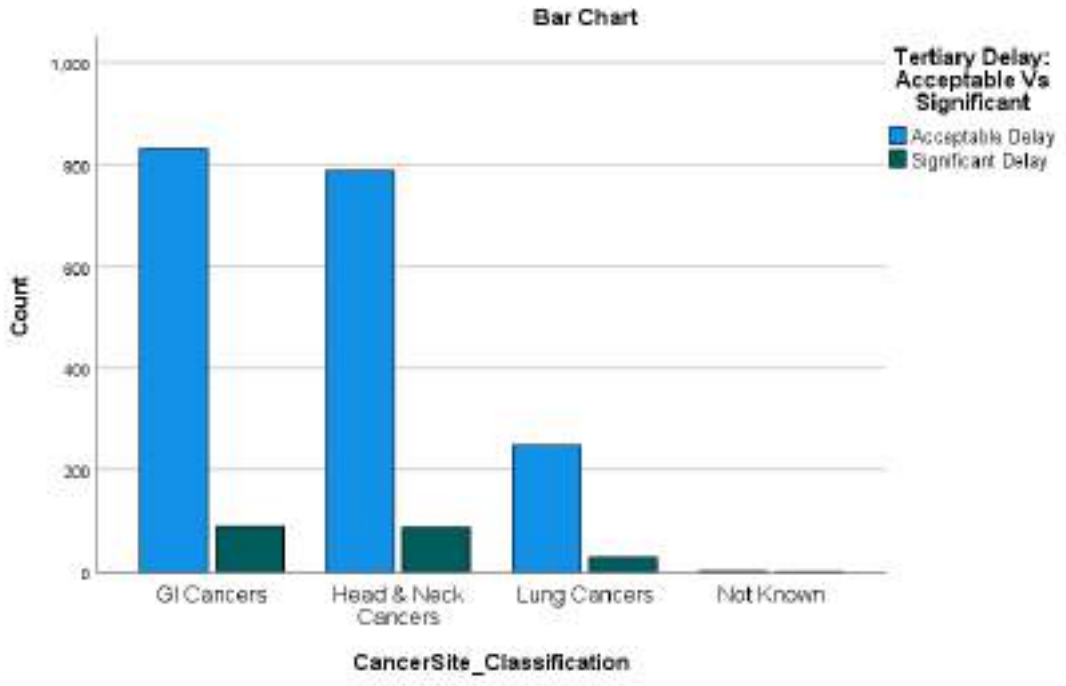


Figure 70: Tertiary Delay Vs. Cancer Site

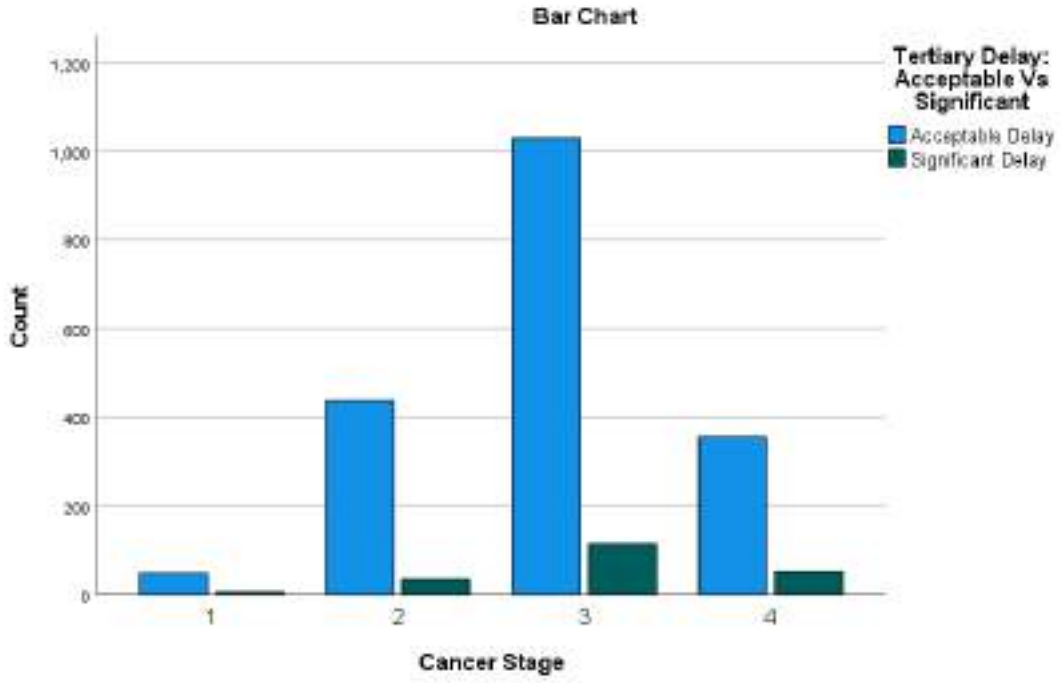


Figure 71: Tertiary Delay Vs. Cancer Stage

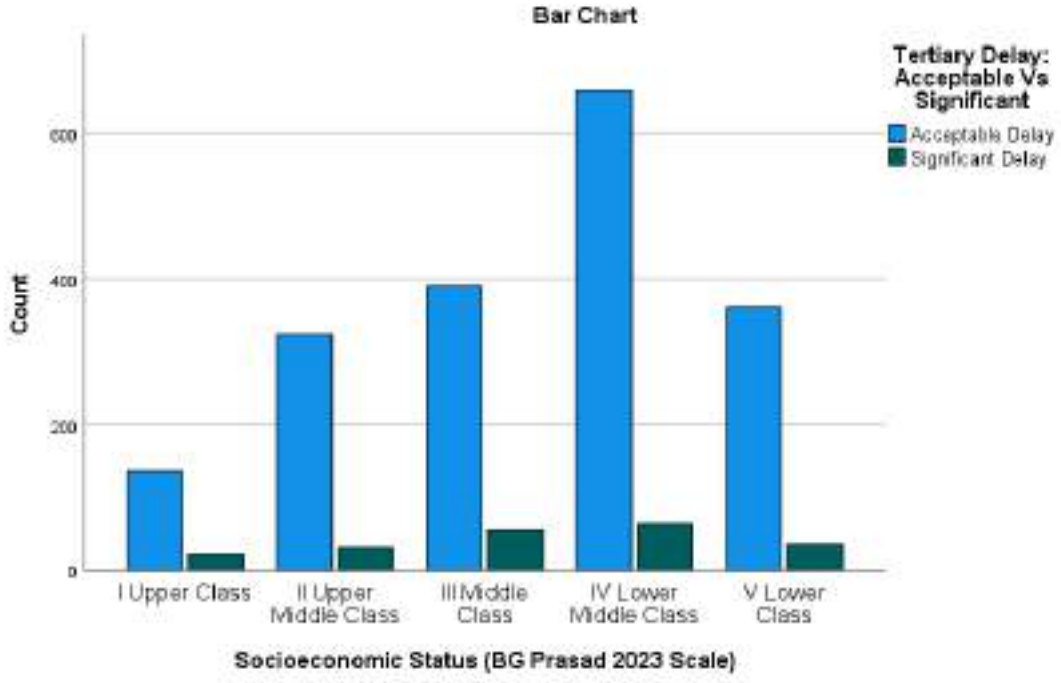


Figure 72: Tertiary Delay Vs. SES

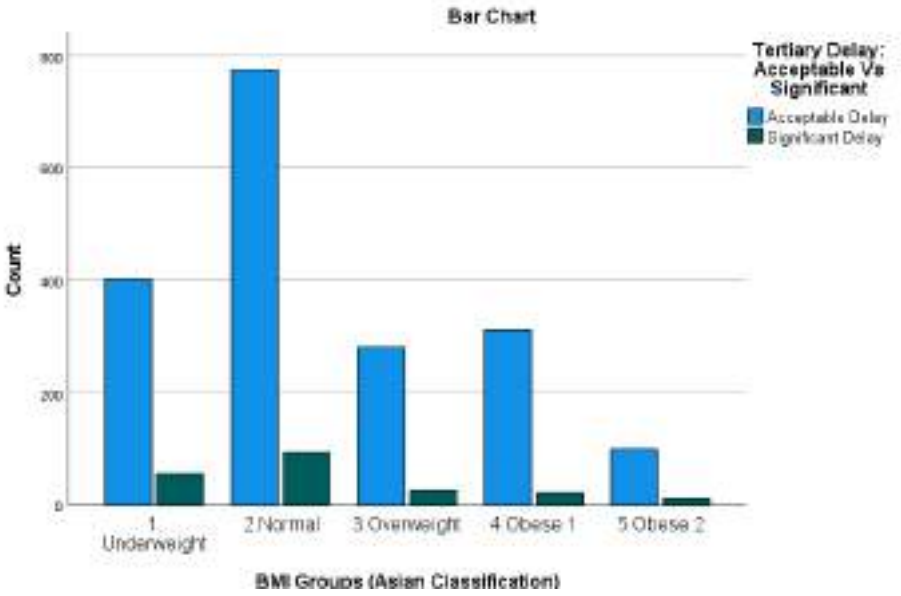


Figure 73: Tertiary Delay Vs. BMI

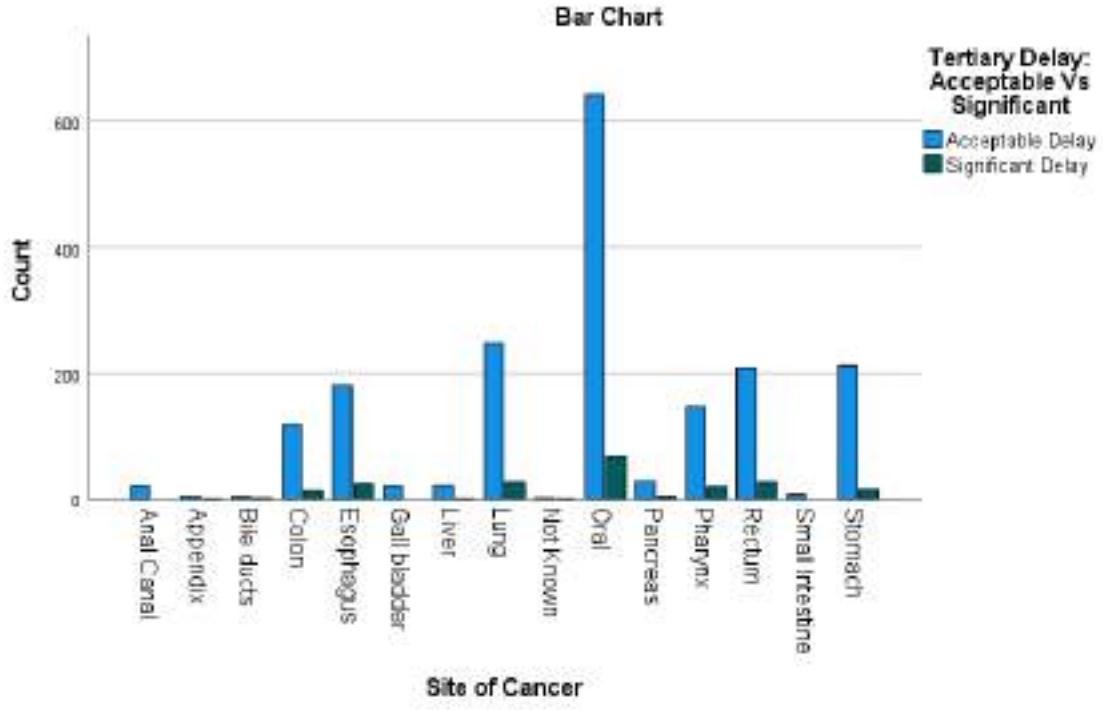


Figure 74: Tertiary Delay Vs. Cancer Site

Table 88: Tertiary Delay Vs. Number of Hospitals and Other Delays

Tertiary Delay		Number of doctors/hospitals visited before start of cancer treatment	Number of hospitals visited for cancer treatment	Total Number of doctors/ hospitals visited	Primary Delay	Referral Delay	Secondary Delay
Acceptable Delay	**Mean**	2.21	1.05	3.25	48.61	25.67	38.47
	Median	2.00	1.00	3.00	30.00	11.00	26.00
	SD	.46	.22	.54	72.85	38.79	43.315
Significant Delay	**Mean**	2.41	1.17	3.58	58.61	27.23	35.89
	Median	2.00	1.00	3.00	31.00	14.00	25.00
	SD	.59	.43	.80	94.71	38.32	41.264
Total	**Mean**	2.23	1.06	3.29	49.61	25.83	38.21
	Median	2.00	1.00	3.00	30.00	11.00	26.00
	SD	.48	.25	.58	75.35	38.74	43.12
P value		**<0.001**	**<0.001**	**<0.001**	0.07	0.58	0.41

Significantly higher tertiary delays were associated with higher number of Number of doctors/hospitals visited before start of cancer treatment, Number of hospitals visited for cancer treatment and Total Number of doctors/ hospitals visited (P<0.001) with moderate strength of association.

Table 89: Primary delay Vs. Tertiary Delay

Primary Delay	Tertiary Delay		Total	Pearson Chi-square P Value	Relative Risk (95% Confidence Interval)
	Acceptable Delay	Significant Delay			
Acceptable Delay	855	88	943	0.38	NS
Significant Delay	1014	119	1133		
Total	**1869**	**207**	**2076**		

Table 90: Referral Delay Vs. Tertiary Delay

Referral Delay	Tertiary Delay		Total	Pearson Chi-square P Value	Relative Risk (95% Confidence Interval)
	Acceptable Delay	Significant Delay			
Acceptable Delay	1389	145	1534	0.19	NS
Significant Delay	480	62	542		
Total	1869	207	2076		

Table 91: Secondary Delay Vs. Tertiary Delay

Secondary Delay	Tertiary Delay		Total	Pearson Chi-square P Value	Relative Risk (95% Confidence Interval)
	Acceptable Delay	Significant Delay			
Acceptable Delay	1020	118	1138	0.51	NS
Significant Delay	849	89	938		
Total	1869	207	2076		

Primary, referral or secondary delays did not significantly affect tertiary delays. Once the cancer was diagnosed, the treatment was initiated without delay in 90% of patients. Similarly, distance from home to healthcare facilities did not significantly affect tertiary delays.

Table 92: Tertiary Delay Vs. Distance from Health Facilities

Distance from Health Facilities		Tertiary Delay		Total	Pearson Chi-square P Value
		Acceptable Delay	Significant Delay		
Nearest GP/PHC	**1-10 Km**	1741	195	1936	0.7 (NS)
	11-20 Km	108	10	118	
	21-30 Km	11	1	12	
	31-40 Km	4	0	4	
	41-50 Km	3	0	3	
	>50 Km	2	1	3	
Nearest Speciality Hospital	**1-10 Km**	987	97	1084	0.33 (NS)
	11-20 Km	551	74	625	
	21-30 Km	220	23	243	
	31-40 Km	69	9	78	
	41-50 Km	25	1	26	
	51-75 Km	17	3	20	
Nearest Cancer Centre	**1-10 Km**	295	28	323	0.33 (NS)
	11-20 Km	404	39	443	
	21-30 Km	283	38	321	
	31-40 Km	190	19	209	
	41-50 Km	249	28	277	
	51-75 Km	352	49	401	
	76 -100 Km	96	6	102	
Current Treating Hospital	**1-10 Km**	213	18	231	0.02
	11-20 Km	352	31	383	
	21-30 Km	273	29	302	
	31-40 Km	185	20	205	
	41-50 Km	246	21	267	
	51-75 Km	351	58	409	
	76 -100 Km	135	11	146	
	101-150 Km	62	16	78	

	151-200 Km	27	2	29	
	201-300 Km	12	0	12	
	301-400 Km	9	1	10	
	401-500 Km	3	0	3	
	> 500 Kms	1	0	1	
Total		**1869**	**207**	**2076**	

Table 93:Tertiary Delay Vs. Distance from Health Facilities

Tertiary Delay		**Nearest GP/PHC from home (in Km)**	**Nearest Speciality Govt/Private Hospital (in Km)**	**Nearest Cancer Center (in Km)**	**Distance between home and current treating hospital (in km)**
Acceptable Delay	**Mean**	4.34	12.99	33.67	45.20
	Median	3.00	10.00	28.00	34.00
	SD	4.10	9.45	22.31	45.28
Significant Delay	**Mean**	4.45	13.49	34.60	48.07
	Median	3.00	11.00	28.00	43.00
	SD	4.69	9.76	21.55	36.84
Total	**Mean**	4.35	13.04	33.76	45.49
	Median	3.00	10.00	28.00	35.00
	SD	4.16	9.48	22.23	44.51
P value		0.72	0.47	0.57	**0.03**

The only geographical distance that had an association with tertiary or treatment delays was the distance of home to the current treating hospital. **Tertiary delays were significantly more with the distance from home to current treating hospital (P=0.02**). When we analysed to identify the distance at which there was significant impact on tertiary delay using a ROC curve analysis, we found that **when the distance of the current treating hospital from home**

was 34.5 km or more, there was higher chance of tertiary delay (71% sensitivity, 70% specificity)

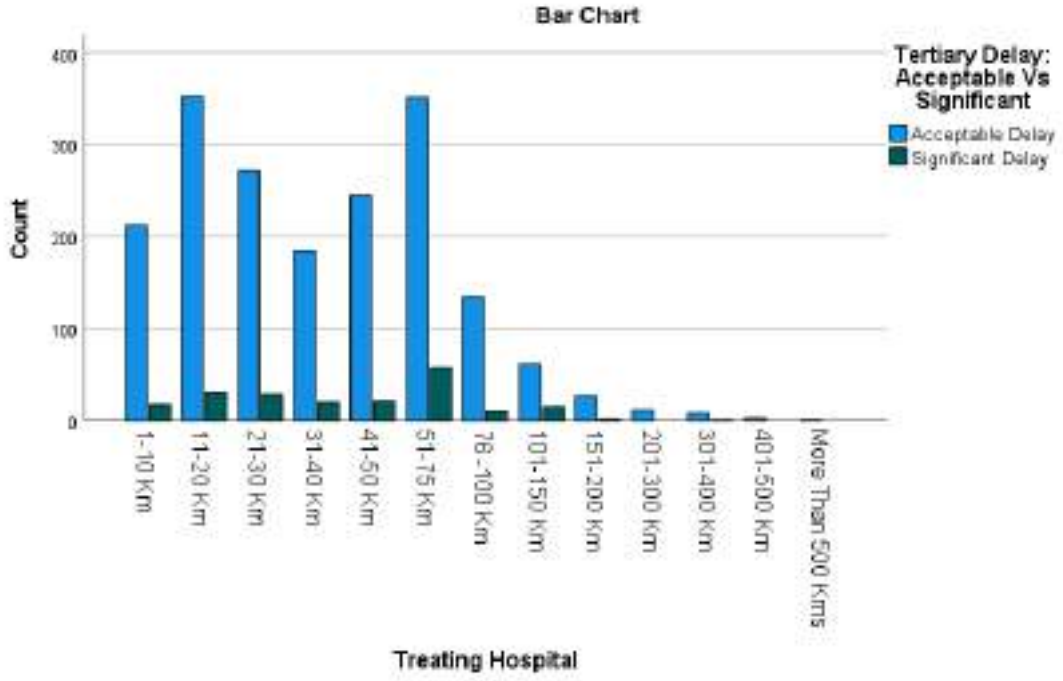


Figure 75:Tertiary Delay Vs. Distance from Health Facilities

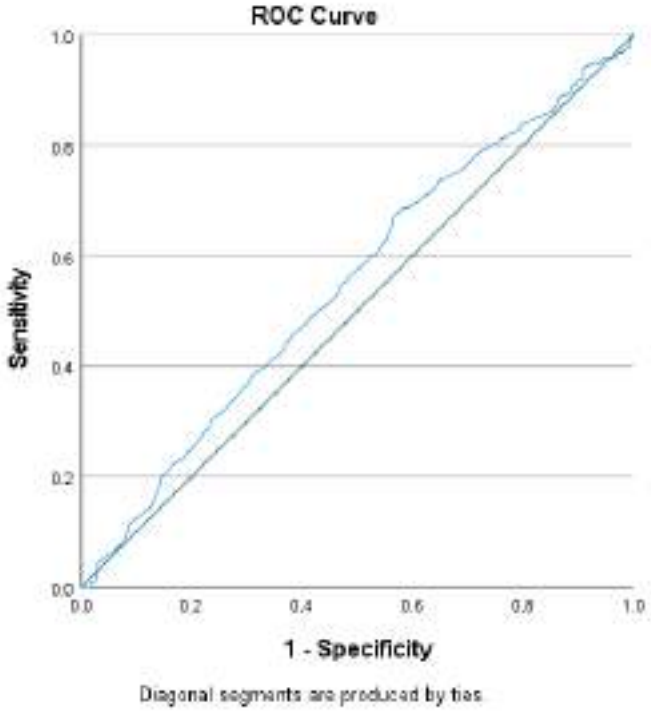


Figure 76: ROC Curve for Tertiary Delay Vs. Distance from Current Treating Hospital

Table 94: ROC Curve for Tertiary Delay Vs. Distance from Current Treating Hospital

Area Under the Curve				
Distance between home and current treating hospital (in km) Vs. Tertiary Delay				
Area	**Std. Error[a]**	**Asymptotic Sig.[b]**	**Asymptotic 95% Confidence Interval**	
			Lower Bound	**Upper Bound**
0.55	0.02	**0.02**	0.507	0.590
The test result variable(s): Distance between home and current treating hospital (in km) has at least one tie between the positive actual state group and the negative actual state group. Statistics may be biased.				
a. Under the nonparametric assumption				
b. Null hypothesis: true area = 0.5				

Table 95:Tertiary Delay Vs. District - First presented

District - First presented	**Tertiary Delay**		**Total**	**Pearson Chi-square P Value**	**Relative Risk (95% Confidence Interval**
	Acceptable Delay	**Significant Delay**			
Different district	302	44	346	0.06	1.35 (0.99-1.84)
Same district	1567	163	1730		
Total	1869	207	2076		

Table 96:Teriary Delay Vs. Hospital where cancer was diagnosed had an oncology department/ specialist

Hospital where cancer was diagnosed had an oncology department/ specialist	**Tertiary Delay**		**Total**	**Pearson Chi-square P Value**	**Relative Risk (95% Confidence Interval**
	Acceptable Delay	**Significant Delay**			
Yes	1484	147	1631	**0.005**	**1.5 (1.13-1.98)**
No	385	60	445		
Total	1869	207	2076		

Absence of an oncologist or an oncology department where the cancer was diagnosed had a significantly increased risk of having a tertiary delay (P=0.005, RR: 1.5 (1.13-198), whereas district of presentation (same vs different) had a non-significantly higher risk of having a tertiary delay, RR: 1.35 (0.99-1.84). The patients' home district did not significantly affect the treatment delays.

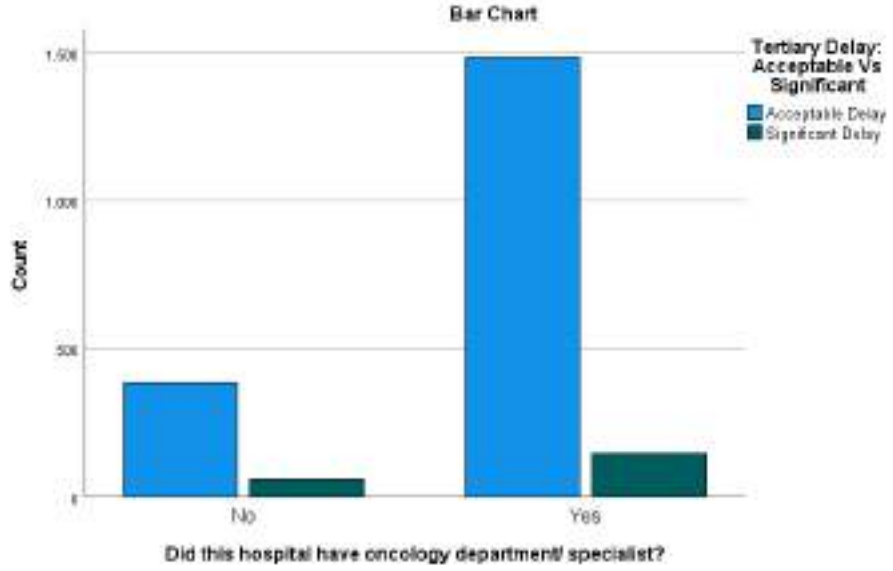


Figure 77:Teriary Delay Vs. Hospital where cancer was diagnosed had an oncology department/ specialist

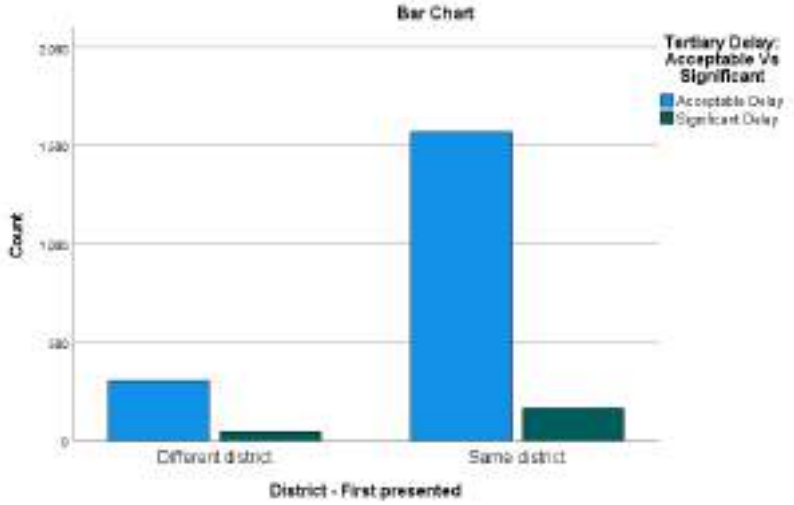


Figure 78:Tertiary Delay Vs. District - First presented

Table 97:Tertiary Delay Vs. Home District

District	Tertiary Delay		Total	Pearson Chi-square P Value
	Acceptable Delay	Significant Delay		
Ariyalur	26	2	28	0.33
Chengalpattu	15	0	15	
Chennai	195	22	217	
Coimbatore	140	19	159	
Cuddalore	32	7	39	
Dharmapuri	12	1	13	
Dindigul	39	6	45	
Erode	96	11	107	
Kallakurichi	3	0	3	
Kancheepuram	28	0	28	
Kanniyakumari	97	8	105	
Karur	30	1	31	
Krishnagiri	14	1	15	
Madurai	108	8	116	
Mayiladuthurai	13	3	16	
Nagapattinam	23	4	27	
Namakkal	64	5	69	
Perambalur	13	2	15	
Pudukottai	41	9	50	
Ramanathapuram	28	3	31	
Ranipet	14	0	14	
Salem	60	4	64	
Sivagangai	40	3	43	
Tenkasi	15	1	16	
Thanjavur	95	19	114	
The Nilgiris	13	2	15	
Theni	39	1	40	
Thirunelveli	63	10	73	

Thiruvallur	45	7	52	
Thiruvarur	34	6	40	
Thoothukudi	26	4	30	
Tirupathur	11	1	12	
Tiruppur	75	4	79	
Tiruvannamalai	33	6	39	
Trichirappalli	126	15	141	
Vellore	76	5	81	
Viluppuram	26	3	29	
Virudhunagar	61	4	65	
Total	**1869**	**207**	**2076**	

Total Medical Related Delay:

The mean **Total Medical Related Delay** defined as the delay in start of cancer treatment from the first point of contact with healthcare (first presentation to GP/PHC) was 51.50 ± 46.34 days ranging from 2 to 440 days (more than 1 year) with a median of 37 days (IQR 23 to 63 days). This data was again non-parametric and skewed to the right. **Significant Medical related delay (more than 56 days or 8 weeks) was seen in 28.9% of patients (n=600).** Medical related delays were **significantly higher in lung cancers** when compared to Gastrointestinal (GI) cancers and Head and Neck Cancers. The other patient demographics did not affect Total medical related delays.

Table 98: Significant Medical Related Delays

Total Medical Related Delay	Patients (N)	Percent (%)
Acceptable Delay (≤ 56 days)	1476	71.1
Significant Delay (> 56 days)	600	28.9
Total	**2076**	**100.0**

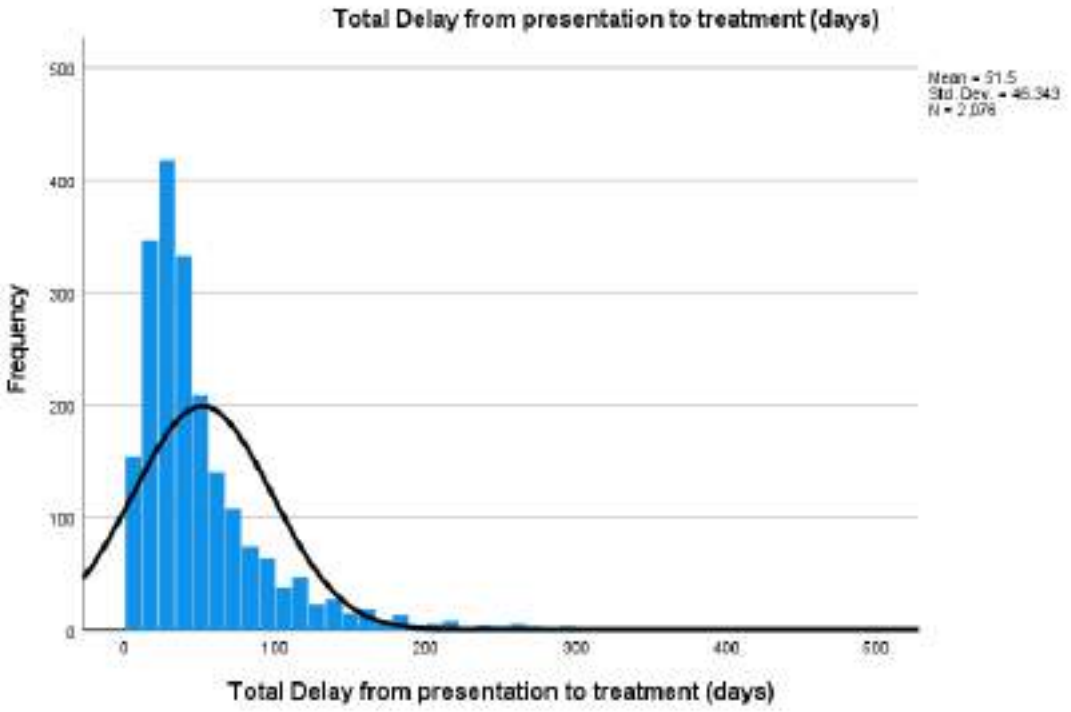


Figure 79:Significant Medical Related Delays

Table 99: Medical Related Delay Vs. Patient Demographics

Patient Demographics		Total Medical Related Delay		Total	Pearson Chi-square P Value
		Acceptable Delay	Significant Delay		
Cancer Site	**GI Cancers**	650	271	921	**0.005**
	Head & Neck Cancers	650	226	876	
	Lung Cancers	**174**	**102**	**276**	
	Not Known	2	1	3	
Cancer Site	**Anal Canal**	13	8	21	0.11 (NS)
	Appendix	3	3	6	
	Bile ducts	6	1	7	
	Colon	91	41	132	
	Esophagus	147	59	206	
	Gall bladder	15	6	21	
	Liver	19	4	23	
	Pancreas	26	8	34	
	Rectum	161	76	237	
	Small Intestine	4	3	7	
	Stomach	165	62	227	
	Oral	530	180	710	
	Pharynx/Larynx	120	46	166	
	Lung	174	102	276	
	Not Known	2	1	3	
Cancer Stage	**1**	40	14	54	0.43 (NS)
	2	346	125	471	
	3	810	333	1143	
	4	280	128	408	
Gender	**Female**	506	202	708	0.89 (NS)
	Male	970	398	1368	
	Rural	705	313	1018	0.08 (NS)

Place of residence	**Tribal**	5	0	5	
	Urban	766	287	1053	
Religion	**Christian**	114	44	158	0.12 (NS)
	Hindu	1298	517	1815	
	Muslim	64	39	103	
Socioeconomic Status (BG Prasad 2023 Scale)	**I Upper Class**	121	37	158	0.11 (NS)
	II Upper Middle Class	241	113	354	
	III Middle Class	303	142	445	
	IV Lower Middle Class	517	205	722	
	V Lower Class	294	103	397	
BMI Groups (Asian Classification)	**1.Underweight**	317	139	456	0.48 (NS)
	2.Normal	611	257	868	
	3.Overweight	224	83	307	
	4.Obese 1	238	96	334	
	5.Obese 2	86	25	111	
Age Groups	**Children**	6	1	7	0.15 (NS)
	Young Adults	590	221	811	
	Middle Age	241	84	325	
	Old Adults	610	283	893	
	Elderly	29	11	40	
Relationship of primary care giver	**Husband**	199	68	267	0.33 (NS)
	Wife	671	288	959	
	Father	30	4	34	
	Mother	34	14	48	
	Daughter	175	81	256	
	Son	235	91	326	
	Grandparent	5	1	6	
	Other Relative	123	50	173	
	Not known	4	3	7	
Marital status	**Never Married**	29	14	43	0.9 (NS)
	Un Married	1	0	1	

	Married	1295	518	1813	
	Divorced	3	2	5	
	Separated	15	7	22	
	Widow (er)	133	59	192	
Type of Family	**Single**	3	3	6	0.19 (NS)
	Nuclear	1144	485	1629	
	Extended	127	46	173	
	Joint	202	66	268	
Patient's Educational Status	**Illiterate**	420	182	602	0.78 (NS)
	Primary school	331	141	472	
	Middle school	260	98	358	
	High school	223	83	306	
	Higher secondary	107	37	144	
	Graduate	112	46	158	
	Professional degree	23	13	36	
Highest education of relatives	**Illiterate**	94	51	145	0.44 (NS)
	High school	148	59	207	
	Middle school	202	73	275	
	Primary school	226	78	304	
	Higher secondary	200	85	285	
	Graduate	503	206	709	
	Professional degree	103	48	151	
Total		**1476**	**600**	**2076**	

Table 100:Medical Related Delay Vs. Patient Demographics

Total Medical Related Delay		Age (years)	BMI	Total members	Total family monthly income (Rs)	Per Capita Monthly Income (Rs/Person)	EORTCQLQC30_Total_Score
Acceptable Delay	**Mean**	56.75	22.11	4.04	15333.94	4124.25	59.92
	Median	58.00	21.48	4.00	10000.00	2500.00	63.00
	SD	12.26	4.83	1.79	24664.99	6000.60	11.13
Significant Delay	**Mean**	56.17	21.72	3.95	13931.67	3856.44	61.43
	Median	56.00	21.11	4.00	10000.00	2500.00	64.00
	SD	11.42	4.60	1.71	14219.92	4324.80	10.59
Total	**Mean**	56.58	22.00	4.01	14928.66	4046.85	60.36
	Median	57.00	21.40	4.00	10000.00	2500.00	63.00
	SD	12.02	4.77	1.77	22163.62	5568.63	10.99
P value		0.32	0.09	0.31	0.19	0.3	**0.01**

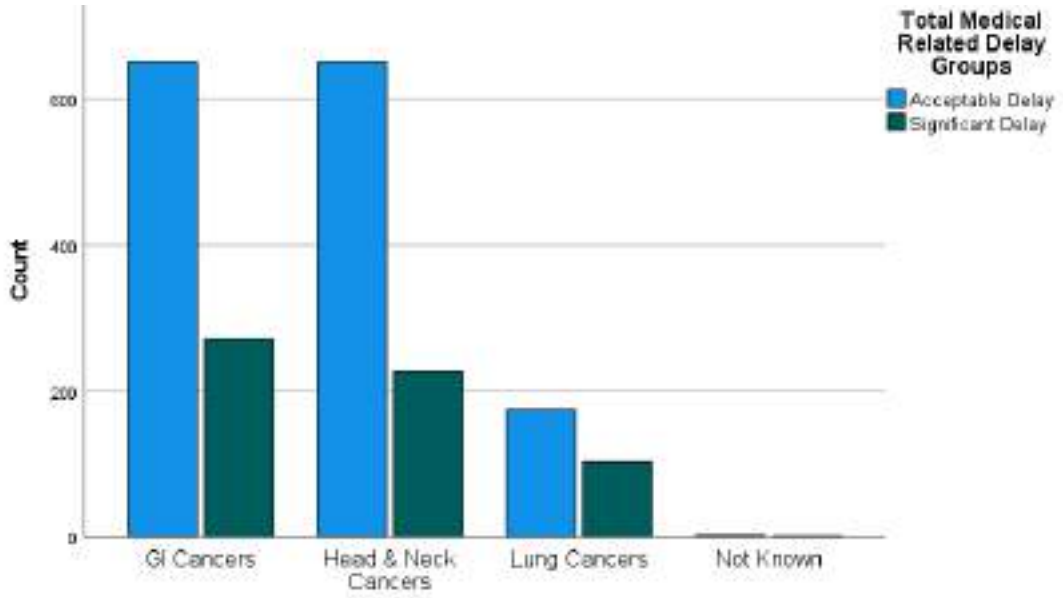


Figure 80:Medical Related Delay Vs. Cancer Site

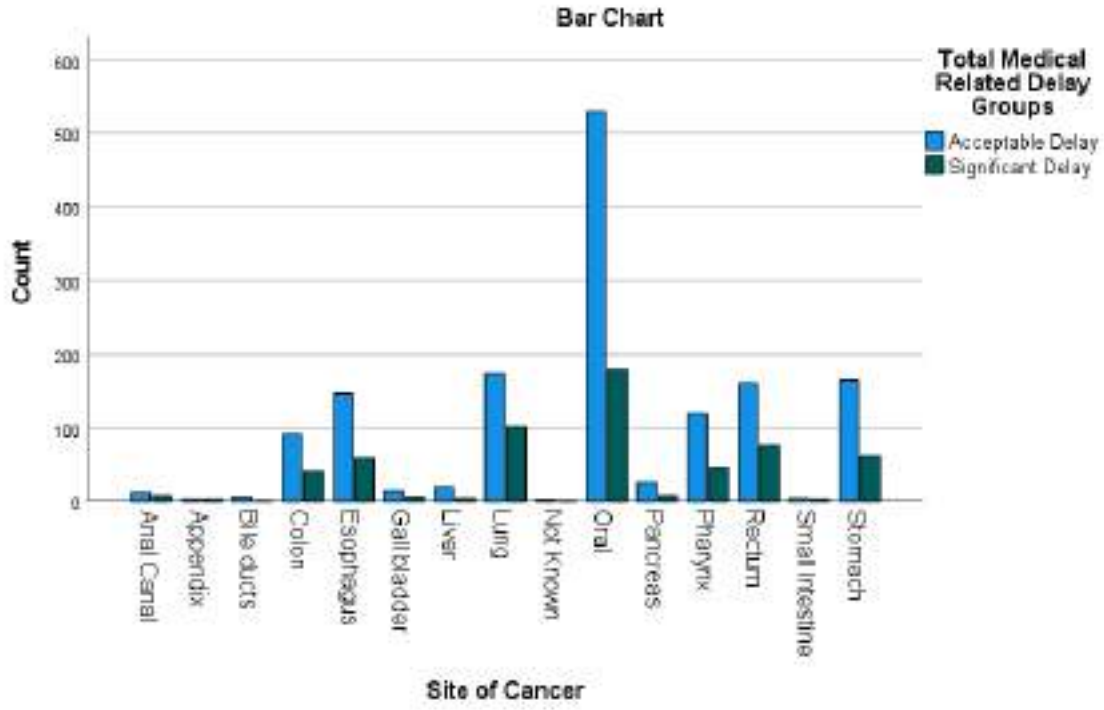


Figure 81:Medical Related Delay Vs. Cancer Site

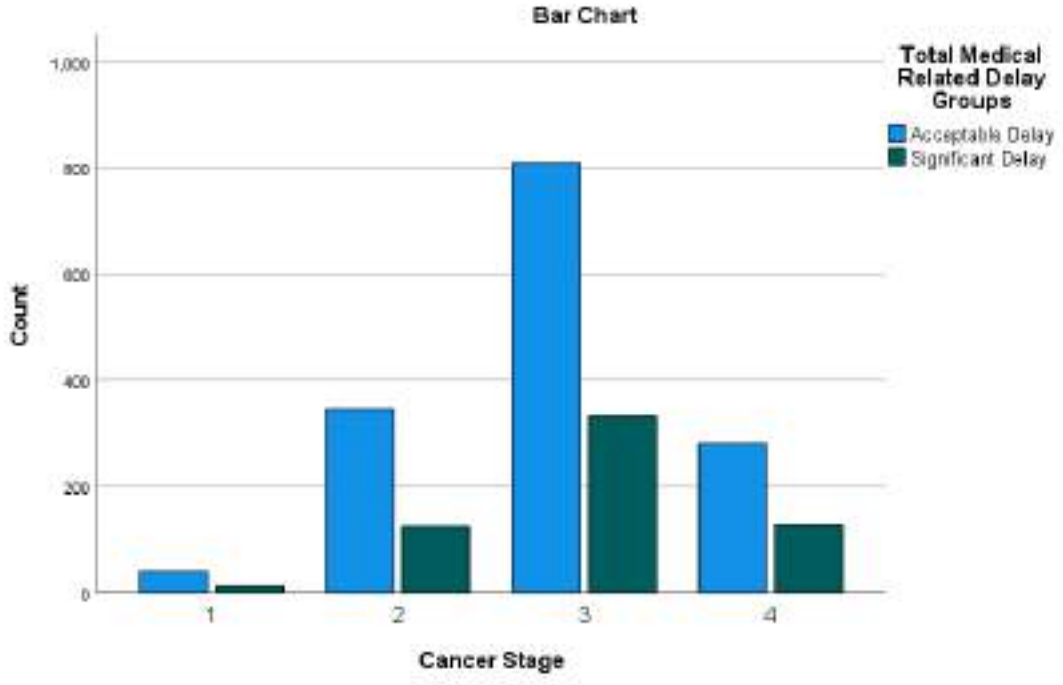


Figure 82:Medical Related Delay Vs. Cancer Stage

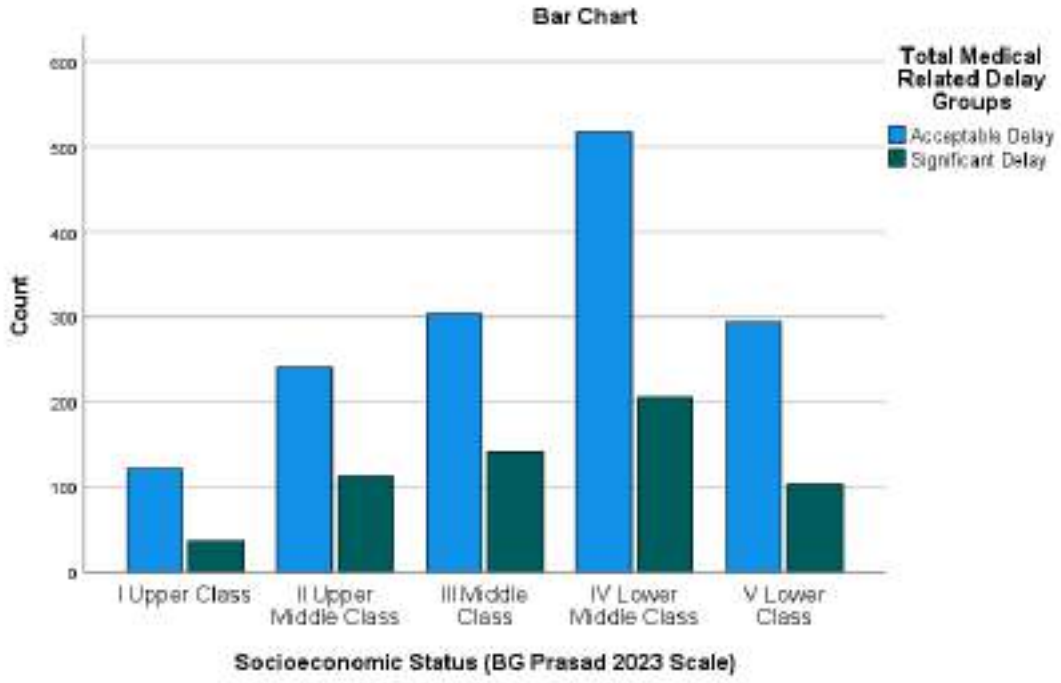


Figure 83:Medical Related Delay Vs. SES

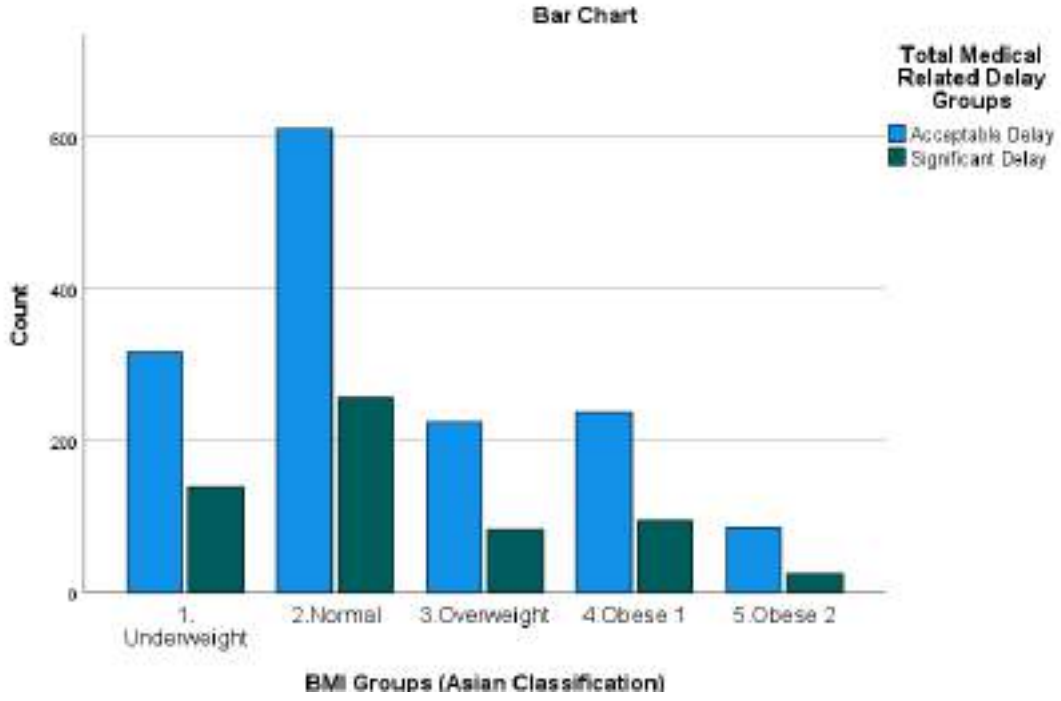


Figure 84:Medical Related Delay Vs. SES

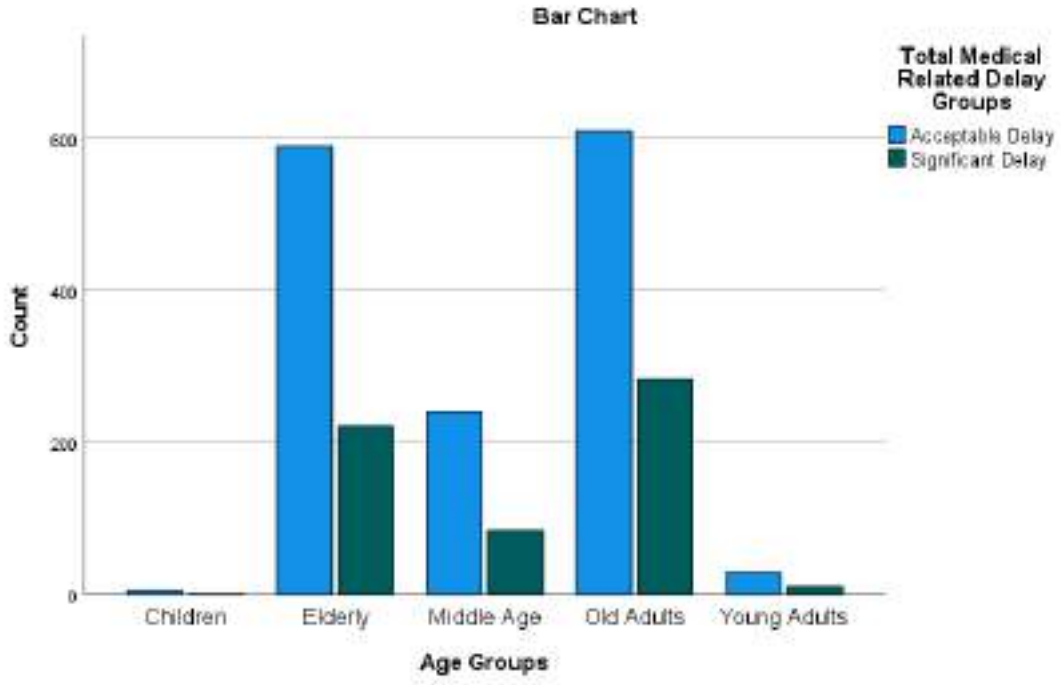


Figure 85:Medical Related Delay Vs. Age

As expected, Total Medical Related Delays were higher with a greater Number of doctors/hospitals visited before start of cancer treatment, Number of hospitals visited for cancer treatment, and Total Number of doctors/ hospitals visited (P<0.001) with moderate strengths of association.

Also, as expected, increase in primary, secondary, referral and tertiary delays also affected total medical related delays. The associations and relative risks for each are given in the tables and figures below. The delays with the highest association with medical related delays were referral and secondary delays (34% and 55% associations respectively and RR: 3.6 (3.1-4.18) and 2.2 (2.04-2.37) respectively)

Table 101: Number of Hospitals and other delays

Total Medical Related Delay		Number of doctors/hospitals visited before start of cancer treatment	Number of hospitals visited for cancer treatment	Total Number of doctors/ hospitals visited	Primary Delay	Referral Delay	Secondary Delay	Tertiary Delay
Acceptable Delay	**Mean**	2.07	1.03	3.11	51.11	11.34	20.08	9.34
	Median	2.00	1.00	3.00	31.00	8.00	19.00	7.00
	SD	0.31	0.19	0.38	74.96	14.50	12.03	8.02
Significant Delay	**Mean**	2.61	1.12	3.73	45.92	61.47	82.83	22.98
	Median	3.00	1.00	4.00	28.50	51.00	68.00	12.00
	SD	0.59	0.36	0.72	76.23	53.76	57.26	27.00
Total	**Mean**	2.23	1.06	3.29	49.61	25.83	38.21	13.29
	Median	2.00	1.00	3.00	30.00	11.00	26.00	8.00
	SD	0.48	0.25	0.58	75.35	38.74	43.11	17.16
P value		**<0.001**	**<0.001**	**<0.001**	0.16	**<0.001**	**<0.001**	**<0.001**
Eta		**0.51**	**0.16**	**0.49**		**0.59**	**0.66**	**0.36**
Eta squared		**0.26**	**0.03**	**0.24**		**0.34**	**0.44**	**0.13**

Table 102: Primary Delay Vs. Total Medical Related Delay

Primary Delay	Total Medical Related Delay		Total	Pearson Chi-square P Value	Relative Risk (95% Confidence Interval)
	Acceptable Delay	Significant Delay			
Acceptable Delay	643	300	943	**0.008**	**1.2 (1.05-1.38)**
Significant Delay	833	300	1133		
Total	**1476**	**600**	**2076**		

Table 103:Referral Delay Vs. Total Medical Related Delay

Referral Delay	Total Medical Related Delay		Total	Pearson Chi-square P Value	Relative Risk (95% Confidence Interval)
	Acceptable Delay	Significant Delay			
Acceptable Delay	1344	190	1534	**<0.001**	**3.6 (3.1-4.18)**
Significant Delay	132	410	542		
Total	b	600	2076		

Table 104:Secondary Delay Vs. Total Medical Related Delay

Secondary Delay	Total Medical Related Delay		Total	Pearson Chi-square P Value	Relative Risk (95% Confidence Interval)
	Acceptable Delay	Significant Delay			
Acceptable Delay	1073	65	1138	**<0.001**	**2.2 (2.04-2.37)**
Significant Delay	403	535	938		
Total	**1476**	**600**	**2076**		

Table 105:Tertiary Delay Vs. Total Medical Related Delay

Tertiary Delay	Total Medical Related Delay		Total	Pearson Chi-square P Value	Relative Risk (95% Confidence Interval)
	Acceptable Delay	Significant Delay			
Acceptable Delay	1423	446	**1869**	**<0.001**	**2.97 (2.35-3.76)**
Significant Delay	53	154	**207**		
Total	**1476**	**600**	**2076**		

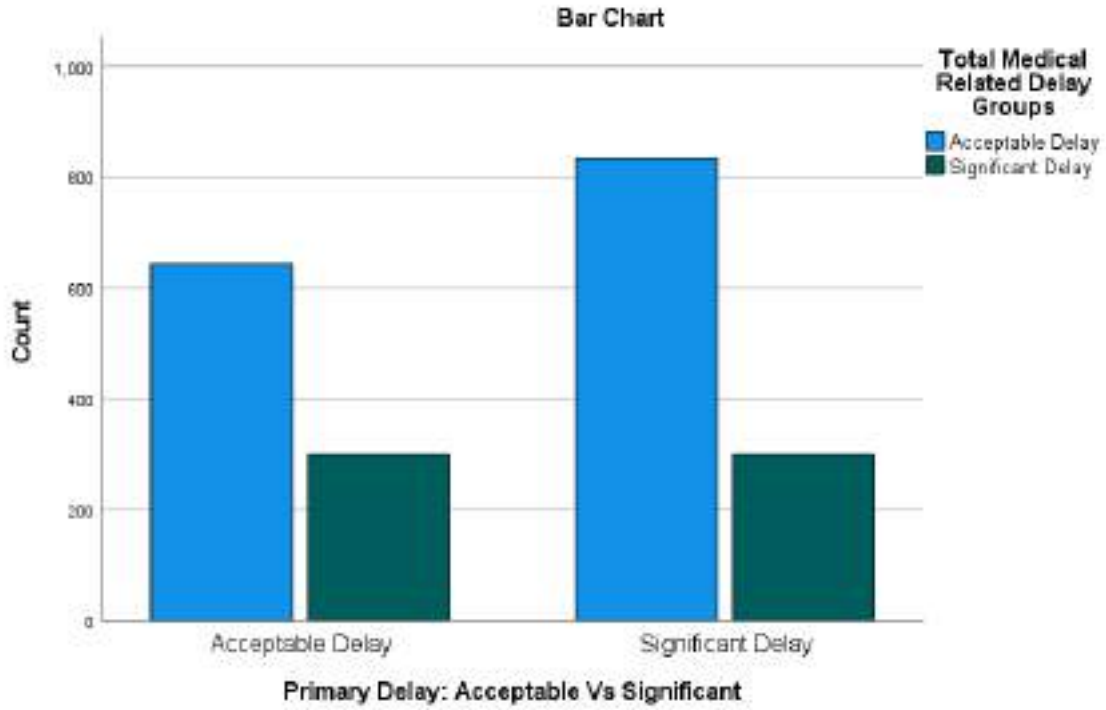


Figure 86:Primary Delay Vs. Total Medical Related Delay

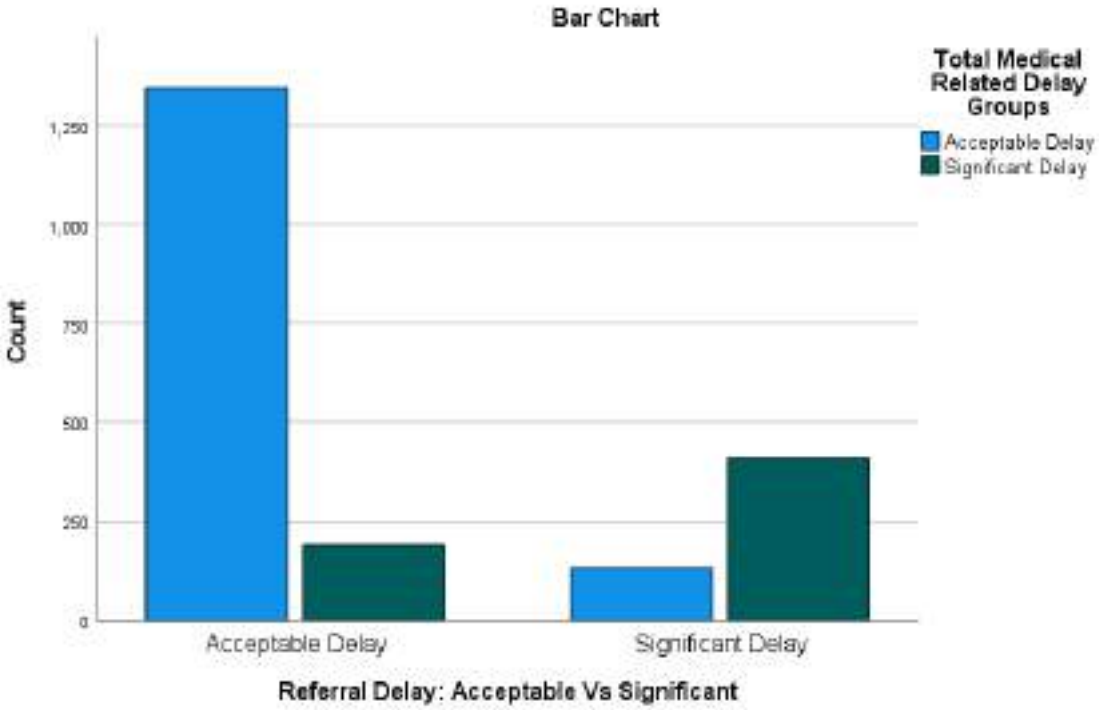


Figure 87:Referral Delay Vs. Total Medical Related Delay

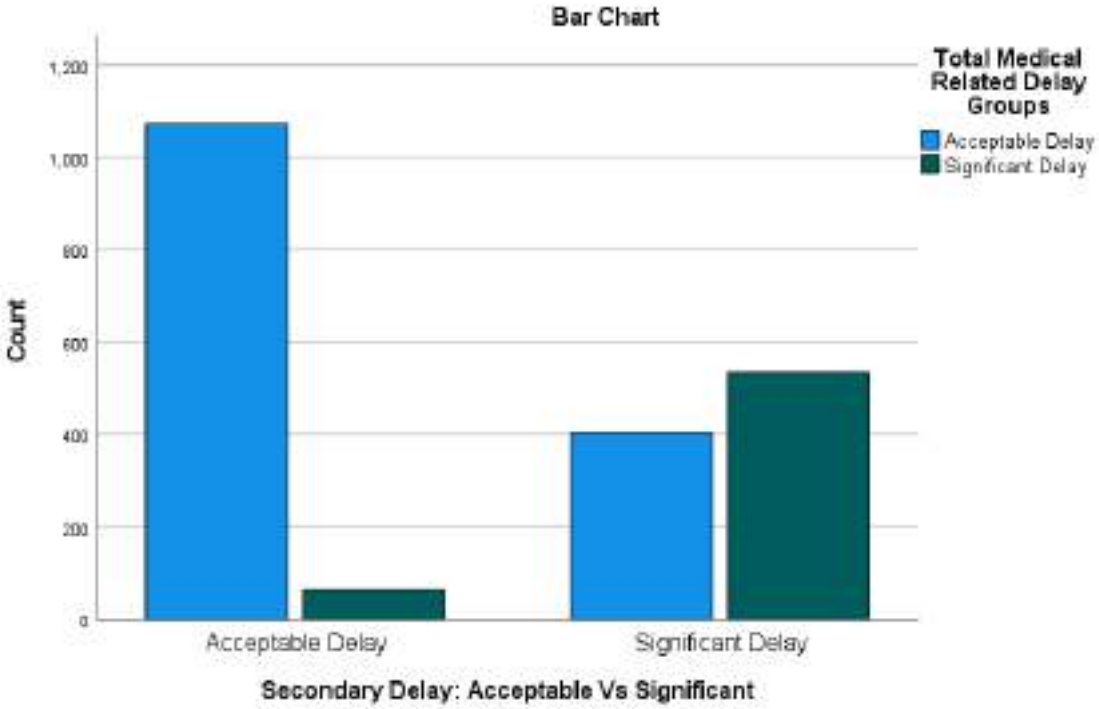


Figure 88:Secondary Delay Vs. Total Medical Related Delay

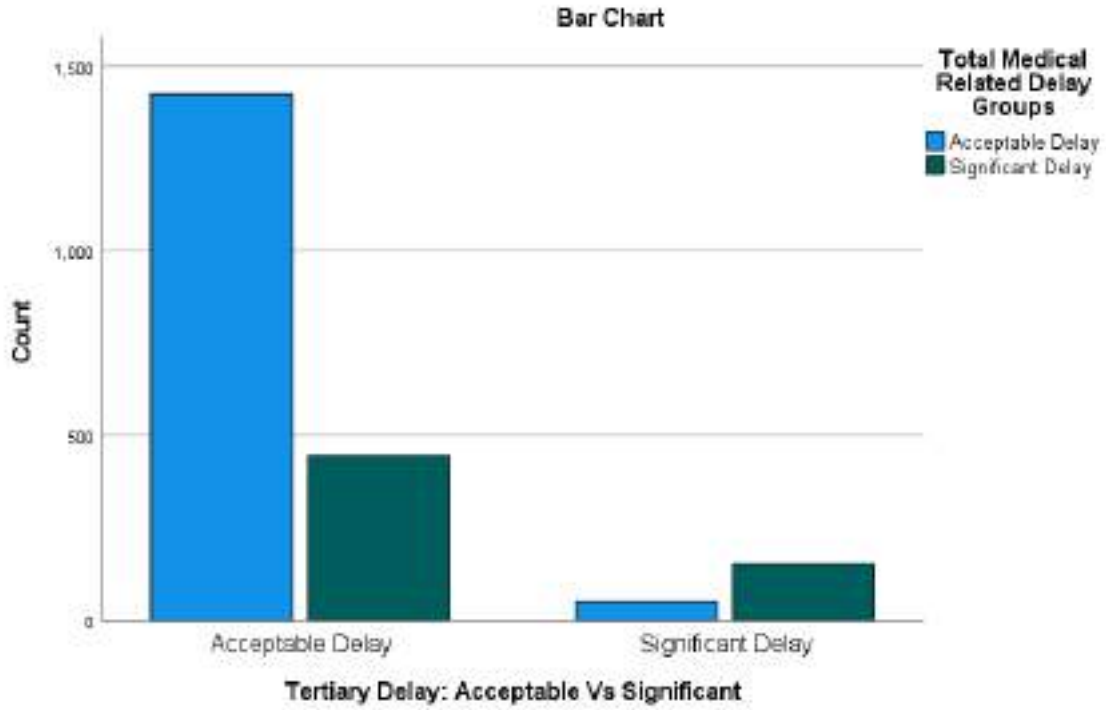


Figure 89:Tertiary Delay Vs. Total Medical Related Delay

The distance from home to healthcare facilities: Nearest GP/PHC from home (in Km), Nearest Speciality Govt/Private Hospital (in Km), Nearest Cancer Centre (in Km) and Distance between home and current treating hospital (in km) did not have a significant effect on the Total medical related delays. Similarly, the patient's home district or whether the patient first presented to a hospital within the same district or not did not affect total medical related delays.

The absence of an oncologist in the hospital where cancer was diagnosed had an increased risk of total medical related delays (RR: 1.11 (1.03-1.18), (P=0.004)

Table 106: Total Medical Related Delay Vs. Distance from Health Facilities

Distance from Health Facilities		**Total Medical Related Delay**			**Pearson Chi-square P Value**
		Acceptable Delay	**Significant Delay**	**Total**	
Nearest GP/PHC	**1-10 Km**	1377	559	1936	0.8 (NS)
	11-20 Km	82	36	118	

	21-30 Km	10	2	12	
	31-40 Km	2	2	4	
	41-50 Km	3	0	3	
	>50 Km	2	1	3	
Nearest Speciality Hospital	**1-10 Km**	785	299	1084	0.7 (NS)
	11-20 Km	430	195	625	
	21-30 Km	175	68	243	
	31-40 Km	55	23	78	
	41-50 Km	17	9	26	
	51-75 Km	14	6	20	
Nearest Cancer Centre	**1-10 Km**	227	96	323	0.36 (NS)
	11-20 Km	326	117	443	
	21-30 Km	221	100	321	
	31-40 Km	159	50	209	
	41-50 Km	189	88	277	
	51-75 Km	279	122	401	
	76 -100 Km	75	27	102	
Current Treating Hospital	**1-10 Km**	164	67	231	0.56 (NS)
	11-20 Km	280	103	383	
	21-30 Km	203	99	302	
	31-40 Km	152	53	205	
	41-50 Km	190	77	267	
	51-75 Km	281	128	409	
	76 -100 Km	104	42	146	
	101-150 Km	56	22	78	
	151-200 Km	23	6	29	
	201-300 Km	11	1	12	
	301-400 Km	9	1	10	
	401-500 Km	2	1	3	
	More Than 500 Kms	1	0	1	
Total		1476	600	2076	

Table 107:Total Medical Related Delay Vs. Distance from Health Facilities

Total Medical Related Delay		Nearest GP/PHC from home (in Km)	Nearest Speciality Govt/Private Hospital (in Km)	Nearest Cancer Center (in Km)	Distance between home and current treating hospital (in km)
Acceptable Delay	**Mean**	4.38	12.90	33.55	46.07
	Median	3.00	10.00	28.00	35.40
	SD	4.22	9.40	22.16	46.43
Significant Delay	**Mean**	4.28	13.38	34.29	44.06
	Median	3.00	10.75	28.00	35.00
	SD	4.01	9.65	22.42	39.39
Total	**Mean**	4.35	33.76	13.04	45.49
	Median	3.00	28.00	10.00	35.00
	SD	4.16	22.23	9.48	44.51
P value		0.63	0.49	0.29	0.35

Table 108:Total Medical Related Delay Vs. District First Presented

District - First presented	Total Medical Related Delay		Total	Pearson Chi-square P Value	Relative Risk (95% Confidence Interval
	Acceptable Delay	Significant Delay			
Different district	250	96	346	**0.06**	**0.95 (0.8-1.14)**
Same district	1226	504	1730		
Total	**1476**	**600**	**2076**		

Table 109: Total Medical Related Delay Vs. Presence of Oncologist

Hospital where cancer was diagnosed had an oncology department/ specialist	Total Medical Related Delay		Total	Pearson Chi-square P Value	Relative Risk (95% Confidence Interval
	Acceptable Delay	Significant Delay			
Yes	542	1089	1631	**0.004**	**1.11 (1.03-1.18)**
No	116	329	445		
Total	**658**	**1418**	**2076**		

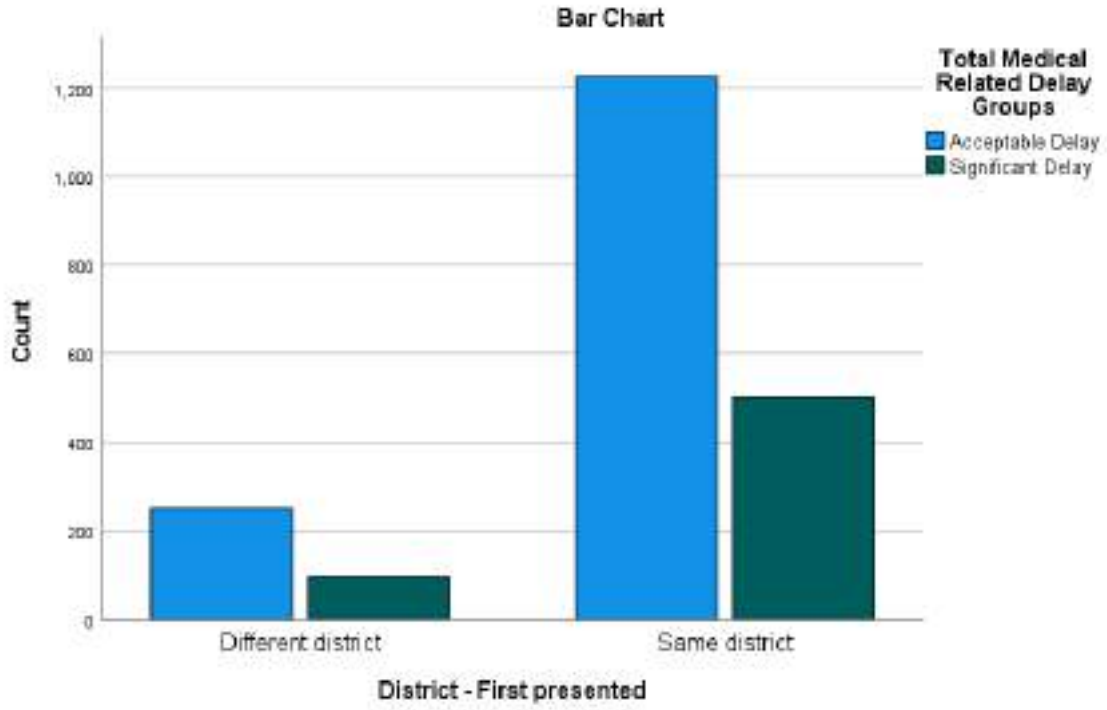


Figure 90:Total Medical Related Delay Vs. District First Presented

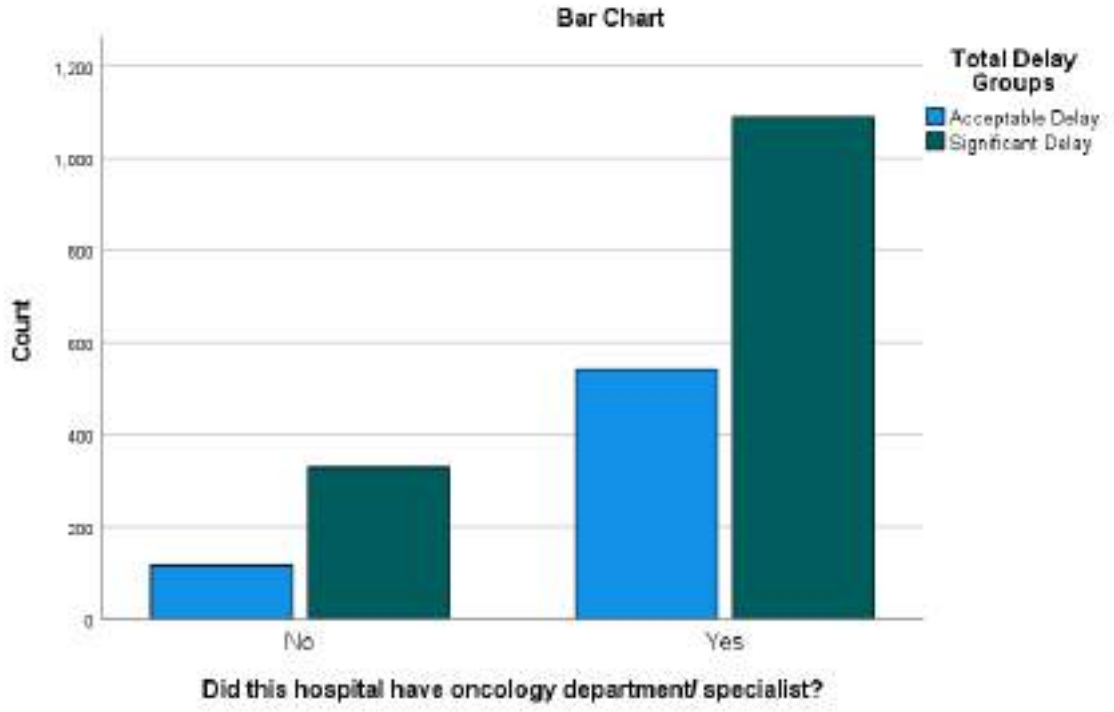


Figure 91:Total Medical Related Delay Vs. Presence of Oncologist

Table 110:Total Medical Related Delay Vs. Home District

District	Total Medical Related Delay		Total	Pearson Chi-square P Value
	Acceptable Delay	Significant Delay		
Ariyalur	17	11	28	0.33
Chengalpattu	10	5	15	
Chennai	151	66	217	
Coimbatore	108	51	159	
Cuddalore	26	13	39	
Dharmapuri	7	6	13	
Dindigul	26	19	45	
Erode	79	28	107	
Kallakurichi	1	2	3	
Kancheepuram	23	5	28	

Kanniyakumari	77	28	105	
Karur	25	6	31	
Krishnagiri	14	1	15	
Madurai	79	37	116	
Mayiladuthurai	13	3	16	
Nagapattinam	17	10	27	
Namakkal	58	11	69	
Perambalur	11	4	15	
Pudukottai	36	14	50	
Ramanathapuram	22	9	31	
Ranipet	10	4	14	
Salem	53	11	64	
Sivagangai	28	15	43	
Tenkasi	10	6	16	
Thanjavur	80	34	114	
The Nilgiris	8	7	15	
Theni	28	12	40	
Thirunelveli	53	20	73	
Thiruvallur	34	18	52	
Thiruvarur	30	10	40	
Thoothukudi	21	9	30	
Tirupathur	7	5	12	
Tiruppur	58	21	79	
Tiruvannamalai	26	13	39	
Trichirappalli	107	34	141	
Vellore	56	25	81	
Viluppuram	23	6	29	
Virudhunagar	44	21	65	
Total	**1476**	**600**	**2076**	

Total Delay:

Mean **Total Delay** defined as time from start of the symptoms to the first cancer treatment was 336.95 ± 250.42 days (range 63 -1470 days), median was 246 days (IQR: 185 - 385 days). This data was again non-parametric and skewed to the right. **Significant Total delay (more than 56 days or 8 weeks) was seen in 68.3% of patients (n=1418).** There was no significant difference in Total Delays between the cancer sites. **There was significant difference in Total Delays between the cancer stages (Higher the stage, longer the delay).** Body Mass Index (BMI) had a significant negative association with Total Delays (lower the BMI, higher the Total Delay)

Table 111: Significant Total Delay

Total Delay	Patients (N)	Percent (%)
Acceptable Delay (≤ 56 days)	658	31.7
Significant Delay (> 56 days)	1418	68.3
Total	**2076**	**100.0**

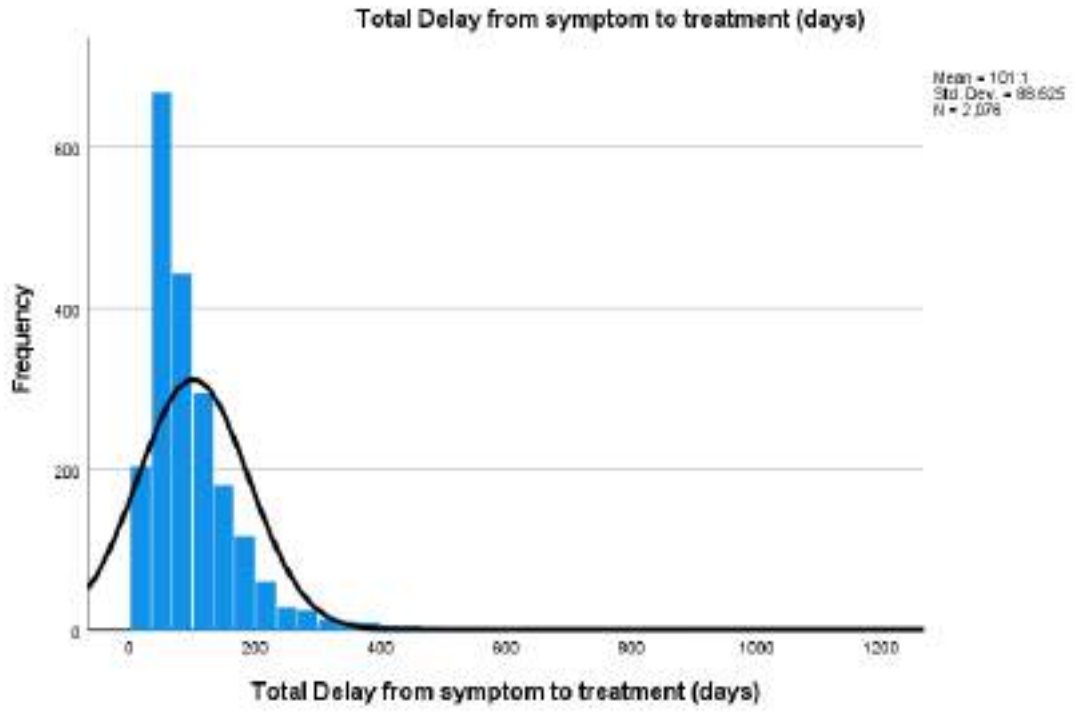


Figure 92:Significant Total Delay

Table 112: Total Delay Vs. Patient Demographics

Patient Demographics		Total Delay			Pearson Chi-square P Value
		Acceptable Delay	Significant Delay	Total	
Cancer Site	**GI Cancers**	297	624	921	0.47 (NS)
	Head & Neck Cancers	281	595	876	
	Lung Cancers	80	196	276	
	Not Known	0	3	3	
Cancer Site	**Anal Canal**	5	16	21	0.39 (NS)
	Appendix	1	5	6	
	Bile ducts	2	5	7	
	Colon	42	90	132	
	Esophagus	67	139	206	
	Gall bladder	12	9	21	
	Liver	12	11	23	
	Pancreas	11	23	34	
	Rectum	73	164	237	
	Small Intestine	2	5	7	
	Stomach	70	157	227	
	Oral	230	480	710	
	Pharynx/Larynx	51	115	166	
	Lung	80	196	276	
	Not Known	0	3	3	
Cancer Stage	**1**	23	31	54	**0.004**
	2	176	295	471	
	3	**343**	**800**	**1143**	
	4	**116**	**292**	**408**	
Gender	**Female**	241	467	708	0.1 (NS)
	Male	417	951	1368	
	Rural	309	709	1018	0.4 (NS)

Place of residence	**Tribal**	2	3	5	
	Urban	347	706	1053	
Religion	**Christian**	48	110	158	0.1 (NS)
	Hindu	587	1228	1815	
	Muslim	23	80	103	
Socioeconomic Status (BG Prasad 2023 Scale)	**I Upper Class**	59	99	158	0.09 (NS)
	II Upper Middle Class	109	245	354	
	III Middle Class	121	324	445	
	IV Lower Middle Class	244	478	722	
	V Lower Class	125	272	397	
BMI Groups (Asian Classification)	**1.Underweight**	126	330	456	**0.02**
	2.Normal	261	607	868	
	3.Overweight	107	200	307	
	4.Obese 1	**122**	**212**	**334**	
	5.Obese 2	**42**	**69**	**111**	
Age Groups	**Children**	4	3	7	0.05 (NS)
	Young Adults	273	538	811	
	Middle Age	114	211	325	
	Old Adults	255	638	893	
	Elderly	12	28	40	
Relationship of primary care giver	**Husband**	103	164	267	**0.008**
	Wife	287	672	959	
	Father	18	16	34	
	Mother	11	37	48	
	Daughter	81	175	256	
	Son	104	222	326	
	Grandparent	4	2	6	
	Other Relative	**48**	**125**	**173**	
	Not known	2	5	7	
Marital status	**Never Married**	14	29	43	0.28 (NS)
	Un Married	1	0	1	

	Married	579	1234	1813	
	Divorced	3	2	5	
	Separated	4	18	22	
	Widow (er)	57	135	192	
Type of Family	**Single**	0	6	6	0.13 (NS)
	Nuclear	512	1117	1629	
	Extended	50	123	173	
	Joint	96	172	268	
Patient's Educational Status	**Illiterate**	172	430	602	0.33 (NS)
	Primary school	149	323	472	
	Middle school	122	236	358	
	High school	104	202	306	
	Higher secondary	53	91	144	
	Graduate	49	109	158	
	Professional degree	9	27	36	
Highest education of relatives	**Illiterate**	44	101	145	0.17 (NS)
	High school	70	137	207	
	Middle school	104	171	275	
	Primary school	96	208	304	
	Higher secondary	95	190	285	
	Graduate	202	507	709	
	Professional degree	47	104	151	
Total		658	1418	2076	

Similarly, the relationship of the primary care giver (P=0.008) had a significant association with total delays (male primary care giver – lesser delay compared to female primary care giver). The total family income (P=0.04) also had a significant association with total delays (lesser income – more delays)

Table 113:Total Delay Vs. Patient Demographics

Total Delay		Age (years)	BMI	Total members	Total family monthly income (Rs)	Per Capita Monthly Income (Rs/ Person)	EORTCQ LQC30 Total Score
Acceptable Delay	**Mean**	56.84	22.50	4.07	16411.25	4323.05	59.74
	Median	58.00	22.10	4.00	10000.00	2500.00	63.00
	SD	12.74	4.71	1.83	31196.45	6883.39	10.86
Significant Delay	**Mean**	56.46	21.77	3.99	14240.69	3918.68	60.65
	Median	57.00	21.09	4.00	10000.00	2500.00	63.50
	SD	11.68	4.78	1.74	16327.89	4836.21	11.05
Total	**Mean**	56.58	22.00	4.01	14928.66	4046.85	60.36
	Median	57.00	21.40	4.00	10000.00	2500.00	63.00
	SD	12.02	4.77	1.77	22163.62	5568.63	10.99
P value		**0.5**	**0.001**	**0.35**	**0.04**	**0.12**	**0.11**

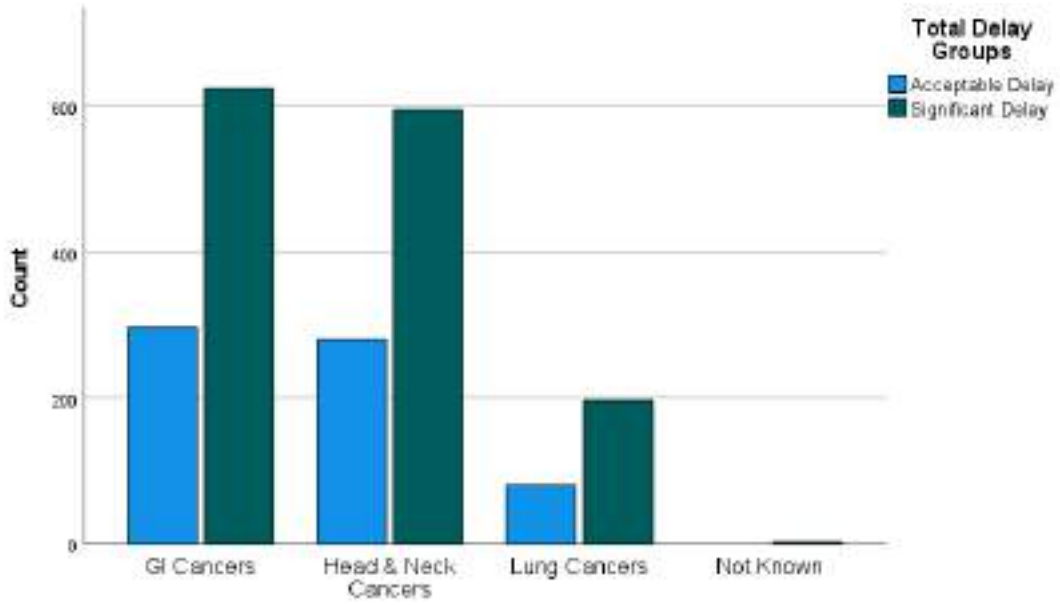


Figure 93: Total Delay Vs. Cancer Site

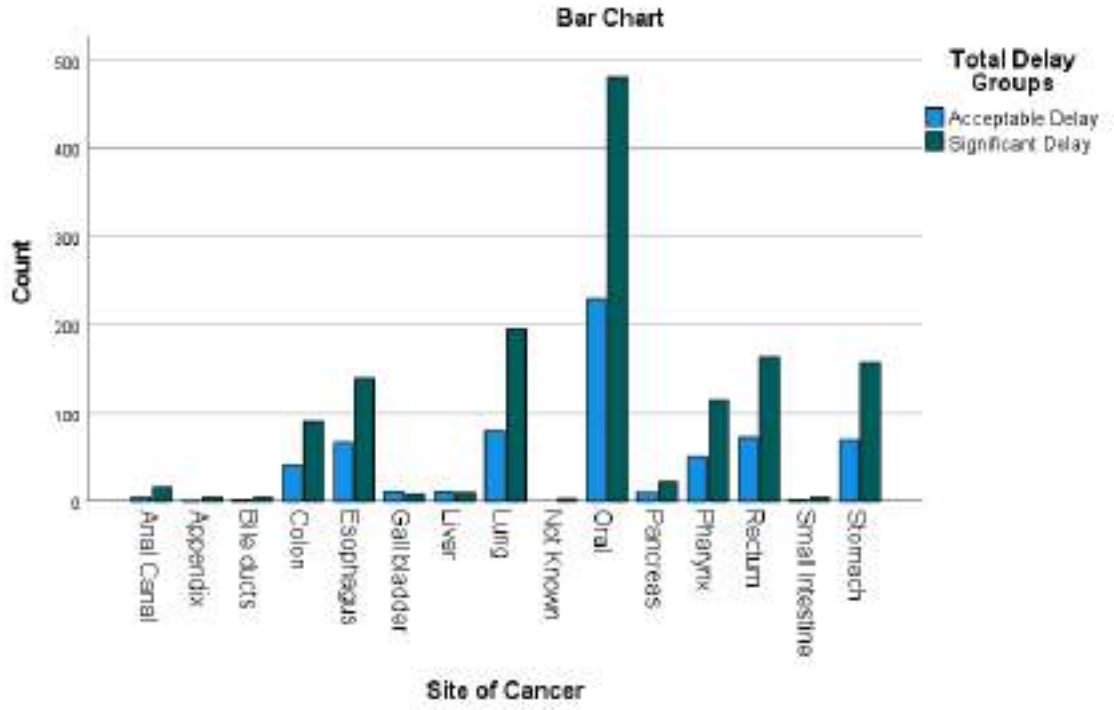


Figure 94:Total Delay Vs. Cancer Site

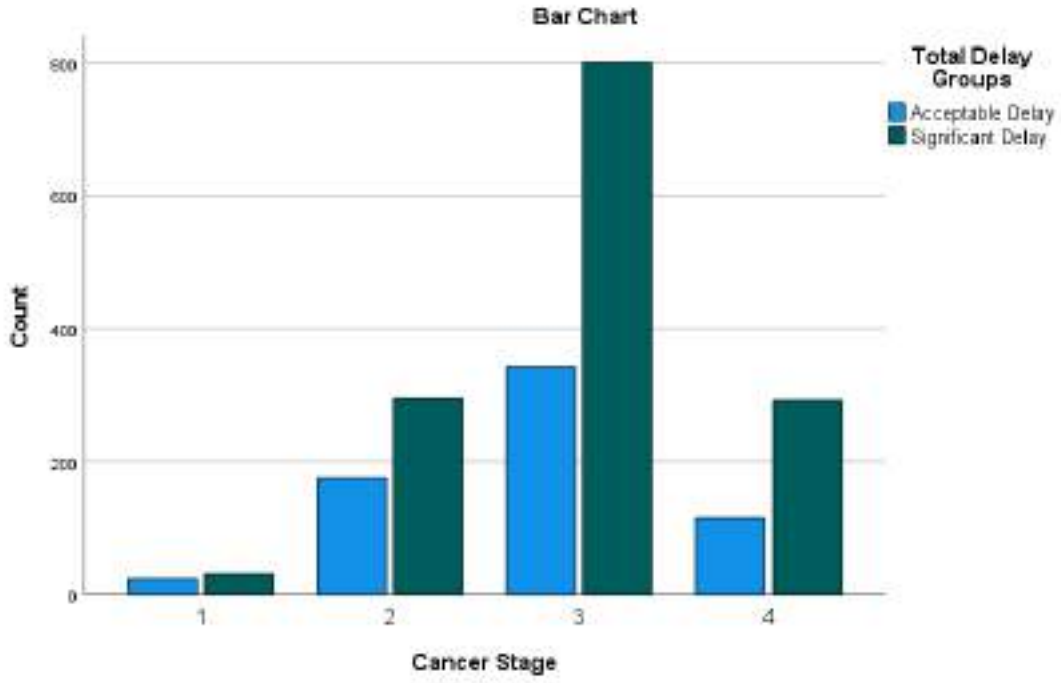


Figure 95: Total Delay Vs. Cancer Stage

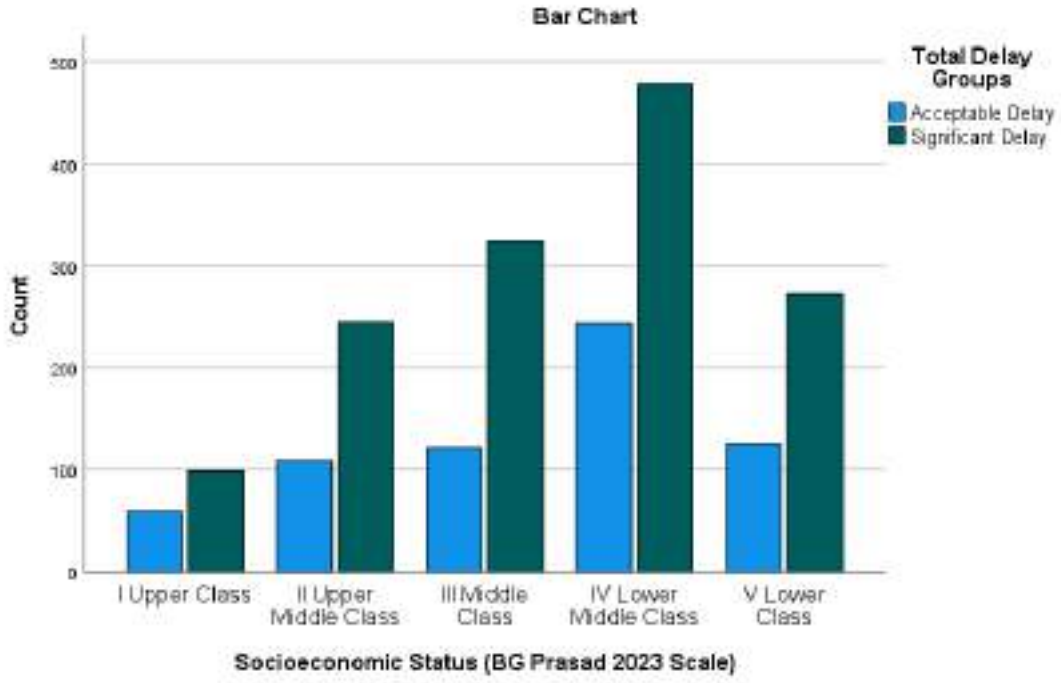


Figure 96: Total Delay Vs. SES

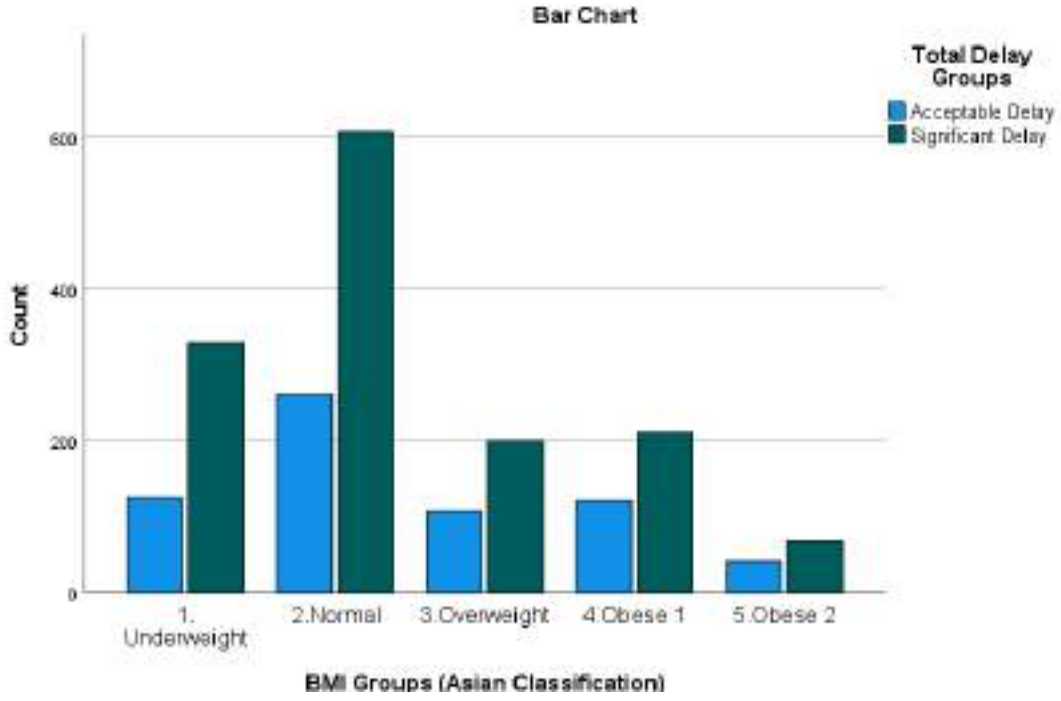


Figure 97: Total Delay Vs. BMI

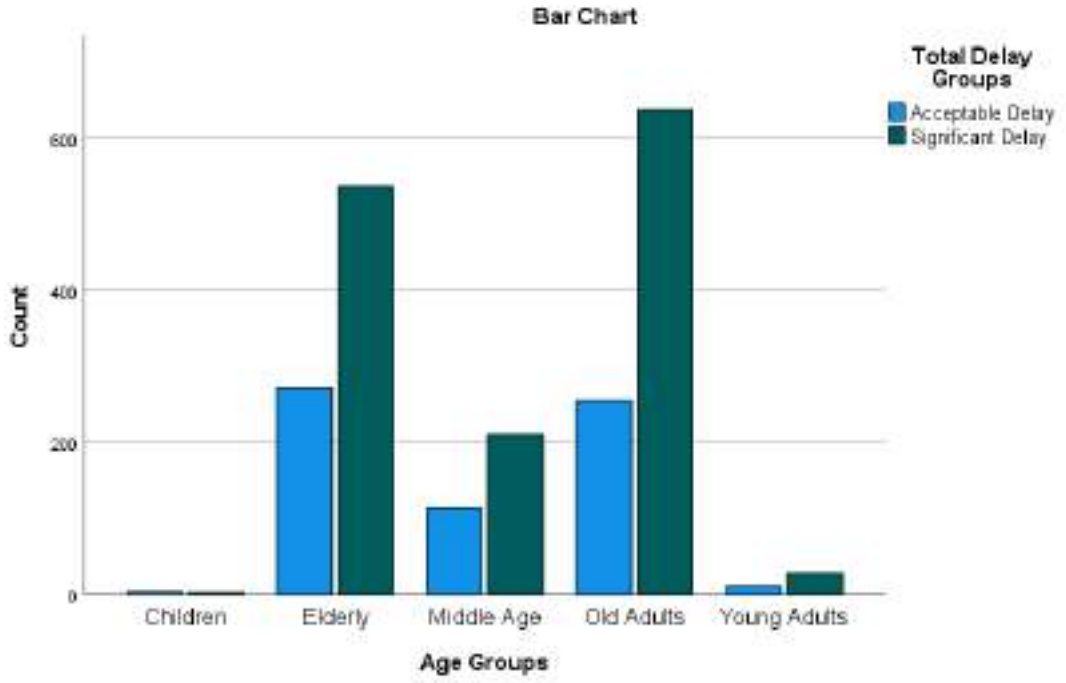


Figure 98: Total Delay Vs. Age Groups

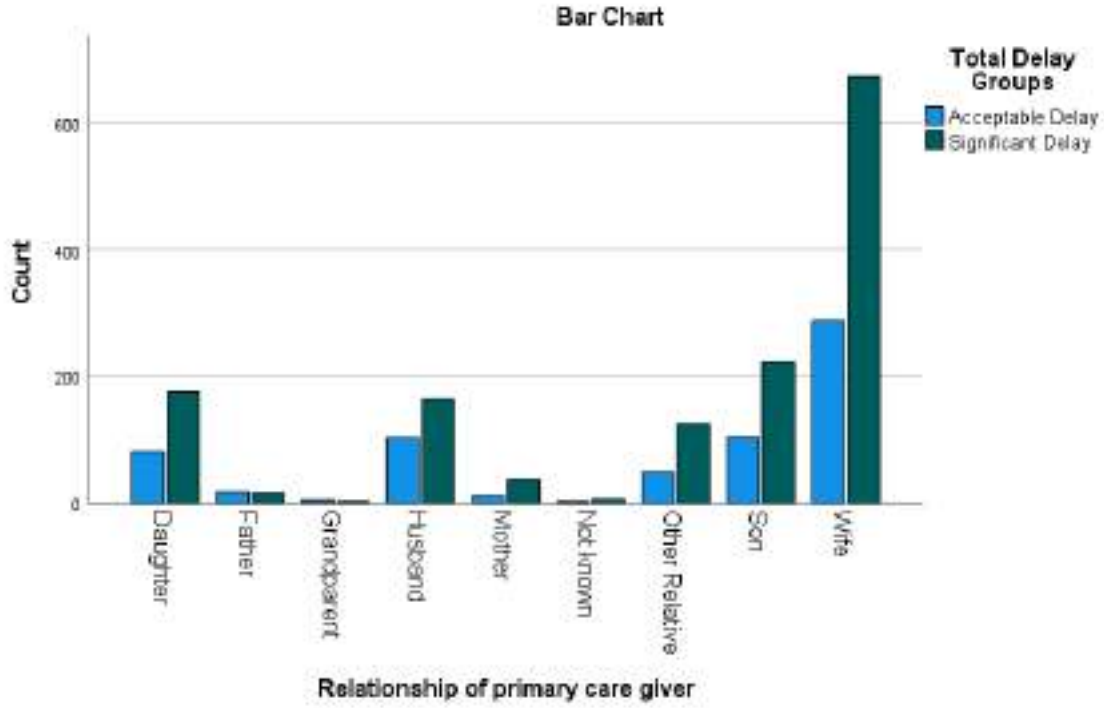


Figure 99: Total Delay Vs. Relationship of the Primary Care Giver

Table 114: Total Delay Vs. Distance from Health Facilities

Distance from Health Facilities		Total Delay			Pearson Chi-square P Value
		Acceptable Delay	Significant Delay	Total	
Nearest GP/PHC	**1-10 Km**	609	1327	1936	0.81 (NS)
	11-20 Km	40	78	118	
	21-30 Km	6	6	12	
	31-40 Km	1	3	4	
	41-50 Km	1	2	3	
	>50 Km	1	2	3	
Nearest Speciality Hospital	**1-10 Km**	361	723	1084	**0.04**
	11-20 Km	194	431	625	
	21-30 Km	72	171	243	
	31-40 Km	26	52	78	
	41-50 Km	**2**	**24**	**26**	
	51-75 Km	**3**	**17**	**20**	
Nearest Cancer Centre	**1-10 Km**	105	218	323	0.48 (NS)
	11-20 Km	154	289	443	
	21-30 Km	96	225	321	
	31-40 Km	65	144	209	
	41-50 Km	83	194	277	
	51-75 Km	117	284	401	
	76 -100 Km	38	64	102	
Current Treating Hospital	**1-10 Km**	80	151	231	0.23 (NS)
	11-20 Km	134	249	383	
	21-30 Km	78	224	302	
	31-40 Km	59	146	205	
	41-50 Km	90	177	267	
	51-75 Km	123	286	409	
	76 -100 Km	52	94	146	

	101-150 Km	21	57	78	
	151-200 Km	9	20	29	
	201-300 Km	6	6	12	
	301-400 Km	5	5	10	
	401-500 Km	1	2	3	
	More Than 500 Kms	0	1	1	
Total		658	1418	2076	

Table 115: Total Delay Vs. Distance from Health Facilities

Total Delay		**Nearest GP/PHC from home (in Km)**	**Nearest Speciality Govt/Private Hospital (in Km)**	**Nearest Cancer Centre (in Km)**	**Distance between home and current treating hospital (in km)**
Acceptable Delay	**Mean**	4.37	12.18	33.14	45.98
	Median	3.00	10.00	28.00	35.50
	SD	4.36	8.33	22.46	47.17
Significant Delay	**Mean**	4.34	13.44	34.05	45.27
	Median	3.00	10.00	28.00	35.00
	SD	4.06	9.94	22.13	43.23
Total	**Mean**	4.35	33.76	13.04	45.49
	Median	3.00	28.00	10.00	35.00
	SD	4.16	22.23	9.48	44.51
P value		0.88	0.005	0.38	0.74

The distance from home to the nearest speciality hospital was significantly associated with Total Delays (P=0.005) (longer the distance – longer the delay – moderate strength of association.

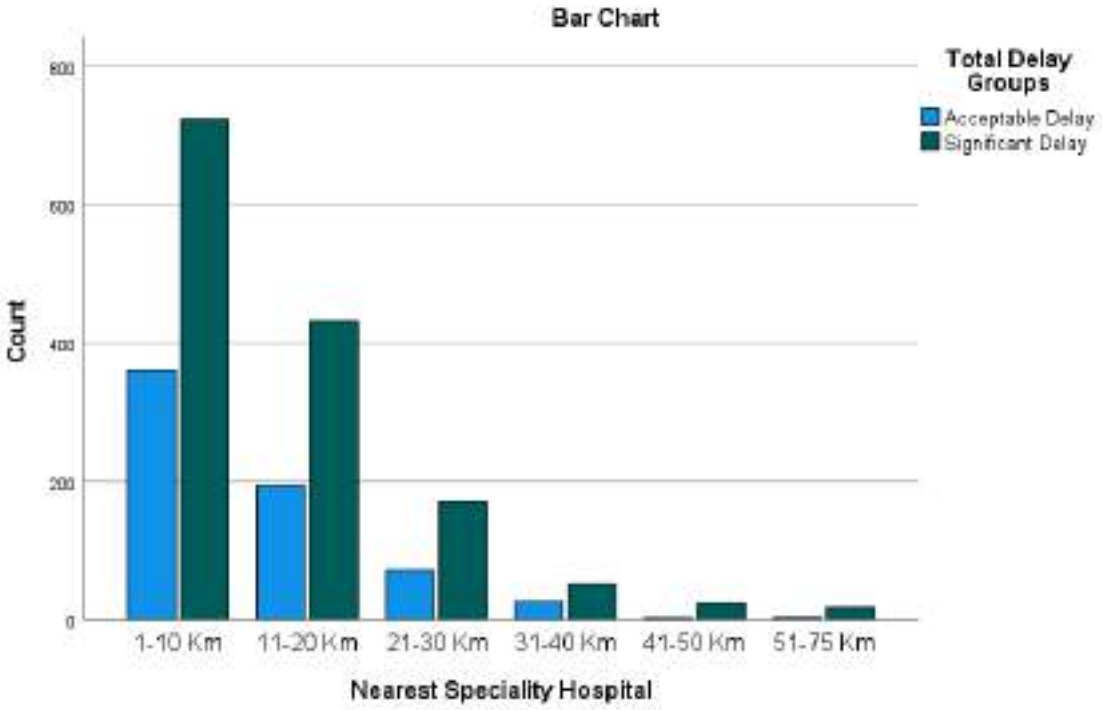


Figure 100: Total Delay Vs. Distance from Home to nearest specialty hospital

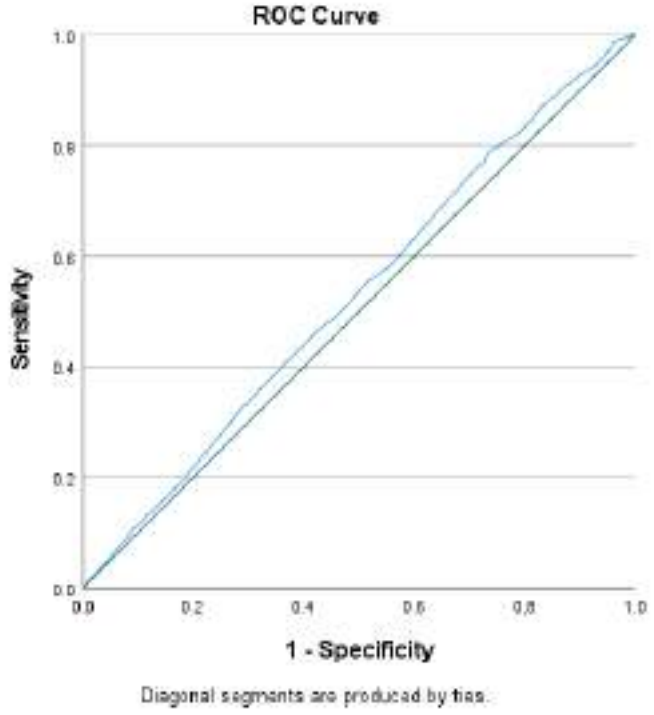


Figure 101:Total Delay Vs. Distance from Home to nearest specialty hospital ROC Curve

Table 116:Total Delay Vs. Distance from Home to nearest specialty hospital ROC Curve

Area Under the Curve				
Test Result Variable(s): Nearest Speciality Govt/Private Hospital (in Km)				
Area	Std. Error[a]	Asymptotic Sig.[b]	Asymptotic 95% Confidence Interval	
			Lower Bound	Upper Bound
.529	.013	.034	.502	.555
The test result variable(s): Nearest Speciality Govt/Private Hospital (in Km) has at least one tie between the positive actual state group and the negative actual state group. Statistics may be biased.				
a. Under the nonparametric assumption				
b. Null hypothesis: true area = 0.5				

Using ROC curve analysis, a cut off distance for home to nearest speciality hospital that leads to a total delay was calculated: 24.25 km had a 91% sensitivity for Total delay and a cutoff of 10.25 km had a sensitivity of 55% and a specificity of 51%.

Patients' home district, district where they first presented, presence of an oncologist in the treating hospital, etc. did not have any significant association with total delays.

Table 117:District - First presented

District - First presented	**Total Delay**		**Total**	**Pearson Chi-square P Value**	**Relative Risk (95% Confidence Interval**
	Acceptable Delay	**Significant Delay**			
Different district	95	251	346	0.06	1.08 (1-1.16)
Same district	563	1167	1730		
Total	658	1418	2076		

Table 118: Total Delay Vs. Home district

District	Total Delay		Total	Pearson Chi-square P Value
	Acceptable Delay	Significant Delay		
Ariyalur	5	23	28	0.11
Chengalpattu	5	10	15	
Chennai	64	153	217	
Coimbatore	66	93	159	
Cuddalore	11	28	39	
Dharmapuri	3	10	13	
Dindigul	14	31	45	
Erode	39	68	107	
Kallakurichi	1	2	3	
Kancheepuram	11	17	28	
Kanniyakumari	26	79	105	
Karur	10	21	31	
Krishnagiri	7	8	15	
Madurai	45	71	116	
Mayiladuthurai	7	9	16	
Nagapattinam	4	23	27	
Namakkal	25	44	69	
Perambalur	4	11	15	
Pudukottai	14	36	50	
Ramanathapuram	8	23	31	
Ranipet	5	9	14	
Salem	24	40	64	
Sivagangai	17	26	43	
Tenkasi	7	9	16	
Thanjavur	25	89	114	
The Nilgiris	4	11	15	
Theni	13	27	40	
Thirunelveli	19	54	73	

Thiruvallur	14	38	52	
Thiruvarur	8	32	40	
Thoothukudi	6	24	30	
Tirupathur	2	10	12	
Tiruppur	28	51	79	
Tiruvannamalai	12	27	39	
Trichirappalli	38	103	141	
Vellore	29	52	81	
Viluppuram	12	17	29	
Virudhunagar	26	39	65	
Total	658	1418	2076	

As expected, there was a significant positive association between total delays and the Number of doctors/hospitals visited before start of cancer treatment, Number of hospitals visited for cancer treatment, and Total Number of doctors/ hospitals visited (P<0.001, moderate strength of associations).

Similarly, there was a significant positive association between total delays and other cancer delays (individually) with the strongest risk factors being referral delays RR: 10.2 (6.7-15.5) and tertiary delays RR: 7.2 (3.9-13.2)

Table 119: Total Delay Vs. Number of Hospitals Visited and other Cancer Delays

Total Delay		**Number of doctors/hospitals visited before start of cancer treatment**	**Number of hospitals visited for cancer treatment**	**Total Number of doctors/ hospitals visited**	**Primary Delay**	**Referral Delay**	**Secondary Delay**	**Tertiary Delay**
Acceptable Delay	**Mean**	2.01	1.03	3.04	15.90	8.41	15.34	7.92
	Median	2.00	1.00	3.00	13.00	5.00	13.00	6.00

	SD	.24	.16	.30	10.59	17.06	10.01	6.63
Significant Delay	**Mean**	2.33	1.08	3.40	65.25	33.91	48.83	15.78
	Median	2.00	1.00	3.00	37.00	19.00	33.00	9.00
	SD	.52	.29	.63	86.54	43.08	48.16	19.78
Total	**Mean**	2.23	1.06	3.29	49.61	25.83	38.21	13.29
	Median	2.00	1.00	3.00	30.00	11.00	26.00	8.00
	SD	0.48	0.25	0.58	75.35	38.74	43.11	17.16
P value		**<0.001**	**<0.001**	**<0.001**	**<0.001**	**<0.001**	**<0.001**	**<0.001**
Eta		**0.31**	**0.09**	**0.29**	**0.31**	**0.31**	**0.36**	**0.21**
Eta squared		**0.09**	**0.008**	**0.09**	**0.09**	**0.09**	**0.13**	**0.05**

Table 120: Primary Delay Vs. Total Delay

Primary Delay	**Total Delay**		**Total**	**Pearson Chi-square P Value**	**Relative Risk (95% Confidence Interval)**
	Acceptable Delay	**Significant Delay**			
Acceptable Delay	515	428	943	**<0.001**	**4.3 (3.7-5.1)**
Significant Delay	143	990	1133		
Total	**658**	**1418**	**2076**		

Table 121: Referral Delay Vs. Total Delay

Referral Delay	**Total Delay**		**Total**	**Pearson Chi-square P Value**	**Relative Risk (95% Confidence Interval)**
	Acceptable Delay	**Significant Delay**			
Acceptable Delay	636	898	1534	**<0.001**	**10.2 (6.7-15.5)**
Significant Delay	22	520	542		
Total	**658**	**1418**	**2076**		

Table 122: Secondary Delay Vs. Total Delay

Secondary Delay	Total Delay		Total	Pearson Chi-square P Value	Relative Risk (95% Confidence Interval)
	Acceptable Delay	Significant Delay			
Acceptable Delay	566	572	1138	**<0.001**	**5.1 (4.1-6.2)**
Significant Delay	92	846	938		
Total	**658**	**1418**	**2076**		

Table 123: Tertiary Delay Vs. Total Delay

Tertiary Delay	Total Delay		Total	Pearson Chi-square P Value	Relative Risk (95% Confidence Interval)
	Acceptable Delay	Significant Delay			
Acceptable Delay	648	1221	1869	**<0.001**	**7.2 (3.9-13.2)**
Significant Delay	10	197	207		
Total	**658**	**1418**	**2076**		

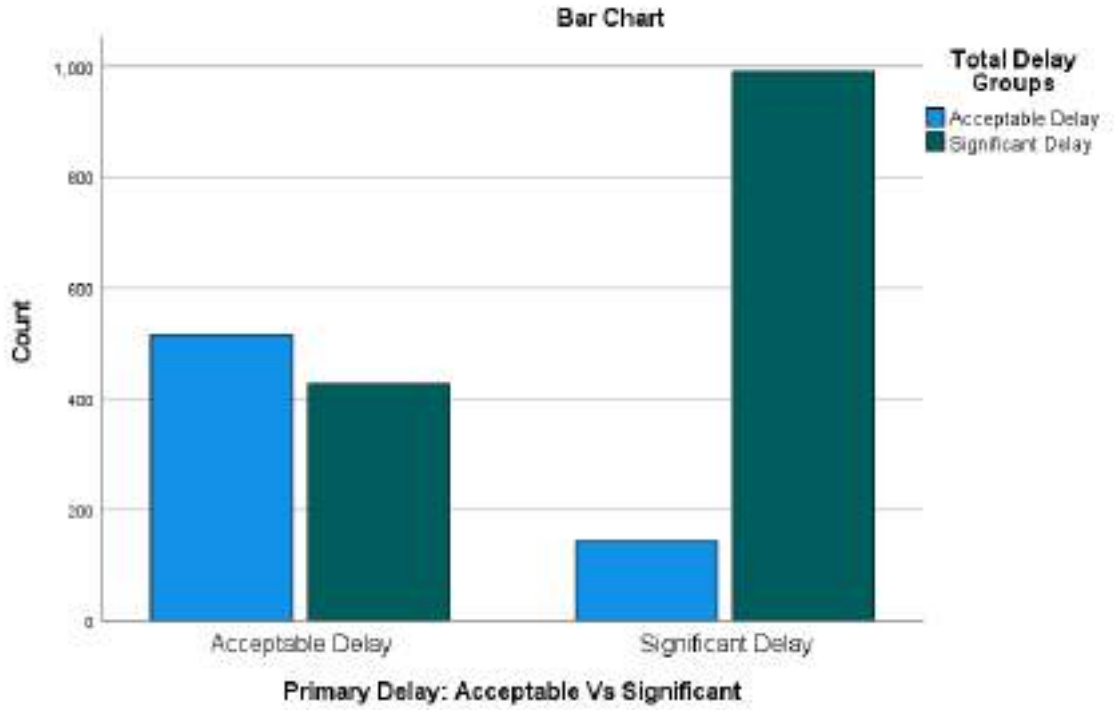


Figure 102:Primary Delay Vs. Total Delay

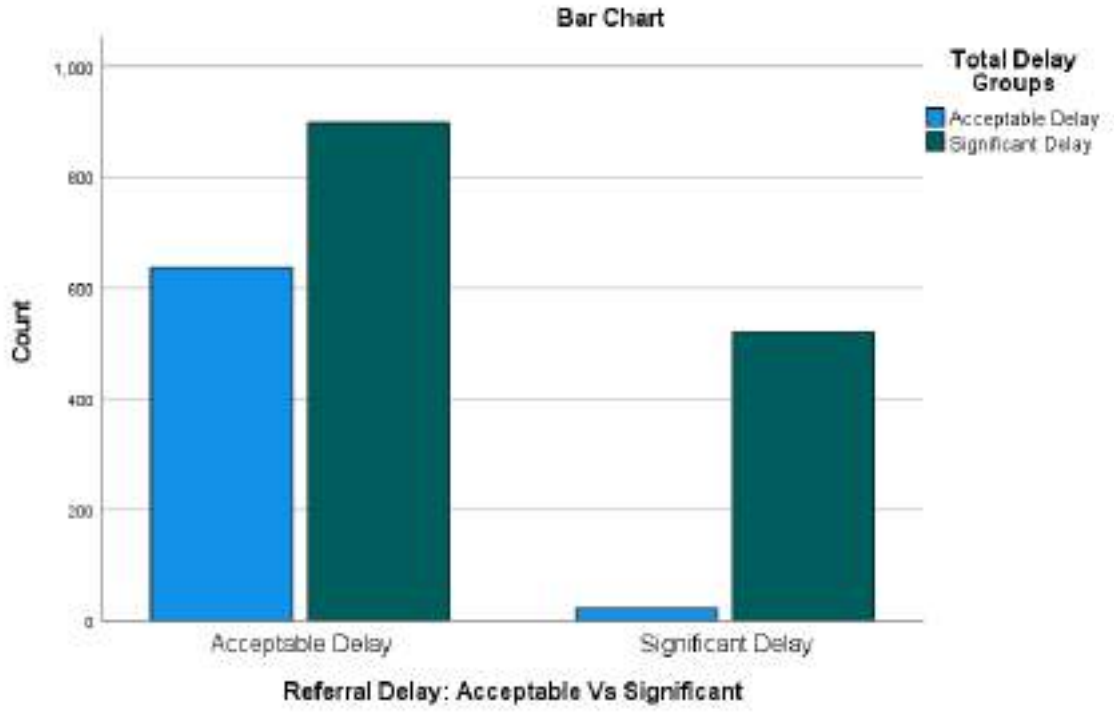


Figure 103:Referral Delay Vs. Total Delay

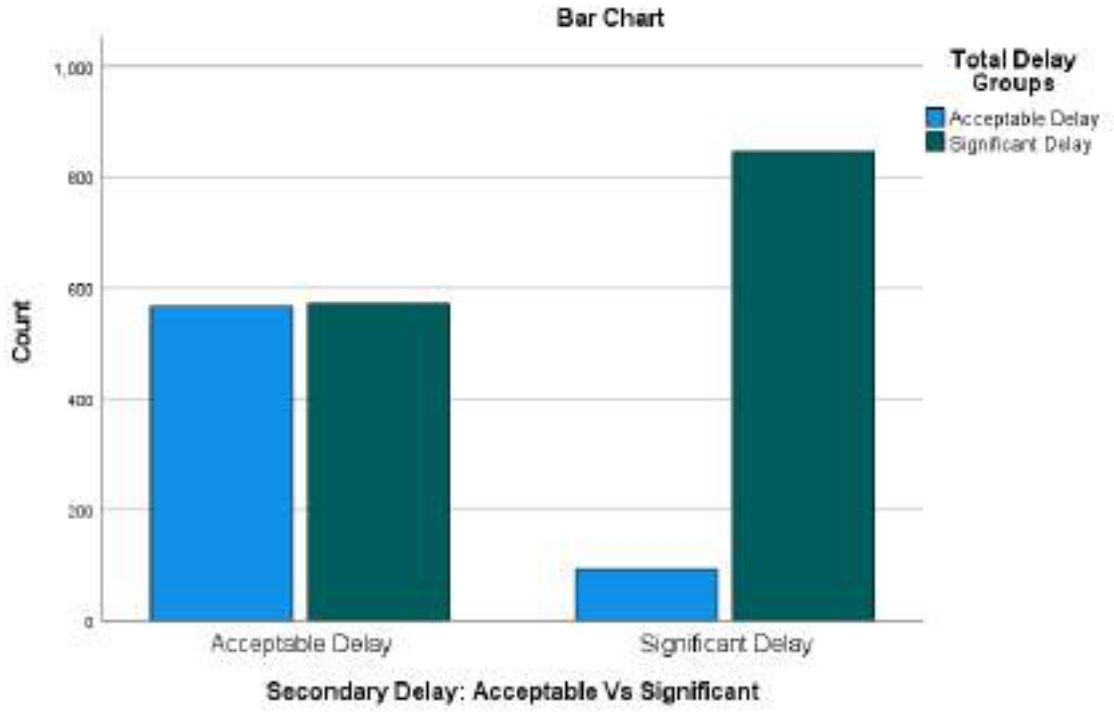


Figure 104:Secondary Delay Vs. Total Delay

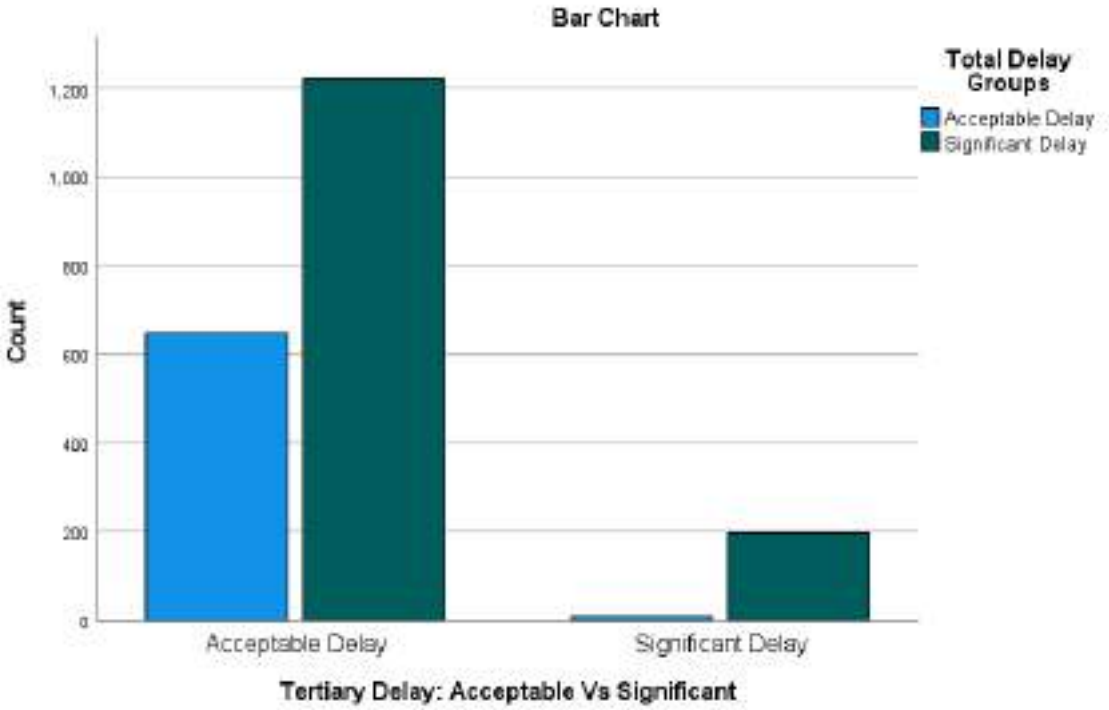


Figure 105:Tertiary Delay Vs. Total Delay

RESULTS - QUALITATIVE STUDY

The Key Informant Interviews (KII) were undertaken with a purposefully selected sample of 6 cancer treating doctors/ Oncologist and 4 primary care doctors who were currently practicing in our study multi centric places. The purpose of the KII was to explore the various determinants of delay for diagnosis and management of cancer.

The result of the 10 Key Informant Interviews was described under two key themes using the thematic analysis: (1) Patient Centric Factors and (2) Health Care system challenges. There were 2 categories under the theme Patient Centric Factors (1) Fear & Denial and (2) Professional Education &Awareness. Two Categories emerged under the theme Health Care System challenges, (1) Infrastructure and (2) Process improvement and standardization.

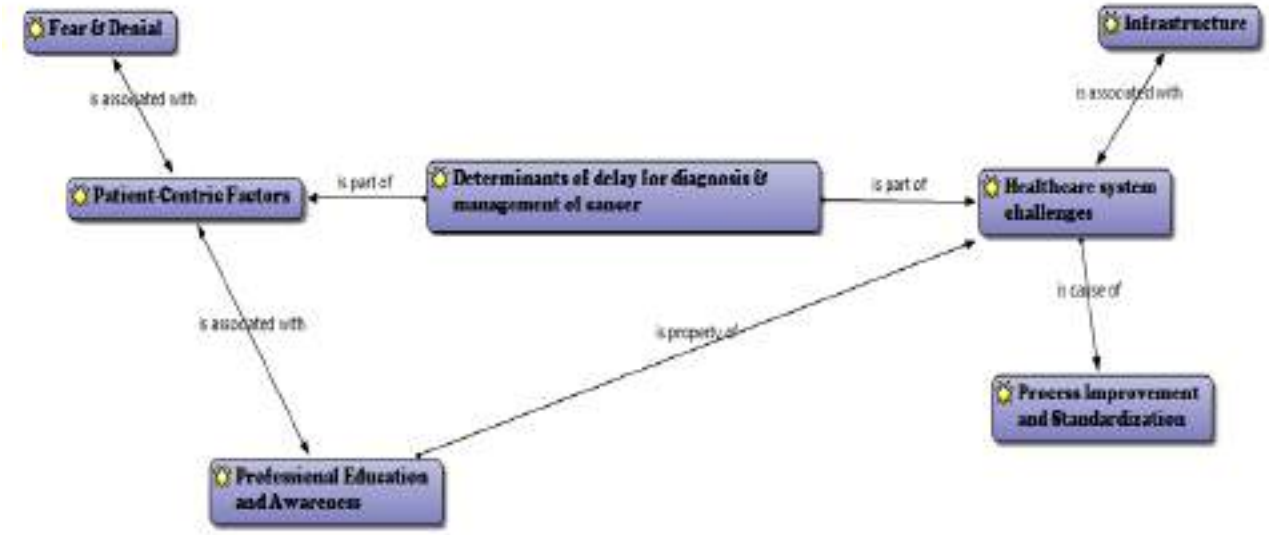


Figure 106:Conceptual Framework: Determinants of delay for Diagnosis & Management of Cancer.

Figure 107:Word Cloud: The Codes Generated.

The codes generated in the content analysis, for the 10 interviews were described in word cloud using QDA Miner Lite Qualitative Analysis Software.

Theme 1: Patient Centric Factors

Category 1.1: Fear & Denial

Subcategory 1.1.1 Financial barriers

Oncologists says most of the cases from rural areas and few from urban also have financial constraints for their day-to-day activities, though in government there is cost free treatment or Insurance Coverage. “Patients often face financial constraints, leading to delays in seeking healthcare, including cancer diagnosis and treatment”

Subcategory 1.1.2 Patient fears

Doctor states that the fear among the patient regarding the investigation and treatment process is existing. “Fear regarding biopsy (myth that cancer spreads by biopsy) among patients, Patients not turning up for biopsy fearing cancer diagnosis" He adds proper counselling and explanation would help to overcome this hurdle for treatment seeking.

Subcategory 1.1.3 Alternative therapy impact

As a combining effect of financial restrictions and fear towards the treatment, Patients are interested in experimenting the AYUSH therapy. “Patients sometimes opt for alternative therapies instead of conventional treatments due to fear or misinformation about cancer treatment side effects”

Category 1.2: Professional Education & Awareness.

Subcategory 1.2.1 Public awareness

Oncologists felt the public awareness also a major concern "Increasing public awareness is crucial to dispel fears and misconceptions, encouraging individuals to seek timely cancer diagnosis.” Another doctor from central part of the state echoed "Public awareness initiatives can help in overcoming challenges such as delayed biopsy reporting and improving accessibility to oncologists.” “Educating the public about cancer symptoms and the importance of early detection is essential for fostering a proactive approach to healthcare."

Subcategory 1.2.2Screening acceptance

Along with the public awareness on the cancer, oncologists urge to motivate and encourage the public to take in screening. “Encouraging screening acceptance among the public is vital to detecting cancers early and improving overall prognosis.” Stressing on early detection and prompt treatment by patient self-driven for cancer screening “Improving access and acceptance of cancer screening can help overcome challenges such as delayed biopsy reporting and treatment delays." "Educating individuals about the benefits of cancer screening is crucial for increasing screening acceptance and facilitating early diagnosis."

Theme 2: Health Care system challenges

Category 2.1: Infrastructure

Subcategory: 2.1.1 Diagnostic challenges

Major concern in the diagnostic delays is interdepartmental collaboration and laboratory departments’ cooperation. "In many institutions, diagnostic challenges arise due to delayed biopsy reporting, often taking 5-7 days, impacting timely cancer diagnosis.” Primary/General Physicians also should have the advanced understanding on the cancer diagnostics." Addressing

challenges in cancer diagnosis requires educating primary care physicians about warning symptoms and appropriate investigations."

Subcategory: 2.1.2 Oncologist accessibility

The oncologist accessibility is questionable in peripheral districts in our state. "Ensuring accessibility to oncologists is crucial, as delayed access may impact the diagnostic process and subsequent cancer management. "Strong referral system should be established to prevent these concerns."Improving access to oncologists, making it easier and mandatory for patients with warning symptoms, is a key step in streamlining cancer diagnosis pathways."

Subcategory: 2.1.3 Insurance barriers

“Financial planning and insurance approval, especially under state/central programs, can be significant barriers, leading to delays in cancer treatment initiation.” While insurance schemes have become pivotal in recent healthcare-seeking behaviours among patients, the time-consuming approval process often forces patients to endure delays in initiating timely treatment.

Subcategory: 2.1.4 Treatment delay factors

Other factors for the treatment delay in cancer patients, "Factors such as the need for increased investigations in complex cancer scenarios, optimization of comorbid conditions before initiating treatment and delays”

Category 2.2: Process improvement and standardization

Subcategory: 2.2.1 Pathway streamlining

Ensuring a smooth and efficient diagnostic process is contingent upon the standardization and optimization of pathways, guaranteeing a more streamlined and effective journey from initial presentation to final cancer diagnosis.” Streamlining pathways involves creating standardized processes, such as timing referral protocols, to enhance the efficiency and effectiveness of the diagnostic journey from primary care to specialized cancer diagnosis."

Subcategory: 2.2.2 Onco pathology standardization

Framing guidelines for the diagnosis and referral system will be significant in mitigating the delay and avoid the potential factors causes delay in diagnosis and treatment “Efforts in standardizing evaluation protocols and

refining referral timing play a pivotal role in streamlining pathways from a patient's initial presentation to a family physician to the final cancer diagnosis."

"Addressing pathway streamlining involves creating standard operating procedures (SOPs) to uniformly follow the evaluation of cancer symptoms, ensuring a seamless and efficient diagnostic process."

DISCUSSION

The study reports about the delays in cancer diagnosis and management for patients with oral cavity, lung, and gastro intestinal tract cancers in Tamil Nadu can be attributed to various factors such as limited access to healthcare facilities, lack of awareness about symptoms, cultural beliefs, and insufficient healthcare infrastructure. These delays can also result from challenges in the referral process, long wait times for appointments and diagnostic tests, and delays in receiving biopsy results and treatment initiation.

Social determinants and geographical barriers can also impact access to healthcare services, leading to delays in cancer diagnosis and management. These include socioeconomic status, education level, cultural beliefs, language barriers, lack of transportation, and distance from healthcare facilities. In rural areas or regions with poor infrastructure, accessing specialized healthcare services for cancer diagnosis and treatment can be particularly challenging. Additionally, stigma associated with cancer or certain symptoms may discourage individuals from seeking timely medical care.

Delays in cancer diagnosis and management can have significant implications for patient outcomes, as longer delays may result in cancer being diagnosed at a more advanced stage, limiting treatment options and decreasing the likelihood of successful outcomes. Delays in treatment initiation can lead to disease progression and worsened overall survival rates. Understanding the factors contributing to delays and addressing them effectively are crucial steps in improving cancer outcomes. Gathering data on healthcare access, diagnostic and treatment timelines, socioeconomic factors, and cancer outcomes among patients with oral cavity, lung, and gastrointestinal tract cancers in Tamil Nadu can provide valuable insights into these challenges and help identify targeted interventions to reduce delays and improve cancer care. Therefore, delays in cancer diagnosis can be attributed to various social and geographical factors.

Demographic and socioeconomic factors contribute to delays, while geographical factors include distance between the patient's nearest GP/PHC, government or specialty hospital, cancer center, and current treating hospital. Delays in cancer diagnosis can be based on actual delays, patient-reported reasons, and significant delays. Cancer outcomes include treatment adherence, follow-up adherence, recurrence and survival data. These factors can impact the patient's overall health and treatment outcomes.

A quantitative study was conducted in 32 cancer hospitals in Tamil Nadu, identifying 2076 patients with a male-to-female ratio of 2:1. The mean age of the patients was 56.58 ±12.02 years, with 7 pediatric patients and 811 elderly patients. The elderly population consisted of 594 patients aged 61-70 years, 190 in the 71-80 years age group, and 27 super senior citizens. The mean height of the patients was 1.57 ± 0.11 meters, and their mean weight was 53.9 ±12.7 kg. The patients had a mean Body Mass Index (BMI) of 22 ±4.8 kg/m2. The study provides valuable insights into patient demographics and health outcomes.

Therefore, the patient population in Tamil Nadu was representative, covering all districts with the highest numbers in Chennai, Coimbatore, Thanjavur, Thoothukudi, and Madurai. The population was equally divided between urban and rural areas, with tribal populations making up less than one percent of the population. Geographic distribution is shown in Tables 6 and Figures 8 and 9.

The study analysed the distance from home to healthcare facilities and hospitals. The mean distance from home to the nearest healthcare facility was 4.35 ± 4.15 km, with 93% living within a 10 km radius. The nearest specialty private hospital or Government Hospital was 13.01 ± 9.5 km, with over 50% having a speciality hospital within a 10 km radius and over 80% within a 20 km radius. The nearest cancer center was 33.76 ± 22.32 km, with over 75% of patients living within a 50 km radius and all (100%) within a 100 km radius of a cancer center. The mean distance from the current treating hospital to home was 45.5 km ± 44.51 km, with two-thirds (66.7%) choosing a cancer hospital within a 50 km radius and 95% of patients choosing a cancer hospital within 100 km radius from their home. The mean distance from nearest healthcare facility was equal between rural and urban areas, but cancer patients from rural areas had to travel significantly longer distances to access a speciality hospital or a cancer center than people in urban areas. They also travelled more than urban area people to get cancer treatment. There was also a significant difference in the distance from the nearest cancer centre and home and distance between home and current treating hospital amongst people of different religions. Christians were closer to cancer centres or choosing nearer cancer centres for treatments than people of other religions.

The patient demographics in Tamil Nadu were predominantly Hindu, with 87.4% being Hindus. The majority of patients were married, with 87.3% being married and 78.5% from

nuclear families, with a mean family strength of 4 members, evenly divided between religions and place of residence. The primary caregiver for 59.1% of patients (n=1226) was their spouse, reflecting their marital status and family structure. Hence over 90% of patients were either illiterate or had only school-level education, while over 40% of the highest-educated family members were either graduates or had a professional degree, according to a study examining patient and relative educational status. The study found significant differences in patient educational status and the highest educational status of primary care giver/head of family between rural and urban populations. Male patients had higher educational status, while female patients had lower education. However, there was no significant difference between Hindus, Muslims, or Christians. Age groups also showed less education in elderly patients, but no significant difference was found between Hindus, Muslims, or Christians.

The patient's monthly family income ranged from Rs. 900 to Rs. 500000, with a per capita income of Rs. 4046.85 ± 5568.63. The Modified BG Prasad Classification (October 2023) classified the patients into 5 social classes, with the majority being from the Lower Middle Class (34.8%), Middle Class (21.4%), and Upper Middle Class (17.1%).The study analysed the occupations of patients and primary caregivers using the Kuppusamy Socioeconomic scale. Over 50% of patients were unskilled or semiskilled workers, with 25.4% unemployed. The majority of primary caregivers were also unskilled or semiskilled workers, with 49.1% being unemployed, 15.8% unemployed, and around 10% professional/semi-professionals. Professionals and semi-professionals made up less than 8% of the population.

The patient population primarily had oral cancers (34.2%), followed by lung cancer (13.3%), rectal cancer (11.4%), and stomach cancer (10.9%). Most patients had advanced stages at presentation, with Stage III being the most common at 55.1% and Stage IV at 19.6%. Hence, the most common presenting symptoms of cancer are persistent abdominal discomfort (21.2%), altered bowel habits (20%), and mouth pain (17.7%). Common comorbidities include diabetes and hypertension. Most patients (83.3%) present to a hospital within their district for symptoms, with private hospitals being preferred more than government hospitals for first presentation (79% vs 21%). 59.4% of patients were suspected or diagnosed at the hospital of their first presentation and referred earlier for treatment. Patients preferred private specialty or tertiary level hospitals for cancer diagnosis.

In 78.6% of cancer cases, an oncologist was available at the hospital where the cancer was diagnosed. Patients preferred private hospitals for treatment, with 98.4% having an

oncologist available at the hospital where treatment began. The majority (77.2%) visited at least two doctors/hospitals for cancer diagnosis, with 20.3% visiting four. The median number of hospitals visited before treatment was two. After diagnosis, 95.5% of patients stayed at a single hospital, with less than 6% changing hospitals. The median number of hospitals visited for cancer treatment was 1, with a total of 3 hospitals visited for diagnosis and treatment. Popularity for cancer treatment (32.7%) and referral from another hospital/doctor (26.4%) were the most common reasons for choosing a particular hospital.

The majority of cancer patients received surgery (62.2%), chemotherapy (79%), and radiotherapy (50.6%), with a small percentage opting for alternate medicine (AYUSH). The intent of treatment was curative in 74.6% of patients, and 86.1% completed the treatment. Financial reasons were the most common reason for incomplete treatment (15.1%). The cost of treatment was covered by CMCHIS in 72.4% of patients, and 31.1% paid out of pocket. However, the total not equal to 100% as one patient would have used multiple methods to cover their treatment costs. The study analysed the status of patients with cancer at the last follow-up, with a median follow-up of 246 days or around 8 months. At the last follow-up, 40.9% of patients were without disease, 33.5% had disease progression or recurrence, and 48 deaths occurred. The patient status was unknown in 18.8% of patients, and no meaningful cancer survival analysis could be derived due to the median follow-up being less than one year. Quality of Life (QOL) assessment was conducted on 1672 patients at the last follow-up, using the Katz Index for daily activities and the EORTC QLQC30 questionnaire for overall health and quality of life. The mean total score was 60.36 ± 10.99, with a median score of 63.

In primary delay in cancer the study found that the mean of the patients ranged from 1 to 1064 days, with a median of 30 days. The majority of patients (54.6%) had a significant primary delay of over 28 days. The most common reason for primary delays was not being aware of symptoms (47.1%). There was no significant difference in primary delays between cancer sites but based on cancer stages (higher stage, longer primary delay). There was no difference between rural or urban patients, but Christian patients tended to have longer primary delays. When the primary care giver was a relative other than the immediate family member, the delay was higher. Married people had more acceptable primary delays than widowed or single patients, but the type of family did not affect primary delays. Only BMI showed a significant correlation with primary delay.

Our study found that patients living in certain districts had significantly higher primary delays compared to those from other districts. Patients from Ariyalur, Chennai, Erode, Kanyakumari, Karur, Nagapattinam, Perambalur, Pudukottai, Thanjavur, Thirunelveli, Thiruvarur, Tiruvannamalai, and Trichy, while those from Chengalpattu, Coimbatore, Dharmapuri, Madurai, Namakkal, Sivagangai, Theni, and Vellore did not experience much primary delays. Patients presenting to a hospital in a different district for cancer treatment had a higher risk of delays. Despite the type of hospital where a patient presents does not affect primary delays. However, a significant primary delay is more likely when the cancer is diagnosed in a tertiary government hospital compared to a private hospital of smaller government hospitals. If the hospital has an oncology department or specialist, the chance of primary delay is low. The number of doctors/hospitals visited before, for, or total cancer treatment is not different when there is a significant primary delay.

In referral delay the study found a mean of 25.83 ± 38.74 days, ranging from 0 to 390 days. The data was non-parametric and skewed to the right. 7.5% of patients were referred to a higher center on the same day of first presentation, but experienced no delays. Significant delays were seen in 26.1% of patients. Referral delays were higher in lung cancer patients but not based on the cancer stage. No other socioeconomic factors significantly affected referral delays. Referral delays did not vary significantly between districts, hospital types, oncology departments, or the type of hospital where the patient presented, was diagnosed, or treated. However, significant referral delays were associated with a higher number of doctors/hospitals visited before start of cancer treatment ($P<0.001$), Number of hospitals visited for cancer treatment ($P<0.001$), and Total Number of doctors/ hospitals visited ($P<0.001$). Overall study found that referral delay did not significantly differ based on the distance from home to healthcare facilities like the nearest GP/PHC, Speciality Hospital, Cancer Centre, or Current Treating Hospital.

In secondary delay the study found that the mean of diagnostic delay in lung cancer patients ranged from 0 to 433 days, with a median of 26 days. The majority of patients experienced no delays (0 days) for diagnosis, and 12.3% were diagnosed within a week of presentation to a higher center. However, 45.2% experienced significant secondary delays, with the most common reason being obtaining a second opinion (25%). Lung cancer patients experienced higher significant secondary delays. Upper class patients had significantly lower

secondary delays, with patients with significant delays having lesser mean total family monthly income and per capita monthly income. However, the levels of association were poor. Patients from certain districts had higher secondary delays compared to other districts. Secondary delays were significantly linked to referral delays, with higher referral delays leading to higher secondary delays. Higher primary delays also resulted in higher secondary delays. However, the presence or absence of an oncology department in a hospital or presentation to a hospital within the same district did not affect secondary delays. Secondary delays were not significantly influenced by the distance from home to healthcare facilities such as nearest GP/PHC, speciality government/private hospital, cancer center, and current treating hospital.

The mean tertiary delay or treatment delay after cancer diagnosis was 13.29 ± 17.16 days, ranging from 0 to 197 days, with a median of 8 days, and the data was non-parametric and skewed to the right. Therefore, the study found that 8% of patients did not experience any tertiary delay, and 47.7% were treated for cancer within a week of diagnosis, while 10% experienced significant delays (over 28 days or 4 weeks).Total Medical Related Delay. Therefore, the mean Total Medical Related Delay defined as the delay in start of cancer treatment from the first point of contact with healthcare (first presentation to GP/PHC) was 51.50 ± 46.34 days ranging from 2 to 440 days (more than 1 year) with a median of 37 days (IQR 23 to 63 days). This data was again non-parametric and skewed to the right. Significant Medical related delay (more than 56 days or 8 weeks) was seen in 28.9% of patients (n=600). Medical related delays were significantly higher in lung cancers when compared to Gastrointestinal (GI) cancers and Head and Neck Cancers.

The mean total delay from symptom onset to first cancer treatment was 336.95 days, with a median of 246 days. A significant total delay was observed in 68.3% of patients, with no significant difference between cancer sites or stages. The data was non-parametric and skewed to the right, with higher stages resulting in longer delays.

The study used Key Informant Interviews (KII) with six cancer treating doctors and four primary care doctors to explore the factors causing delays in cancer diagnosis and management. The interviews were categorized into two themes: Patient Centric Factors (Fear & Denial and Professional Education & Awareness) and Health Care System Challenges (Infrastructure and Process Improvement and Standardization). The results were analysed using thematic analysis to identify two main themes: patient-centred factors and healthcare system challenges. The content analysis of 10 interviews revealed patient-centric factors, including

fear and denial, financial barriers, and patient fears. Oncologists found that patients often face financial constraints, leading to delays in seeking healthcare, including cancer diagnosis and treatment. Fear of the biopsy (myth that cancer spreads by biopsy) and not turning up for the biopsy are also prevalent. Proper counselling and explanation can help overcome these hurdles. The impact of alternative therapies was also discussed, with the doctor suggesting that proper counselling and explanation could help patients overcome these barriers.

Patients are increasingly interested in AYUSH therapy due to financial restrictions and fear of treatment side effects. Oncologists emphasize the importance of public awareness and screening acceptance to dispel misconceptions and encourage timely cancer diagnosis. They believe that public awareness initiatives can help overcome challenges like delayed biopsy reporting and improve accessibility to oncologists. Educating the public about cancer symptoms and the importance of early detection is crucial for fostering a proactive approach to healthcare. Oncologists also urge the public to take part in screening, as it is vital for early detection and improving overall prognosis. Improving access and acceptance of cancer screening can help overcome challenges such as delayed biopsy reporting and treatment delays. Educating individuals about the benefits of cancer screening is crucial for increasing screening acceptance and facilitating early diagnosis.

The healthcare system faces several challenges, including diagnostic challenges, oncologist accessibility, insurance barriers, and treatment delay factors. Diagnostic delays often arise due to interdepartmental collaboration and laboratory department cooperation, with delayed biopsy reporting impacting timely cancer diagnosis. Primary/General Physicians should be educated about cancer diagnostics and appropriate investigations. Oncologist accessibility is crucial, especially in peripheral districts, and a strong referral system should be established to prevent delays.

Insurance barriers, particularly under state/central programs, can lead to delays in cancer treatment initiation. The time-consuming approval process often forces patients to endure delays in initiating timely treatment. Treatment delay factors include the need for increased investigations in complex cancer scenarios and optimization of comorbid conditions before initiating treatment.

Streamlining pathways is essential for a smooth and efficient diagnostic process, ensuring a more streamlined journey from initial presentation to final diagnosis. Standardizing evaluation protocols and refining referral timing play a pivotal role in streamlining pathways

from a patient's initial presentation to the final cancer diagnosis. Addressing pathway streamlining involves creating standard operating procedures (SOPs) to uniformly follow the evaluation of cancer symptoms, ensuring a seamless and efficient diagnostic process.

Previous studies aimed to evaluate the baseline routes and time to diagnosis for pediatric brain tumours in Tamil Nadu (TN) to promote early intervention. A total of 144 cases were analysed, with 94% from city/district areas, 40% self-referred, and 90% having one to three health care professional visits before diagnosis. The median TDI, PI, and DI were 3.5, 0.6, and 0.6 weeks, respectively. The study found that infrastructure may not be a problem in this cohort, and increased training and proper cancer registries could enhance early diagnosis for these children.[1]

Another study aimed to describe the presentation of OSCC and identify correlations between certain factors and the disease at Kenyatta National Hospital. The study involved 58 participants, with a majority being males. The tongue was the most affected site, and most cases had pain and stage 4 disease. Significant associations were found between farming, weight loss, tobacco, inflammation, P53, and OSCC. The study recommends healthcare providers be sensitized to OSCC signs and symptoms, early referral to tertiary facilities, nutritional support, and pain control. CRP assays should be performed for all cases to control inflammation. Further research is needed on gene mutations and their role in treatment and prognosis.[2]

Recent study observed gallbladder cancer (GBC) is a rare malignancy with aggressive advanced stages, rarely metastasing to the mandible. Numb chin syndrome (NCS) is a rare neurological manifestation linked to various underlying causes. A 69-year-old Japanese woman with GBC, mandibular metastasis, and NCS presented with numbness and mild pain for three months. Palliative chemotherapy and radiation treatment were initiated, but the patient died six months later. The study highlights the importance of timely confirmatory testing for accurate diagnosis and appropriate management.[3] Biomedical sensing technology is rapidly developing, transforming laboratory prototypes into commercially feasible clinical disease detection devices. It has expanded to measure gastrointestinal physiological parameters, non-invasive screening of oral and lung diseases, and non-invasive detection of diseases like oral cancer.

This review discusses the practical application of sensors in disease detection, their detection mechanisms, clinical utility, and future development in medicine, aiming to inspire medical practitioners. [4] Head-and-neck cancer (HNC) can present with life-threatening

symptoms in the emergency department, leading to delayed diagnosis and potentially devastating consequences. This article explores contemporary risk factors, common presenting symptoms, and initial management for HNC patients. It discusses the wide range of emergency presentations and how clinicians can help determine appropriate examinations and investigations to reduce the risk of delaying diagnosis and further treatment.[5]

Despite, genomic medicine is a crucial tool for cancer treatment, enabling the right drug at the right dose and time. A 2023 conference in Canada highlighted challenges in accessing biomarker testing and reporting at various levels. Issues included limited patient awareness, failure to discuss genomic medicine with patients, delays in hereditary testing, lack of timely reporting, disparities in access, funding, lack of standardized testing, and social determinants of health impact. Canada must standardize its approach to biomarker testing and prioritize access to advanced molecular testing to ensure innovation and evidence-based treatments for cancer patients.[6] A study examining the impact of patient characteristics (PCs), hospital characteristics (HCs), case volume (CV), and social determinants of health (SDoH) on in-hospital mortality (IHM) after complex cancer surgery in California found that PCs were the most significant contributor to IHM. The study involved 52,838 patients who underwent esophagectomy, pneumonectomy, pancreatectomy, or proctectomy between 2010 and 2020. The IHM varied from 4.4% for ES to 0.8% for PR. PCs contributed the most to IHM variance, with CV being the second highest contributor. HCs were more important for patients who underwent PR. The unexplained variance in IHM was highest among ES (72.4%), followed by PD (67.5%) and PN (64.6%) patient groups. The study suggests that optimizing patients and exploring unexplained sources of IHM can improve surgical care quality.[7]

Gastric cancer is the fifth most prevalent cancer and the fourth leading cause of cancer-related deaths globally. Treatment options include surgical resection, chemotherapy, and radiotherapy. However, disparities in treatment time are often due to factors such as age, sex, race, socioeconomic status, insurance status, and demographics. A retrospective study conducted between 2004 and 2019 found significant disparities in treatment timing for various demographic groups. These include longer treatment times for males, Native Americans, low-income patients, academic patients, and those in academic settings. The study also found longer treatment times for those over 70, black race, low-income individuals, and females. Understanding these disparities is crucial for developing targeted strategies to improve timely access to appropriate treatments and improve patient outcomes. Future research with updated

data and prospective study designs could provide a more comprehensive understanding of these factors.[8]

Recent study aimed to explore the intersections of race and social determinants of health (SDoH) with healthcare access and outcomes of glioblastoma (GBM) patients in a large metropolitan area. The study involved 276 unique patients, with 46% being female and 45% being non-White. The racial proportion differed from previous reports, with 80% of patients with GBM being White. The proportion of non-White patients was similar to the general US population and significantly lower than that of New York City. Non-White patients predominantly composed the lowest AHRQ SES index quartile, while white patients constituted the highest quartile. White patients were older at diagnosis compared to non-White patients, and older age, higher NCI-CI, and lack of insurance reduced the odds of a home discharge. Private insurance, younger age, and the highest AHRQ SES index quartile predicted a lower hospital length of stay (LOS). Patients who underwent gross-total resection had greater OS than those who received a subtotal resection or biopsy, independent of race and SDoH.[9] The socioeconomic burden of psychiatric cancer patients is a significant issue, affecting their healthcare costs, treatment adherence, and quality of life. This burden is exacerbated by the coexistence of mental health challenges such as depression, psychosis, anxiety, and addictions. Factors such as gender or age can exacerbate these impacts. Physicians can help mitigate these risks by adopting integrated care strategies that address the unique needs of patients navigating the complex intersection of cancer and mental health disorders. Proactive measures, personalized support, and tailored interventions are recommended to improve outcomes and enhance the overall well-being of individuals facing these dual challenges. This review aims to promote the development of more effective and integrated care strategies for this vulnerable patient population.[10]

A study at the Uganda Cancer Institute (UCI) found that 65% of head and neck cancer patients (65%) had delayed diagnosis. Factors such as sociodemographic factors, clinical characteristics, and access to healthcare facilities were associated with delayed diagnosis. The median age of the patients was 49.5 years, 70% were male, and 70% had tumour stage 4. The median time from symptom onset to definitive diagnosis was 8.1 months, with 70% of patients having delayed diagnosis. The study suggests that public awareness campaigns, a national care pathway, and rotation of surgeons to underserved regions could help mitigate diagnostic delay in HNC patients.[11]

Despite global reductions in lung cancer incidence and mortality rates, African Americans still face higher mortality rates than other ethnic or racial groups. Factors such as smoking patterns, social determinants, tumour biology, immunity, and comorbid conditions contribute to these disparities. This review emphasizes the interplay of social, biological, and environmental conditions that make African Americans more susceptible to developing lung cancer and experiencing poorer outcomes, despite progress in treatment and screening efforts.[12] A study examining the impact of social determinants of health (SDH) on ocular cancer patients found that factors such as race, income, and comorbidities, such as age, were associated with advanced cT classification and 30-day readmission. Female sex and top income quartile had a lower likelihood of advanced cT classification at presentation, while no insurance or Medicaid primary payer status increased the likelihood of advanced cT classification. Patients in rural areas were more likely to be readmitted within 30 days after initial treatment.[13]

Another study examines the impact of insurance types on cancer clinical care quality. Data from 13,340 cancer patients with Purchased or Medicaid insurance was collected from the All of Us database. Results showed that African American, lower socioeconomic, or lower educational cancer patients are more likely to be insured by Medicaid. Medicaid patients were less likely to receive primary care and specialist physician access and more likely to request lower-cost medications. The study highlights the inequities in the US healthcare system for cancer patient care, with access to physicians and medications being highly varied and dependent on insurance types.[14]

Further studies showed increasing incidence of oral cancers, particularly HPV-related oropharyngeal cancer, poses a significant healthcare challenge. A study in Alberta, Canada, examined trends and predictors of unplanned hospitalizations for oral cavity cancer (OCC) and oropharyngeal cancer (OPC) patients. The study used administrative data from all Alberta hospitals and identified a cohort of adult patients diagnosed with a single primary OCC or OPC between 2010 and 2017. The study found that 48.8% of patients experienced unplanned hospitalizations, significantly associated with a higher mortality rate. The rate of unplanned hospitalization per patient decreased from 0.69 to 0.54 visits, with common diagnoses being palliative care and post-surgical convalescence. The study suggests that enhanced care coordination could lead to a decline in unplanned hospitalizations.[15]

Recent study examines cancer burden estimates by GLOBOCAN 2022 and projections up to 2050. It compares cancer incidences and deaths of the top 10 cancers in China and four

HDI-classified regions. The top five cancer types are categorized by sex and age group. Results show that prostate cancer is prevalent in countries with low, high, and very high HDI, while breast and cervical cancers are prevalent in countries with low-to-medium HDI. Lung and colorectal cancer incidence and deaths increase with high HDI for both sexes. ASIRs and ASMRs for breast, prostate, lung, and colorectal cancers in the top 10 economies are higher than the global average. Hematologic malignancies are prevalent among children aged 0-14 years in China, while thyroid cancer leads among adolescents and young adults aged 15-39 years. Projected trends indicate substantial increases in new cancer cases and deaths over the next three decades.[16]

Qualitative study:

The goal of the study was to determine the reasons behind Tamil Nadu's delayed use of cancer treatment services. The study discovered that a few variables pertaining to the availability of cancer services were involved in the delays in cancer diagnosis and treatment. These consist of the time it takes to get from one's house to the facility, the time spent waiting there, and getting all the services one needs at the institution that is closest to them.

These results demonstrate the need for decentralization of services, community-based screening for early detection, shorter wait times in medical institutions, and the provision of cancer services closer to the patient's home in order to minimize delays in cancer care. Building infrastructure and educating primary and general physicians. It has been noted that waiting times have an impact on the use and accessibility of health services, and other research has suggested that decentralizing cancer services will enhance cancer treatment. **(101,102)**

The study discovered that, even in cases where a person experienced normal symptom, delaying screening for cancer or seeking medical attention was caused by fear of receiving a cancer diagnosis. The belief held by family members and the community that cancer is a sickness that inevitably ends in death exacerbated these worries. These results highlight the importance of educating families and communities about cancer in order to relieve these worries and motivate them to get screened early for early identification and treatment, which can enhance the prognosis for cancer patients.

This study also discovered that although though the individuals may be adults, some of the delays might be attributed to decisions made by other family members on the use of health services or the payment for such services. This is usually the case when the head of the household, who is usually the male parent or the female parent in his absence, makes the

majority of the decisions regarding the household's finances and health. These results suggest that in order to guarantee cancer service uptake, all family members in each household must be involved. Other studies have also discussed the role that families play in cancer care. Since receiving a cancer diagnosis is a family experience, it is important for the entire family to be involved in order to minimize delays in cancer care.[103]

The study also noted that when a patient receives a cancer diagnosis, they are taken aback and experience overwhelming feelings of disbelief and mortality anxiety. A patient's personal life is negatively impacted by cancer as it advances, and social and marital relationships are gradually deteriorated to the point that a patient may lose support from friends and family. The patient's acceptance of the cancer treatment is delayed as a result. According to other research, receiving a cancer diagnosis drastically alters a patient's and their family's life, causing a tremendous deal of stress. Frequently, the family experiences as much or even more suffering than the patient.[104]

A lack of financial support can have an impact on hospital attendance and treatment adherence for certain individuals. A portion of the delays in cancer screening, diagnosis, or treatment can be attributed to a lack of local cancer knowledge. Patients believe they are receiving care from inexperienced local physicians. Occasionally, local facilities are not equipped with the necessary diagnostic tools, resources, or knowledge to properly diagnose and treat patients. Other studies have identified a lack of infrastructure or a shortage of resources as obstacles to cancer detection and treatment.[105,106]

Primary and general physicians should receive training in basic oncology in order to resolve delays in the health system, eliminate the need for needless referrals, and make required referrals. To address concerns with screening attentiveness, guidelines for cancer screening quality assurance should be established and followed. Guidelines for cancer care that address awareness, prevention, screening, diagnosis, referrals, and treatment services **can help achieve this.**

SUMMARY

The study was a multicentric mixed model study to understand the Understanding the Correlation Between Social Determinants of Delays in Diagnosis, Management and Outcomes for Solid Cancers in Tamil Nadu. We collected data from 2076 cancer patients (Oral, head and neck, Lung and Gastrointestinal cancers only) from 32 cancer hospitals from all districts across Tamil Nadu. The Male: Female was 2:1, mean age of the patients was 56.58 ±12.02 years (range: 4 to 92 years) and no. of elderly patients (more than 60 years) was 811 (39.1%). The patient population was representative of Tamil Nadu covering all districts with the highest numbers from **Chennai (217 patients)**, **Coimbatore (159 patients)**, **Thanjavur (114 patients)**, **Thoothukudi (141 patients) and Madurai (116 patients) districts**, with equal distribution between rural and urban areas.

The socioeconomic and demographic profile of the patients was comparable to the general population of Tamil Nadu with 87.4% hindus,87.3% married, 78.5% from nuclear families. The spouse was the primary care giver in 59.1% of patients. Majority (>90%) of our patients were either illiterate or had only school level of education but the highest educational status within the family was either a graduate or had a professional degree. This was probably reflective of the age group of patients, their occupation and socioeconomic status of the patient population.

The mean distance from home to the **nearest healthcare facility** (the nearest General Practitioner doctor or private clinic or Primary Health centre - where they regularly go for check-ups) was 4.35 ± 4.15 km (range: 1 – 61 km), with 93% living within a 10 km radius from their nearest healthcare facility. The **nearest specialty private hospital or Government Hospital** was located at a mean distance of 13.01 ± 9.5 km (range: 1 to 63 km), with more than 50% having a speciality hospital within a 10 km radius and more than 80% within a 20 km radius from their home. The **nearest cancer centre** was located at a mean distance of 33.76 ± 22.32 km (range: 1- 99 km) with more than 75% of patients living within a 50 km radius and all (100%) within a 100 km radius of a cancer centre. **The mean distance from the current treating hospital to home** was 45.5 km ± 44.51 km (range 1 to 533 km), with two-thirds (66.7%) choosing a cancer hospital within a 50 km radius and 95% of patients choosing a cancer hospital within 100 km radius from their home.

Oral cancers were the most common cancers among our patient population (34.2%, n=710), followed by lung cancer (13.3%, n=276), rectal cancer (11.4%, n= 237) and stomach cancer (10.9%, n=227). Majority of the patients had more advanced stage at presentation, Stage III – 55.1% and Stage IV -19.6%. Most patients (83.3%) presented to a hospital within their same district for their symptoms, private hospitals were preferred more than government hospitals for their first presentation (79% vs 21%). For 59.4% of patient's caner was suspected or diagnosed (without biopsy proof) at the hospital of their first presentation and were referred earlier to a higher centre for treatment. Again, for cancer diagnosis, patients preferred private specialty or tertiary level hospitals over government specialty/ tertiary hospitals (59% vs 41%). In 78.6% of cases an oncologist was available in the hospital where the cancer was diagnosed.

For cancer treatment also, the patients preferred private hospitals over government hospitals (55.7% Vs. 44.2%). In 98.4% of cases, there was an oncologist available at the hospital where cancer treatment was started. A majority (77.2%) of patients (n=1603) visited at least 2 doctors/hospitals for diagnosis of cancer. The most common reason for choosing a particular hospital for treatment was its popularity for cancer treatment (32.7%) and a referral from another hospital/doctor (26.4%).

Surgery (62.2%), chemotherapy (79%) and radiotherapy (58.6%) formed the bulk of the treatment options. Forty patients (1.9%) opted for alternate medicine (AYUSH). The intent of treatment was curative in 74.6% of patients and 86.1% of patients completed the planned treatment. Once treatment was started, 86.1% of patients completed the treatment. The most common reason for incomplete treatment was financial reasons (15.1%). The cost of treatment was covered by CMCHIS/Insurance in 77% of patients and 31.1% percent of patients paid out of pocket for their treatment.

The median follow-up was 246 days or around 8 months (IQR 185 – 385 days). At the last follow up, 40.9% were without disease, 33.5% had disease progression or recurrence and there were 48 deaths. The status of the patient was not known in 18.8% of patients. Since the median follow-up was less than 1 year, no meaningful cancer survival analysis could be derived. Quality of Life (QOL) assessment was done in 1672 patients at the time of last follow-up.

The mean **primary delay or patient delay or presentation delay** was 49.61± 75.35 days ranging from 1 to 1064 days (almost 3 years) with a median of 30 days (Inter quartile range IQR: 12 to 61 days). More than half or 54.6% had a significant primary delay (more than

28 days or 4 weeks). The **most common reason** given by the patient for the primary delay was that they were **not aware of the symptoms (48.6%).**

The following patient factors had a **significant positive association with primary delays**: **cancer stage (**higher the stage, longer the primary delay, in stage 3 and 4 cancers**), relationship of the primary care giver** (When the primary care giver was a relative other than the immediate family member, the delay was higher), **marital status** (Married people had more acceptable primary delays than widowed or single patients), **BMI** (lower BMI, higher primary delay), **home district** (patients living in Ariyalur, Chennai, Erode, Kanyakumari, Karur, Nagapattinam, Perambalur, Pudukottai, Thanjavur, Thirunelveli, Thiruvarur, Thiruvannamalai and Trichy) had significantly high primary delays), **patients presenting to a hospital in a different district than home district** for cancer treatment had a significantly higher risk of having primary delays (RR:1.13, 95% CI: 1.03-1.25), and **absence of oncology department or specialist in the hospital where they first presented** (RR 1.17 (1.07-1.28)

The mean **Referral Delay** was 25.83 ± 38.74 days ranging from 0 to 390 days (more than one year) with a median of 11 days (IQR: 4 to 30 days). **Significant referral delays (**more than 28 days or 4 weeks) from primary healthcare practitioners to a higher centre was seen only in 26.1% of patients.

Referral Delays were significantly higher in lung cancer patients. significant referral delays were associated with a higher number of doctors/hospitals visited before start of cancer treatment, Number of hospitals visited for cancer treatment, and Total Number of doctors/ hospitals visited.

The mean **Secondary Delay or Diagnostic Delay** was 38.21 ± 43.11 days ranging from 0 to 433 days (more than 1 year) with a median of 26 days (IQR: 13 to 44 days). Almost half or 45.2% of patients experience significant secondary delays (more than 28 days or 4 weeks). The **most common reason for secondary delays** was that the patient obtained a **second opinion (25%).**

The following patient related factors had a **significant positive association with secondary delays: cancer site** (more in lung cancer patients), **socioeconomic status** (lower in upper class patients, higher per capita income and higher monthly income), **home district (**Dharmapuri, Kallakurichi, Madurai, The Nilgiris, Tenkasi, Theni, Thiruvallur, Thoothukudi, Tirupathur, Vellore and Virudhunagar had higher secondary delays when compared to other districts), Significant Secondary Delays was associated **with Number of doctors/hospitals**

visited before start of cancer treatment, **Number of hospitals visited for cancer treatment** and **Total Number of doctors/ hospitals visited**. **Higher primary delay** RR: 1.12(1.02-1.23) or a **referral delay** RR: 36(20.15-65.02) also led to significant secondary delays.

The mean **Tertiary delay or Treatment delay (after diagnosis of cancer)** was 13.29 ± 17.16 days ranging from 0 to 197 days (more than 6 months) with a median of 8 days (IQR: 4 to 16 days). Only 10% of patients (n=207) experienced **significant Tertiary delay or Treatment delay (after diagnosis of cancer) (**more than 28 days or 4 weeks). The **most common reason for tertiary or treatment delays** was **financial reasons (23.8%).**

The following patient related factors had a **significant positive association with tertiary delays: Patient Age group** (Old Adults and Elderly patients had significantly high tertiary delays), **type of family (**Patients from joint families had significantly lessor tertiary delays), **number of family members** (More the family members, lesser the tertiary delay) and **presence/absence of an oncologist in the hospital where cancer was diagnosed RR: 1.5 (1.13-198).** Significant tertiary Delays was associated **with Number of doctors/hospitals visited before start of cancer treatment**, **Number of hospitals visited for cancer treatment** and **Total Number of doctors/ hospitals visited.** Primary, referral or secondary delays did not significantly affect tertiary delays. Once the cancer was diagnosed, the treatment was initiated without delay in 90% of patients. Tertiary delays were significantly more with the **distance from home to current treating hospital:** when the distance of the current treating hospital from home was 34.5 km or more, there was a significant tertiary delay (71% sensitivity, 70% specificity).

The mean **Total Medical Related Delay** defined as the delay in start of cancer treatment from the first point of contact with healthcare (first presentation to GP/PHC) was 51.50 ± 46.34 days ranging from 2 to 440 days (more than 1 year) with a median of 37 days (IQR 23 to 63 days). This data was again non-parametric and skewed to the right. **Significant Medical related delay (more than 56 days or 8 weeks) was seen in 28.9% of patients (n=600).** Medical related delays were **significantly higher in lung cancers**. The other patient demographics did not affect Total medical related delays. As expected, Total Medical Related Delays were higher with a greater **Number of doctors/hospitals visited before start of cancer treatment, Number of hospitals visited for cancer treatment, and Total Number of doctors/ hospitals visited**. Also, as expected, increase in **primary, secondary, referral and tertiary delays** also affected total medical related delays. The delays with the highest

association with medical related delays were referral and secondary delays (RR: 3.6 (3.1-4.18) and 2.2 (2.04-2.37) respectively). The **absence of an oncologist in the hospital where cancer was diagnosed** had an increased risk of total medical related delays (RR: 1.11 (1.03-1.18).

Mean **Total Delay** defined as time from start of the symptoms to the first cancer treatment was 336.95 ± 250.42 days (range 63 -1470 days), median was 246 days (IQR: 185 -385 days). **Significant Total delay (more than 56 days or 8 weeks) was seen in 68.3% of patients (n=1418).**

The following patient factors had a positive association with total delays: ca**ncer stages** (Higher the stage, longer the delay), **BMI** (lower the BMI, higher the Total Delay), **relationship of the primary care giver (**male primary care giver – lesser delay compared to female primary care giver), **total family income** (lesser income – more delays) and **distance from home to the nearest speciality hospital** (longer the distance – longer the delay). As expected, there was a significant positive association between total delays and the **Number of doctors/hospitals visited before start of cancer treatment, Number of hospitals visited for cancer treatment, and Total Number of doctors/ hospitals visited.** (P<0.001, moderate strength of associations). Similarly, there was a significant positive association between total delays and **other cancer delays** with the strongest risk factors being **referral delays RR: 10.2 (6.7-15.5)** and **tertiary delays RR: 7.2 (3.9-13.2)**

Table 124: Summary of Cancer Delays

Cancer Delays	**Mean ± SD (days)**	**Longest Delay (days)**	**Significant Delays N (%)**	**Most common Reason**
Primary or Patient Delay	49.61 ± 75.35	1064 days	1133 (54.6%)	Patient not aware of symptoms
Referral Delay	25.83 ± 38.74	390 days	542 (26.1%)	Second Opinions
Secondary Delay or Diagnostic Delay	38.21 ± 43.11	433 days	938 (45.2%)	Second Opinions
Tertiary delay or Treatment delay	13.29 ± 17.16	97 days	207 (10%)	Financial Reasons

Total Medical Related Delay	51.50 ± 46.34	440 days	600 (28.9%)	Referral/Diagnostic Delay
Total Delay	336.95 ± 250.42	1470 days	1418 (68.3%)	Referral/Treatment Delay

From the Qualitative part of the study which included 10 doctors, 2 key themes emerged on thematic analysis **1) Patient centric factors** (patient fears, financial barriers, impact of alternative therapy and experimentation, screening acceptance, public awareness and education) **2) Healthcare system challenges** (infrastructure availability, diagnostic challenges, oncologist accessibility, insurance barriers, process improvement and pathway streamlining, standardisation of evaluation protocols, referral pathways, onco-pathology reports).

RECOMMENDATIONS:

We propose the following recommendations to reduce delays in cancer diagnosis and management in Tamil Nadu

1. **Enhance Awareness and Education Initiatives:**
    - Develop comprehensive educational campaigns targeting both the general public and healthcare professionals to raise awareness about the signs, symptoms, and risk factors of solid cancers.
    - Utilize multiple channels including mass media, community events, and digital platforms to disseminate information effectively.
2. **Improve Access to Screening, Diagnostic Services and Oncologists**
    - Strengthen healthcare infrastructure to ensure timely access to diagnostic services, including imaging and pathology.
    - Establishing Oncology Departments at all Government Tertiary Hospitals/Medical College Hospitals (Government and Private) to provide cancer care through a **Hub and Spoke Model**
3. **Promote Early Detection Practices:**
    - Encourage regular health check-ups and screenings among high-risk groups, emphasizing the importance of early detection in improving cancer outcomes.
    - Train healthcare providers especially in the primary care setting to recognize early warning signs and facilitate prompt referral for further evaluation.
4. **Reduce Financial Barriers to Cancer Care:**
    - Implement policies to reduce out-of-pocket expenses associated with cancer diagnosis and treatment, such as subsidizing screening tests and treatment costs for low-income individuals.
    - Expand health insurance coverage to include comprehensive cancer care including diagnostic procedures, alternate systems of medicine, palliative care, day care treatments and home-based cancer care.
5. **Strengthen Referral Pathways through a Targeted Approach**

- Establish standardized referral pathways to streamline the process of transferring patients from primary care facilities to specialized cancer centres for further evaluation and treatment.
- Establish dedicated care pathways for targeted cancers/targeted patient population in specific districts
- Create dedicated care pathways for elderly patients with cancers
- Foster collaboration between primary care providers, specialists, and community health workers to ensure continuity of care and timely follow-up.
- Aim to reduce referral delays and medical related delays in cancer care

6. **Enhance Training for Primary and Secondary Healthcare Providers:**
   - Offer continuing medical education programs focusing on cancer detection and management for primary care physicians, nurses, and allied healthcare professionals.
   - Incorporate training modules on cultural competency and patient-centred communication to address potential barriers to care.
7. **Leverage Technology for Telemedicine and Teleconsultation:**
   - Implement telemedicine and tele mentoring services (doctor to patient and doctor to doctor) to facilitate remote consultation and follow-up care, especially in rural and remote areas where access to specialized healthcare is limited.
   - Invest in digital health solutions for patient education, appointment scheduling, and health record management to improve care coordination.
8. **Promote Research and Data Collection:**
   - Support multicentric research initiatives to further understand cancer care disparities across different regions of Tamil Nadu.
   - Promote long term research on effects of cancer delays in patient outcomes.
   - Establish robust surveillance systems (apart from cancer registries) to monitor cancer incidence, stage at diagnosis, treatment patterns, and outcomes to inform evidence-based interventions.
9. **Foster Community Engagement and Support:**
   - Engage local community leaders, grassroots organizations, advocacy groups and faith-based institutions in cancer awareness, especially about early detection, timely care, treatment options available and importance of completion of treatment.

- Provide psychosocial support services for cancer patients and their families to address emotional distress and improve coping mechanisms.

10. Advocate for Policy Change and Resource Allocation

- Advocate for policy reforms at the state and national levels to prioritize cancer control and allocate sufficient resources for early detection and early treatment services.
- Establish Cancer referral and treatment timelines similar to NHS UK 2-week rule or 60-day rule to monitor delays.
- Collaborate with government agencies, non-governmental organizations, and civil society stakeholders to develop and implement comprehensive cancer control programs tailored to the needs of the population.

Examples of dedicated/Targeted Cancer Pathways:

1. **Dedicated Multidisciplinary clinics** - Lung Cancer Clinics, Breast Cancer Clinics, Women's Wellness clinics, Senior citizens' cancer clinic, blood disorders clinic, etc.
2. **Dedicated Multidisciplinary Teams –** Including of Oncologists (Medical, surgical, radiation), radiologists, pathologists, psychologists, dietitians, specialist nurses, social workers
3. **Elderly Cancer Care pathways**
    - Geriatric cancer clinic (include a geriatrician in the care)
    - Geriatric cancer registry
    - Dedicated queue/treatment times – preferably first in the morning so that the care giver can go for his /her job after treatment of patient
    - Free/Subsidised Transport services from home to hospital
4. **Subsidised/free dormitories or Sathrams** with lodging and dining facilities for cancer patients and care givers to stay during treatment
5. **Standard referral templates for common symptoms for primary care physicians**

By implementing these recommendations, Tamil Nadu can work towards reducing delays in the diagnosis and management of solid cancers, ultimately improving outcomes and reducing the burden of this disease on individuals and communities.

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APPENDICES

Appendix 1: Training and Data Collection

Training of data collectors before the data collection at PSG IMSR

Interview of patients in the presence of TNHSRP team

Appendix 2: Case Report Form

Appendix 3: Informed Consent and Patient Information Sheets

Appendix 4: Approvals

TNHSRP – ORP

Tamil Nadu Health System Reform Programme – Operational Research Programme

Understanding correlation between social determinants of delays in diagnosis and management and outcomes for solid cancers in Tamil Nadu- Multicentric mixed method study

Trial Number:	Affix Sticker here
Centre Name:	
Patient Name:	
Patient ID:	
Age:	
Gender: 1. Male ☐ 2. Female ☐ 3. Others ☐ 4. Not Known ☐	
Hospital Number:	
Contact Number 1:	Contact Number 2:
Address:	
House No:	Road:
Area/Locality:	Village/Town/City:
Pin code:	Landmark:
District:	State/UT:

TNHSRP – ORP Research

Understanding correlation between social determinants of delays in diagnosis and management and outcomes for solid cancers in Tamil Nadu- Multicentric mixed method study

PATIENT QUESTIONNAIRE – ENGLISH

Instructions: This form should be filled by the designated person. Do not leave any question unmarked. Put a "tick" in the appropriate box or fill in the relevant information. The information recorded in this form captures data from onset of cancer till present date.

Section 1. Basic Information

1.1 How long have you lived in the current address? .....

If less than 1 year, List all previous addresses:.....

.....

1.2 Name of Relative/Next of Kin/ Accompanying person .....

1.3 Relationship 1.Father ☐ 2.Mother ☐ 3.Husband ☐ 4.Wife ☐ 5.Son ☐ 6.Daughter ☐

7.Grandparent ☐ 8.Other Relative _____ 9.Others _____ 10.Not Known ☐

Relationship of the primary care giver *(if different from above)*

1.Father ☐ 2.Mother ☐ 3.Husband ☐ 4.Wife ☐ 5.Son ☐ 6.Daughter ☐ 7.Grand parent ☐

8.Other Relative _____ 9.Others _____ 10.Not Known ☐

1.4 Anthropometry : A. Weight ☐ B. Height ☐ C. BMI ☐

Section 2. Socio Economic Information

2.1 Religion: A. Hindu ☐ B. Christian ☐ C. Muslim ☐ D.Others ☐

2.2 Marital status: A) Married ☐ B) Never Married ☐ C) Widow ☐ D) Separated ☐ E)Divorced ☐

2.3 What is your highest level of education: 1. Illiterate ☐ 2. Primary school ☐ 3.Middle school ☐ 4. High school ☐

5. Higher secondary ☐ 6. Graduate ☐ 7. Professional degree ☐

2.4 What is the highest level of education among first degree relatives:

1. Illiterate ☐ 2. Primary school ☐ 3.Middle school ☐ 4. High school ☐ 5. Higher secondary ☐

6. Graduate ☐ 7. Professional degree ☐

2.5 Education of Head of family (if patient is not HOF):

1. Illiterate ☐ 2. Primary school ☐ 3.Middle school ☐ 4. High school ☐ 5. Higher secondary ☐

6. Graduate ☐ 7. Professional degree ☐

2.6 Occupation of Patient: .....

2.7 Occupation of Head of family (if different): .....

2.8 Type of Family: A. Nuclear ☐ B. Extended ☐ C. Joint ☐ D. others ☐ Specify .....

2.9 How many members are there in your family? .....

2.10 What is your total family monthly income of family (give closest estimate in Rs.) .....

Accessibility to Health facilities

2.11 How far is the nearest GP/PHC you contact usually for any minor ailments from your home?

(estimate in km. Use Google Maps if required) .....

2.12 How far is the nearest Government Hospital or Specialty Hospital with > 50 beds to whom/which you usually consult from your home?(estimate in km. Use Google Maps if required) .....

2.13 How far is the nearest Cancer Center (Government or Private) from your home?

(estimate in km. Use Google Maps if required) .....

2.14 What is the distance between your home and current treating hospital?

(estimate in km. Use Google Maps if required) .....

Section 3. Details of Cancer

(Collect this information from patient/ LAR through interview and review of medical records)

3.1 Site of Cancer (Use ICD 10 Codes) (Tick all that is applicable)

1. Oral ☐ 2. Lung ☐ 3. Pharynx ☐ 4. Esophagus ☐ 5. Stomach ☐ 6. Small Intestine ☐ 7. Appendix ☐
8. Colon ☐ 9. Rectum ☐ 10. Anal Canal ☐ 11. Liver ☐ 12. Bile ducts ☐
13. Pancreas ☐ 14. Gall bladder ☐ 15. Not Known ☐

3.2 Pathological Type of Cancer (Use ICDO 3 Codes) .....

Stage of Cancer (Use UICC/AJCC TNM Stage + Composite Stage) .....

Section 4. Co morbidities

4.1

Chronic Illness	Status	Duration since diagnosis
Have you had a heart attack /angina or heart surgery?	1. Yes, on treatment 2. Yes, not on treatment 3. No 4. Do not know	☐ Years ☐ Months ☐ Days
Have you had a stroke?	1. Yes, on treatment 2. Yes, not on treatment 3. No 4. Do not know	☐ Years ☐ Months ☐ Days
Do you have any kidney problem or undergoing dialysis?	1. Yes, on treatment 2. Yes, not on treatment 3. No 4. Do not know	☐ Years ☐ Months ☐ Days

Chronic Illness	Status	Duration since diagnosis
Have you been diagnosed with HIV-AIDS	1. Yes, on treatment 2. Yes, not on treatment 3. No 4. Do not know	☐ Years ☐ Months ☐ Days
Have you undergone any organ transplant?	1. Yes, on treatment 2. Yes, not on treatment 3. No 4. Do not know	☐ Years ☐ Months ☐ Days
Did you previously have tuberculosis?	1. Yes, on treatment 2. Yes, not on treatment 3. No 4. Do not know	☐ Years ☐ Months ☐ Days
Do you have diabetes mellitus?	1. Yes, on treatment 2. Yes, not on treatment 3. No 4. Do not know	☐ Years ☐ Months ☐ Days
Do you have Hypertension?	1. Yes, on treatment 2. Yes, not on treatment 3. No 4. Do not know	☐ Years ☐ Months ☐ Days
Do you have any other medical problem? If Yes, what? _____	1. Yes, on treatment 2. Yes, not on treatment 3. No 4. Do not know	☐ Years ☐ Months ☐ Days

Section 5. Delay in Cancer Diagnosis & Management

(Collect this information from patient/ LAR through interview and review of medical records)

From Symptoms to First contact with a Doctor (Primary Delay)

5.1 What were the symptoms that you initially had? (Tick all that is applicable)

1. Diarrhea ☐ 2. Constipation ☐ 3. Blood in your stool ☐ 4. Persistent abdominal discomfort ☐
5. Weakness or fatigue ☐ 6. A white or reddish patch on the inside of your mouth ☐
7. A lip or mouth sore that doesn't heal ☐ 8. A growth or lump inside your mouth ☐
9. Difficulty or pain while swallowing, opening your mouth or chewing ☐ 10. Mouth pain ☐
11. Ear pain ☐ 12. Coughing that gets worse or doesn't go away ☐ 13. Shortness of breath ☐
14. Coughing up blood ☐ 15. Weight loss with no known cause ☐ 16. Chest pain ☐
17. Jaundice ☐ 18.Abdominal lump ☐ 19. Others .....

5.2 When did your symptoms first start? **Or** For how long did you have the symptoms before you went to a Doctor/Hospital/PHC? (If exact date is not known), please give the nearest estimate in weeks

DD MM YYYY ..... Days/ Weeks/Months

5.3 Name of Doctor/Hospital/PHC to whom you first presented with the above symptoms .....

Address of Doctor/Hospital/PHC .....

House No/Building Name .....

Road/Street .....

Locality/ Area/Village Name ..... Post office .....

City/Town/Taluk ..... District .....Pin code.....

Urban/Rural/Tribal .....

5.4 Date of presentation to the above Doctor/Hospital/PHC (If exact date is not known, please give the nearest estimate in weeks) DD MM YYYY **Or**..... Days/ Weeks/Months

5.5 If you had presented to the above doctor after 4 weeks of having the problems/symptoms, list the reason(s)

a. I was not aware ☐ b. I thought that symptoms will resolve spontaneously ☐

c. I didn't have knowledge or information ☐ d. I didn't have time ☐

e. There was a family problem during that time ☐ f. There was no one to take me to the hospital ☐

g. the hospital was far from home ☐ Other reason, specify .....

5.6 Was cancer diagnosed by this hospital/doctor : Yes ☐ No ☐

5.7 Any Treatment given by Doctor/Hospital/PHC

1. No treatment given ☐ 2. Symptomatic treatment ☐ 3. Alternate medicine ☐

4. Tests/scans done ☐ 5. Surgery done ☐ 6. Chemotherapy given ☐ 7. Radiotherapy given ☐

8. Advised Referral to another specialist ☐ 9. Advised referral to oncologist ☐ 10.Others .....

5.8 Date of Referral if any (If exact date is not known, please give the nearest estimate in weeks)

DD MM YYYY **Or**..... Days/ Weeks/Months

From First Contact with Doctor to Diagnosis of Cancer (Secondary Delay)

5.9 Name of Doctor/Hospital where cancer was diagnosed (if different from above) .....

Address of Doctor/Hospital/PHC .....

House No/Building Name .....

Road/Street .....

Locality/ Area/Village Name ..... Post office .....

City/Town/Taluk ..... District .....Pin code.....

Urban/Rural/Tribal .....

5.10 Was this doctor an oncologist? Yes ☐ No ☐

5.11 Did this hospital have oncology departments/specialists: Yes ☐ No ☐ If Yes, What/Who all?

1. Surgical Oncologist ☐ 2. Medical Oncologist ☐ 3. Radiation Oncologist ☐ 4. Nuclear Medicine ☐

5. Palliative Care ☐ 6. Others .....

5.12 Date of first visit to this hospital

(If exact date is not known,please give the nearest estimate in weeks) D D M M Y Y Y Y

5.13 Date of First Diagnosis of Cancer

(If exact date is not known, please give the nearest estimate in weeks) D D M M Y Y Y Y

5.14 Any Treatment given

1. No treatment given ☐ 2. Symptomatic treatment ☐ 3. Alternate medicine ☐

4. Tests/scans done ☐ 5. Surgery done ☐ 6. Chemotherapy given ☐ 7. Radiotherapy given ☐

8. Advised Referral to another specialist ☐ 9. Advised referral to oncologist ☐ 10.Others .....

5.15 If you had presented to the above doctor after 4 weeks of having the problems/symptoms, list the reason(s)

a. I was not aware ☐ b. I thought that symptoms will resolve spontaneously ☐

c. I didn't have knowledge or information ☐ d. I didn't have time ☐

e. There was a family problem during that time ☐ f. There was no one to take me to the hospital ☐

g. the hospital was far from home ☐ Other reason, specify .....

5.16 Were you referred to another specialist/hospital? Yes ☐ No ☐

5.17 Was this specialist an oncologist or did the hospital had oncology department Yes ☐ No ☐

5.18 Date of Referral if any (If exact date is not known, please give the nearest estimate in weeks)

D D M M Y Y Y Y **Or**..... Days/ Weeks/Months

5.19 Did you visit any other hospital before the cancer diagnosis was made in this hospital? Yes ☐ No ☐

If Yes, Address of the hospital (s) .....

.....

If Yes, reason

1. Second Opinion ☐ 2. Known Doctor/Hospital ☐ 3. The hospital was nearer to home ☐

4. Alternate medicine ☐ 5. Financial Reasons ☐ 6. Suggested by Friend/Relative ☐

7. Facilities not available in the referred hospital ☐ 10. Others.....

From Diagnosis of Cancer to Start of Treatment (Tertiary Delay)

5.20 Name of Doctor/Hospital where cancer was Treated (if different from above) .....

Address of Doctor/Hospital/PHC .....

House No/Building Name .....

Road/Street .....

Locality/ Area/Village Name ..... Post office .....

City/Town/Taluk ..... District .....Pin code.....

Urban/Rural/Tribal .....

5.21 Was this doctor an oncologist? Yes ☐ No ☐

5.22 Did this hospital have oncology departments/specialists: Yes ☐ No ☐ If Yes, What/Who all?

1. Surgical Oncologist ☐ 2. Medical Oncologist ☐ 3. Radiation Oncologist ☐ 4. Nuclear Medicine ☐

5. Palliative Care ☐ 6. Others .....

Date of Commencement of Cancer Directed Treatment (If exact date is not known, please give the nearest estimate in weeks) ☐☐ ☐☐ ☐☐☐☐ **Or**..... Days/ Weeks/Months

5.23 Any Treatment given

1. No treatment given ☐ 2. Symptomatic treatment ☐ 3. Alternate medicine ☐ 4. Tests/scans done ☐

5. Surgery done ☐ 6. Chemotherapy given ☐ 7. Radiotherapy given ☐ 8.Hormone Therapy ☐

8. Advised Referral to another specialist ☐ 9. Advised referral to oncologist ☐ 10.Others .....

5.24 If you had presented to the above doctor after 4 weeks of having the problems/symptoms, list the reason(s)

a. I was not aware ☐ b. I thought that symptoms will resolve spontaneously ☐

c. I didn't have knowledge or information ☐ d. I didn't have time ☐

e. There was a family problem during that time ☐ f. There was no one to take me to the hospital ☐

g. the hospital was far from home ☐ Other reason, specify .....

5.23 Intent of treatment 1. Curative ☐ 2. Palliative ☐ 3. Pain relief only ☐ 4. Symptomatic ☐ 5. No Treatment ☐

Section 6. Details of cancer Management

(Collect this information from medical records.
Enter date as 01/01/1981 if the date is unknown or not available.)

6.1

Type of treatment	Given/Done/Not	Date of treatment- beginning
Surgery	1. Yes ☐ 2. No ☐	DD/MM/YYYY
Chemotherapy	1. Yes ☐ 2. No ☐	DD/MM/YYYY
Radiotherapy	1. Yes ☐ 2. No ☐	DD/MM/YYYY
Hormonal therapy	1. Yes ☐ 2. No ☐	DD/MM/YYYY
Immunotherapy	1. Yes ☐ 2. No ☐	DD/MM/YYYY
Alternate Medicine - AYUSH	1. Yes ☐ 2. No ☐	DD/MM/YYYY
Others	1. Yes ☐ 2. No ☐	DD/MM/YYYY

6.2 Status of treatment

a. No Treatment ☐ b. Completed ☐ c. Modified ☐ d. Under regular treatment but not completed ☐

e. Delayed ☐ f. Partial / incomplete / Irregular follow up ☐

6.3 Date of Completion of Cancer Directed Treatment (If treatment completed)

(If exact date is not known, please give the nearest estimate in weeks)

DD/MM/YYYY ☐☐ ☐☐ ☐☐☐☐ **Or**..... Days / Weeks / Months

6.4 Reasons for Non-treatment/partial/ incomplete treatment

a. Declined Treatment ☐ b. Advise to take planned Treatment outside this treatment ☐

c. Advised to take treatment elsewhere ☐ d. Death during treatment ☐

e. Unable to tolerate treatment ☐ f. Financial Reasons ☐

g. Social Reasons, please specify: .....

h. Chose Alternate medicine ☐ Other reason, specify .....

6.5 Name(s) and addresses of other Hospital / doctors where you received treatment .....

.....

6.6 Cost of treatment covered by:

a. Self ☐ b. CMCHIS ☐ c. AB-PMJAY ☐ d. ESI ☐ e. CGHS/EHS ☐

f. Private Health Insurance ☐ g.Other reason, specify .....

Section 7. Follow up

7.1 Date of last Follow Up/Contact: ☐☐ ☐☐ ☐☐☐☐

7.2 Frequency of follow up: a) Regular ☐ b) Irregular ☐

7.3 Adherent to treatment Follow up Schedule Yes ☐ No ☐

7.4 Disease status at last Follow up or at 6 months (whichever is earlier)

a. No evidence of Disease ☐ b. Cancer in regression/residual disease ☐

c. Cancer in Progression/recurrence ☐ d. New cancer/second primary ☐

e. Too advanced/cachexia ☐ f. Patient Dead ☐

Other reason, specify .....Not Known.....

7.5 Date of death: ☐☐ ☐☐ ☐☐☐☐

7.6 Quality of Life (at the time of interview): As per EORTC QLQC30&Katz index below

Assessment of daily life activities through Katz index of independence		
Activities	**Currently: Point (0/1)**	**At the time of diagnosis: Point (0/1)**
Bathing		
Dressing		
Toileting		
Transferring		
Continence		
Feeding		
TOTAL		

Independence (1) - No supervision or personal assistance

Dependence (0) - With supervision, direction, personal assistance or total care

S.No	Question	Not at all	A little	Very much	Quite a bit
1	Do you have any trouble doing strenuous activities, like carrying a heavy shopping bag or a suitcase?	1	2	3	4
2	Do you have any trouble taking a long walk?	1	2	3	4
3	Do you have any trouble taking a short walk outside of the house?	1	2	3	4
4	Do you need to stay in bed or a chair during the day?	1	2	3	4
5	Do you need help with eating, dressing, washing yourself or using the toilet?	1	2	3	4
During the past week					
6	Were you limited in doing either your work or other daily activities?	1	2	3	4
7	Were you limited in pursuing your hobbies or other leisure time activities?	1	2	3	4
8	Were you short of breath?	1	2	3	4

S.No	Question	Not at all	A little	Very much	Quite a bit
9	Have you had pain?	1	2	3	4
10	Did you need to rest?	1	2	3	4
11	Have you had trouble sleeping?	1	2	3	4
12	Have you felt weak?	1	2	3	4
13	Have you lacked appetite?	1	2	3	4
14	Have you felt nauseated?	1	2	3	4
15	Have you vomited?	1	2	3	4
16	Have you been constipated?	1	2	3	4
17	Have you had diarrhea?	1	2	3	4
18	Were you tired?	1	2	3	4
19	Did pain interfere with your daily activities?	1	2	3	4
20	Have you had difficulty in concentrating on things, like reading a newspaper or watching television?	1	2	3	4
21	Did you feel tense?	1	2	3	4
22	Did you worry?	1	2	3	4
23	Did you feel irritable?	1	2	3	4
24	Did you feel depressed?	1	2	3	4
25	Have you had difficulty remembering things?	1	2	3	4
26	Has your physical condition or medical treatment interfered with your family life?	1	2	3	4
27	Has your physical condition or medical treatment interfered with your social activities?	1	2	3	4
28	Has your physical condition or medical treatment caused you financial difficulties?	1	2	3	4

29	How would you rate your overall health during the past week?	1	2	3	4	5	6	7
		 Really Bad	 Bad	 Just a little Bad	 Okay	 Just a little Good	 Good	 Really Good
30	How would you rate your overall quality of life during the past week?	1	2	3	4	5	6	7
		 Really Bad	 Bad	 Just a little Bad	 Okay	 Just a little Good	 Good	 Really Good

TNHSRP – ORP Research

Understanding correlation between social determinants of delays in diagnosis and management and outcomes for solid cancers in Tamil Nadu- Multicentric mixed method study

தகவலறிந்த ஒப்புதல் படிவம் (பெரியவர்கள்)

தலைப்பு:

தமிழ்நாட்டில் புற்றுநோய் கண்டறிதல் மற்றும் சிகிச்சையில் ஏற்படும் தாமதங்களின் மற்றும் அதன் விளைவுகளில் சமூக நிர்ணயிப்பாளர்களுக்கு இடையே உள்ள தொடர்பைப் புரிந்துகொள்வது- மல்டிசென்ட்ரிக் கலப்பு முறை ஆய்வு

நோயாளி / பங்கேற்பாளர் பெயர்: .....

முகவரி:.....

.....

.....

.ஆய்வு விவரங்கள் அடங்கிய தகவல் தாளின் நகல் என்னிடம் கொடுக்கப்பட்டுள்ளது. மேற்கூறிய ஆய்வில் பங்கேற்க நான் முன்வந்துள்ளேன்.

ஆய்வின் விவரங்கள் எனக்கு எழுத்துப்பூர்வமாக வழங்கப்பட்டு எனது சொந்த மொழியில் எனக்கு விளக்கப்பட்டுள்ளது. மேற்கூறிய ஆய்வைப் புரிந்துகொண்டு கேள்விகளைக் கேட்கும் வாய்ப்பைப் பெற்றுள்ளேன் என்பதை உறுதிப்படுத்துகிறேன். இழப்பீடு மற்றும் இந்த ஆராய்ச்சியில் உள்ள அபாயங்கள் மற்றும் நன்மைகள் பற்றி நான் புரிந்துகெ-ாண்டேன் என்பதை உறுதிப்படுத்துகிறேன். இந்த ஆய்வில் எனது பங்கேற்பு தன்னார்வமானது என்பதையும், எந்த காரணமும் கூறாமல், இந்த மருத்துவமனையில் எனது வழக்கமான மருத்துவச் சேவை பாதிக்கப்படாமல், எந்த நேரத்திலும் நான் விலகிக்கெ-ாள்ள சுதந்திரமாக இருக்கிறேன் என்பதையும் புரிந்துகொள்கிறேன். எனது அடையாளத்தின் ரகசியத்தன்மை ஆராய்ச்சிக் காலத்திலும், அது முடிந்த பிறகும், முடிவுகளை வெளியிடும் போதும் பராமரிக்கப்படும் என்பதை நான் புரிந்துகொள்கிறேன்.

ஆய்வு நோக்கங்களுக்காக/முடிவுகளைத் தெரிந்துகொள்வதற்காக தொலைபேசியில் தொடர்புகொள்ளவும் சம்மதிக்கிறேன்

இதைப் புரிந்துகொண்டு, அவர்கள் என்னை நேர்காணல் செய்ய என் சம்மதத்தைத் தெரிவித்துக் கொள்கிறேன். இந்த ஆய்வில் பங்கேற்பதற்கான எனது சம்மதத்தையும் விருப்பத்தையும் குறிக்க எனது கையொப்பம் / இடது கட்டைவிரல் பதிவை ஒட்டுகிறேன் (அதாவது, படிப்புத் தேவைகளுக்கு விருப்பத்துடன் இணங்குகிறேன்).

நோயாளி/பங்கேற்பாளர் / சட்டப் பிரதிநிதியின் பெயர் மற்றும்
கையொப்பம் /இடது கட்டைவிரல் பதிவு தேதியுடன்:

நேர்காணல் செய்பவரின் பெயர் மற்றும் கையொப்பம் தேதியுடன்:

சாட்சியின் பெயர் மற்றும் கையொப்பம் தேதியுடன்:

TNHSRP – ORP Research

Understanding correlation between social determinants of delays in diagnosis and management and outcomes for solid cancers in Tamil Nadu- Multicentric mixed method study

பெற்றோர் ஒப்புதல் படிவம்

(13-18 வயதுக்குட்பட்ட குழந்தைகளுக்கு)

தலைப்பு:

தமிழ்நாட்டில் புற்றுநோய் கண்டறிதல் மற்றும் சிகிச்சையில் ஏற்படும் தாமதங்களின் மற்றும் அதன் விளைவுகளில் சமூக நிர்ணயி-ப்பாளர்களுக்கு இடையே உள்ள தொடர்பைப் புரிந்துகொள்வது- மல்டிசென்ட்ரிக் கலப்பு முறை ஆய்வு

நோயாளி/பங்கேற்பாளர் பெயர்:.....

பெற்றோர் பெயர்: .....

முகவரி:.....

ஆய்வு விவரங்கள் அடங்கிய தகவல் தாள் நகல் எங்களிடம் வழங்கப்பட்டுள்ளது. நாங்கள் (என் குழந்தையும் நானும்) மேற்கூறிய ஆய்வில் பங்கேற்க முன்வருகிறோம்.

ஆய்வின் விவரங்கள் எழுத்துப்பூர்வமாக் புரிந்துகொண்டோம் என்பதையும்
கேள்விகளைக் கேட்கும் வாய்ப்பைப் பெற்றுள்ளோம் என்பதையும் உறுதிப்படுத்துகிறோம். இழப்பீடு மற்றும் இந்தஆராய்ச்சியில் உள்ள அபாயங்கள் மற்றும் பலன்கள் பற்றி நாங்கள் (எனது குழந்தையும் நானும்) புரிந்து கொண்டுள்ளோம் என்பதை உறுதிப்படுத்துகிறோம். நாங்கள் (என் குழந்தையும் நானும்) ஆய்வில் பங்கேற்பது தன்னார்வமானது என்பதையும், எந்தக் காரணமும் கூறாமல், இந்த மருத்துவமனையில் எனது வழக்கமான மருத்துவச் சேவை பாதிக்கப்படாமல், எந்த நேரத்திலும் விலகிக் கொள்ளலாம் என்பதையும் நாங்கள் புரிந்துகொள்கிறோம். எனது அடையாளத்தின் ரகசியத்தன்மை ஆராய்ச்சிக் காலத்-திலும், அது முடிந்த பிறகும், முடிவுகளை வெளியிடும் போதும் பராமரிக்கப்படும் என்பதை நாங்கள் (எனது குழந்தையும் நானும்) புரிந்துகொள்கிறோம்.

நாங்கள் (எனது குழந்தையும் நானும்) ஆய்வு நோக்கங்களுக்காக/ முடிவுகளை அறிவதற்காக தொலைபேசியில் தொடர்பு கொள்ள சம்மதிக்கிறோம்

இதைப் புரிந்துகொண்டு, அவர்கள் எங்களை நேர்காணல் செய்ய என் சம்மதத்தைத் தருகிறோம். எனது குழந்தை இந்த ஆய்வில் பங்கேற்பதற்கான எனது சம்மதத்தையும் விருப்பத்தையும் குறிக்க எனது கையொப்பம் / இடது கட்டைவிரல் பதிவை ஒட்டுகிறேன் (அதாவது, படிப்புத் தேவைகளுக்கு விருப்பத்துடன் இணங்குகிறேன்).

பெற்றோர் / சட்டப் பிரதிநிதியின் பெயர் மற்றும் கையொப்பம் /இடது கட்டைவிரல் பதிவு தேதியுடன்:

நேர்காணல் செய்பவரின் பெயர் மற்றும் கையொப்பம் தேதியுடன்:

தேதியுடன் குழந்தையின் பெயர் மற்றும் கையொப்பம் (குழந்தை சம்மதம் இருந்தால்)

சாட்சியின் பெயர் மற்றும் கையொப்பம் தேதியுடன்:

PSG Institute of Medical Sciences & Research
Peelamedu, Coimbatore 641 004, India
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நோயாளி தகவல் தாள் (பெரியவர்கள் மற்றும் குழந்தைகள்)

தலைப்பு:

தமிழ்நாட்டில் புற்றுநோய் கண்டறிதல் மற்றும் சிகிச்சையில் ஏற்படும் தாமதங்களின் மற்றும் அதன் விளைவுகளில் சமூக நிர்ணயிப்பாளர்களுக்கு இடையே உள்ள தொடர்பைப் புரிந்துகொள்வது- மல்டிசென்ட்ரிக் கலப்பு முறை ஆய்வு

பின்னணி:

வாய்வழி குழி (14%), நுரையீரல் (10.4%) மற்றும் இரைப்பை குடல் (சுமார் 20%) புற்றுநோய்கள் இந்தியாவிலும் தமிழகத்திலும் புற்றுநோய் சுமையின் பெரும்பகுதியை உருவாக்குகின்றன. இந்த புற்றுநோய்களைக் கண்டறிதல் மற்றும் நிர்வகிப்பதில் ஏற்படும் தாமதங்களும் விளைவுகளில் குறிப்பிடத்தக்க தாக்கத்தை ஏற்படுத்துகின்றன. இந்தத் திட்டத்தின் முக்கிய குறிக்கோள்கள், இந்த புற்றுநோய்களைக் கண்டறிதல் மற்றும் நிர்வகிப்பதில் ஏற்படும் தாமதங்கள், அதன் காரணங்கள் மற்றும் இந்த தாமதங்கள் புற்றுநோய் விளைவுகளை எவ்வாறு பாதிக்கின்றன என்பதைக் கண்டறிவதாகும்.

இது தமிழ்நாடு சுகாதார அமைப்புகள் ஆராய்ச்சித் திட்டம் **(TNHSRP)**, தமிழ்நாடு அரசின் சுகாதாரம் மற்றும் குடும்ப நல அமைச்சகம் மூலம் PSG மருத்துவமனையில் நடத்தப்படும் கல்வியியல் ஆராய்ச்சி ஆய்வாகும். தமிழகம் முழுவதும் உள்ள பல்வேறு புற்றுநோய் மையங்களில் இருந்து சுமார் 2000 புற்றுநோயாளிகளை சேர்க்க எதிர்பார்க்கிறோம்.

நீங்கள் தமிழகத்தை பூர்வீகமாகக் கொண்டவர் என்பதாலும், உங்களுக்கோ அல்லது உங்கள் குடும்பத்தாருக்கோ மேற்கூறிய புற்றுநோய்களில் (வாய் புற்றுநோய், நுரையீரல், உணவுக் குழாய், வயிறு, குடல், கல்லீரல், பித்தப்பை, கணையம், முதலியன) ஒன்று இருப்பது கண்டறியப்பட்டதால் இந்த ஆராய்ச்சி ஆய்வில் பங்கேற்க அழைக்கப்படுகிறீர்கள்.

இந்த ஆய்வு எதைப் பற்றியது?

ஆய்வில், சமூக மற்றும் பொருளாதார பின்னணி, நீங்கள் வசிக்கும் இடம், உங்கள் நோய், நீங்கள் பெற்ற சிகிச்சை, நீங்கள் எங்கு சிகிச்சை பெற்றீர்கள் மற்றும் உங்களுக்கான செலவு எவ்வளவு, சிகிச்சையின் போது நீங்கள் எதிர்கொள்ளும் சிரமங்கள் அல்லது தாமதங்கள் பற்றிய தரவுகளை சேகரிப்போம். பின்தொடர்தல் மற்றும் அத்தகைய தாமதங்கள் அல்லது சிரமங்களுக்கான காரணங்கள் பற்றிய உங்கள் கருத்துகள். இந்தத் தகவல் கேள்வித்தாள் வடிவில் சேகரிக்கப்படும், அதை நீங்கள் எங்கள் புல ஆய்வாளர்களின் உதவியுடன் நிரப்புவீர்கள். இந்தத் தகவலைச் சேகரிப்பதற்காக உங்களிடமிருந்தோ அல்லது உங்கள் மருத்துவமனையிடமிருந்தோ உங்கள் மருத்துவப் பதிவுகளையும் நாங்கள் கேட்கலாம். நோயறிதலுக்கு முன் உங்கள் நோய் ஆரம்பம், முதலில் GP தொடர்பு கொண்டு சிகிச்சை தொடங்கப்பட்ட நேரம் பற்றிய தரவை நாங்கள் சேகரிப்போம். உங்கள் வருமானம், கல்வி மற்றும் தொழில் பற்றிய சில விவரங்களுடன் ஒரு கணக்கெடுப்பை நிரப்பும்படி கேட்கப்படுவீர்கள். ஏதேனும் கேள்விகள் உங்களுக்கு சங்கடமானதாக இருந்தால், அதற்கு நீங்கள் பதிலளிக்க வேண்டியதில்லை.

இந்த ஆய்வில் பங்கேற்பது உங்கள் சிகிச்சையில் அல்லது பின்தொடர்வதில் எந்த தாக்கத்தையும் ஏற்படுத்தாது. நீங்கள் பங்கேற்க முடிவு செய்தாலும் இல்லாவிட்டாலும் உங்கள் சிகிச்சையில் எந்த மாற்றமும் செய்யப்படாது.

ஆய்வில் பங்கேற்கும் போது கேள்விகளைப் புரிந்துகொள்வதில் உங்களுக்கு ஏதேனும் சிரமம் இருந்தால் மொழிபெயர்ப்பாளர் வழங்கப்படும்.

நேர அர்ப்பணிப்பு:

உங்களுக்கான நேர அர்ப்பணிப்பு மிகவும் குறைவு (சுமார் 20 நிமிடங்கள்). நீங்கள் மருத்துவமனையில் இருக்கும்போது, ஆராய்ச்சிக்கு பதிலளிக்க உங்களை அழைப்போம், மேலும் இது குறித்து உங்களுக்கு ஏதேனும் கேள்விகள் இருந்தால் நாங்கள் உங்களுக்கு ஆதரவளிப்போம். இதற்குப் பிறகு, உங்கள் பங்கேற்பு முடிந்துவிடும், மேலும் எதுவும் செய்ய வேண்டியதில்லை.

அபாயங்கள் மற்றும் நன்மைகள்:

உங்களுக்கான ஆய்வில் பங்கேற்பதால் நேரடியான அபாயங்கள் அல்லது நன்மைகள் எதுவும் இல்லை. மறைமுகமான பலன் என்னவென்றால், ஆய்வின் முடிவுகள் அரசாங்கத்திற்கு உதவும். தமிழ்நாடு அவர்களின் கொள்கைகளை மேம்படுத்துவதன் மூலம் சிறந்த புற்றுநோய் சிகிச்சை சேவைகளை வழங்க வேண்டும்.

இரகசியத்தன்மை:

உங்களைப் பற்றிய தகவல்கள் ரகசியமாக வைக்கப்படும். ஆய்வு முடிவுகளைப் பற்றிய கருத்தைப் பெற விரும்பினால், உங்கள் மின்னஞ்சலைப் பகிர்வதற்கான தேர்வு உங்களுக்கு வழங்கப்படும். நீங்கள் அதைப் பகிர விரும்பவில்லை அல்லது மின்னஞ்சல் கணக்கை வைத்திருக்கவில்லை என்றால், நீங்கள் ஆர்வமாக இருந்தால், இந்தத் தகவலை உள்ளூர் ஆராய்ச்சி கூட்டாளர்களிடம் (அந்தந்த தளம் PI) எப்போதும் கேட்கலாம். உங்களைப் பற்றிய ஆராய்ச்சிக்குத் தேவைப்படும் குறைந்தபட்ச தகவல் இந்த ஆய்வை ஒருங்கிணைக்கும் தமிழ்நாடு அரசுக்கு (TNHSRP) அனுப்பப்படும். இது 10 ஆண்டுகள் சேமிக்கப்படும், ஆனால் பின்னர் அழிக்கப்படும். தரவை முடிந்தவரை பாதுகாப்பாகவும் குறைவான விவரமாகவும் வைத்திருப்போம்; உங்கள் பெயர் மின்னஞ்சல் அல்லது தொலைபேசி பற்றிய பதிவுகள் ஆய்வு மைய கோப்புகளில் வைக்கப்படாது.

ஒப்புதல்:

படிப்பில் சேருவது உங்கள் விருப்பம். நீங்கள் பங்கேற்க ஒப்புக்கொண்டால், ஒப்புதல் படிவத்தில் கையொப்பமிட (அல்லது கைரேகை) உங்களிடம் கேட்போம். நேர்முகத் தேர்வின் போது எங்களின் ஏதேனும் கேள்விகளுக்குப் பதிலளிப்பதில் உங்களுக்கு அசௌகரியம் இருந்தால், எந்த நேரத்திலும் நேர்காணலில் இருந்து / படிப்பிலிருந்து விலக உங்களுக்கு உரிமை உண்டு. எந்த நேரத்திலும் படிப்பிலிருந்து விலக உங்களுக்கு சுதந்திரம் உள்ளது. நீங்கள் எந்த நிலையிலும் பங்கேற்க மறுப்பது அல்லது திரும்பப் பெறுவது, நீங்கள் அவ்வாறு முடிவு செய்தால், வழங்கப்படும் சேவைகளில் எந்தவிதமான சமரசம் அல்லது பாரபட்சம் ஏற்படாது அல்லது அபராதம் விதிக்கப்படாது என்பதை தயவுசெய்து உறுதியளிக்கவும். நோயாளிக்கு வழங்கப்படும் வழக்கமான சேவைகளை நீங்கள் தொடர்ந்து அணுகுவீர்கள். படிப்பில் இருந்து விலகுவது நீங்கள் பெறும் கவனிப்பைப் பாதிக்காது.

இந்த நேர்காணல்/படிப்புக்காக நீங்கள் எங்களுடன் செலவழித்த நேரத்திற்கு எந்த ஊதியமும் உங்களுக்கு வழங்கப்படாது. நீங்கள் வழங்கிய தகவல்கள் நம்பிக்கையுடன் வைக்கப்படும். எந்தச் சூழ்நிலையிலும், பதிலளிப்பவர் அல்லது அவர்களது குடும்பத்தினரின் அடையாளத்தை நாங்கள் யாருக்கும் தெரிவிக்க மாட்டோம். நாங்கள் சேகரிக்கும் தகவல்கள் அங்கீகரிக்கப்பட்ட ஆராய்ச்சி நோக்கங்களுக்காக மட்டுமே பயன்படுத்தப்படும். ஏதேனும் குறிப்பிடத்தக்க புதிய

கண்டுபிடிப்புகள் - பாதகமான நிகழ்வுகள், ஏதேனும் இருந்தால் - உங்களுக்கு அல்லது இந்த ஆய்வின் பிற பங்கேற்பாளர்களுடன் நேரடியாக தொடர்புடையதாக இருந்தாலும், இந்த ஆராய்ச்சியின் போது உருவாக்கப்பட்ட, தொடர்ந்து பங்கேற்பதற்கான உங்கள் விருப்பத்துடன் தொடர்புடையதாக இருக்கலாம்.

மேலும் விவரங்களுக்கு எந்த நேரத்திலும் ஆய்வுக் குழுவைத் தொடர்புகொள்ளலாம்:

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தகவலறிந்த ஒப்புதல் படிவம் (பெரியவர்கள்)

தலைப்பு:
தமிழ்நாட்டில் புற்றுநோய் கண்டறிதல் மற்றும் சிகிச்சையில் ஏற்படும் தாமதங்களின் மற்றும் அதன் விளைவுகளில் சமூக நிர்ணயிப்பாளர்களுக்கு இடையே உள்ள தொடர்பைப் புரிந்துகொள்வது- மல்டிசென்ட்ரிக் கலப்பு முறை ஆய்வு

நோயாளி/பங்கேற்பாளர் பெயர்: _____

முகவரி: _____

_____

ஆய்வு விவரங்கள் அடங்கிய தகவல் தாளின் நகல் என்னிடம் கொடுக்கப்பட்டுள்ளது. மேற்கூறிய ஆய்வில் பங்கேற்க நான் முன்வந்துள்ளேன்.
ஆய்வின் விவரங்கள் எனக்கு எழுத்துப்பூர்வமாக வழங்கப்பட்டு எனது சொந்த மொழியில் எனக்கு விளக்கப்பட்டுள்ளது. மேற்கூறிய ஆய்வைப் புரிந்துகொண்டு கேள்விகளைக் கேட்கும் வாய்ப்பைப் பெற்றுள்ளேன் என்பதை உறுதிப்படுத்துகிறேன். இழப்பீடு மற்றும் இந்த ஆராய்ச்சியில் உள்ள அபாயங்கள் மற்றும் நன்மைகள் பற்றி நான் புரிந்துகொண்டேன் என்பதை உறுதிப்படுத்துகிறேன். இந்த ஆய்வில் எனது பங்கேற்பு தன்னார்வமானது என்பதையும், எந்த காரணமும் கூறாமல், இந்த மருத்துவமனையில் எனது வழக்கமான மருத்துவச் சேவை பாதிக்கப்படாமல், எந்த நேரத்திலும் நான் விலகிக்கொள்ள சுதந்திரமாக இருக்கிறேன் என்பதையும் புரிந்துகொள்கிறேன். எனது அடையாளத்தின் ரகசியத்தன்மை ஆராய்ச்சிக் காலத்திலும், அது முடிந்த பிறகும், முடிவுகளை வெளியிடும் போதும் பராமரிக்கப்படும் என்பதை நான் புரிந்துகொள்கிறேன்.

ஆய்வு நோக்கங்களுக்காக/முடிவுகளைத் தெரிந்துகொள்வதற்காக தொலைபேசியில் தொடர்புகொள்ளவும் சம்மதிக்கிறேன்

இதைப் புரிந்துகொண்டு, அவர்கள் என்னை நேர்காணல் செய்ய என் சம்மதத்தைத் தெரிவித்துக் கொள்கிறேன். இந்த ஆய்வில் பங்கேற்பதற்கான எனது சம்மதத்தையும் விருப்பத்தையும் குறிக்க எனது கையொப்பம் / இடது கட்டைவிரல் பதிவை ஒட்டுகிறேன் (அதாவது, படிப்புத் தேவைகளுக்கு விருப்பத்துடன் இணங்குகிறேன்).

நோயாளி/பங்கேற்பாளர் / சட்டப் பிரதிநிதியின் பெயர் மற்றும் கையொப்பம் /இடது கட்டைவிரல் பதிவு தேதியுடன்:

நேர்காணல் செய்பவரின் பெயர் மற்றும் கையொப்பம் தேதியுடன்:

சாட்சியின் பெயர் மற்றும் கையொப்பம் தேதியுடன்:

PSG Institute of Medical Sciences & Research
Peelamedu, Coimbatore 641 004, India
Phone: +91-0422-4345818 Fax: +91-422-2594400

பெற்றோர் ஒப்புதல் படிவம்

(13-18 வயதுக்குட்பட்ட குழந்தைகளுக்கு)

தலைப்பு:
தமிழ்நாட்டில் புற்றுநோய் கண்டறிதல் மற்றும் சிகிச்சையில் ஏற்படும் தாமதங்களின் மற்றும் அதன் விளைவுகளில் சமூக நிர்ணயிப்பாளர்களுக்கு இடையே உள்ள தொடர்பைப் புரிந்துகொள்வது- மல்டிசென்ட்ரிக் கலப்பு முறை ஆய்வு

நோயாளி/பங்கேற்பாளர் பெயர்: _____

பெற்றோர் பெயர்: _____

முகவரி: _____

ஆய்வு விவரங்கள் அடங்கிய தகவல் தாள் நகல் எங்களிடம் வழங்கப்பட்டுள்ளது. நாங்கள் (என் குழந்தையும் நானும்) மேற்கூறிய ஆய்வில் பங்கேற்க முன்வருகிறோம்.

ஆய்வின் விவரங்கள் எழுத்துப்பூர்வமாக எங்களுக்கு வழங்கப்பட்டுள்ளது மற்றும் எங்கள் சொந்த மொழியில் எங்களுக்கு விளக்கப்பட்டுள்ளது. நாங்கள் (எனது குழந்தை மற்றும் நான்) மேற்கூறிய படிப்பைப் புரிந்துகொண்டோம் என்பதையும் கேள்விகளைக் கேட்கும் வாய்ப்பைப் பெற்றுள்ளோம் என்பதையும் உறுதிப்படுத்துகிறோம். இழப்பீடு மற்றும் இந்த ஆராய்ச்சியில் உள்ள அபாயங்கள் மற்றும் பலன்கள் பற்றி நாங்கள் (எனது குழந்தையும் நானும்) புரிந்து கொண்டுள்ளோம் என்பதை உறுதிப்படுத்துகிறோம். நாங்கள் (என் குழந்தையும் நானும்) ஆய்வில் பங்கேற்பது தன்னார்வமானது என்பதையும், எந்தக் காரணமும் கூறாமல், இந்த மருத்துவமனையில் எனது வழக்கமான மருத்துவச் சேவை பாதிக்கப்படாமல், எந்த நேரத்திலும் விலகிக் கொள்ளலாம் என்பதையும் நாங்கள் புரிந்துகொள்கிறோம். எனது அடையாளத்தின் ரகசியத்தன்மை ஆராய்ச்சிக் காலத்திலும், அது முடிந்த பிறகும், முடிவுகளை வெளியிடும் போதும் பராமரிக்கப்படும் என்பதை நாங்கள் (எனது குழந்தையும் நானும்) புரிந்துகொள்கிறோம்.

நாங்கள் (எனது குழந்தையும் நானும்) ஆய்வு நோக்கங்களுக்காக/ முடிவுகளை அறிவதற்காக தொலைபேசியில் தொடர்பு கொள்ள சம்மதிக்கிறோம்

இதைப் புரிந்துகொண்டு, அவர்கள் எங்களை நேர்காணல் செய்ய என் சம்மதத்தைத் தருகிறோம். எனது குழந்தை இந்த ஆய்வில் பங்கேற்பதற்கான எனது சம்மதத்தையும் விருப்பத்தையும் குறிக்க எனது கையொப்பம் / இடது கட்டைவிரல் பதிவை ஒட்டுகிறேன் (அதாவது, படிப்புத் தேவைகளுக்கு விருப்பத்துடன் இணங்குகிறேன்).

பெற்றோர் / சட்டப் பிரதிநிதியின் பெயர் மற்றும் கையொப்பம் /இடது கட்டைவிரல் பதிவு தேதியுடன்:

நேர்காணல் செய்பவரின் பெயர் மற்றும் கையொப்பம் தேதியுடன்:

தேதியுடன் குழந்தையின் பெயர் மற்றும் கையொப்பம் (குழந்தை சம்மதம் இருந்தால்)

சாட்சியின் பெயர் மற்றும் கையொப்பம் தேதியுடன்:

PSG Institute of Medical Sciences & Research
Peelamedu, Coimbatore 641 004, India
Phone: +91-0422-4345818 Fax: +91-422-2594400

Patient Information Sheet (Adult and Paediatric)

Study Title:

Understanding correlation between social determinants of delays in diagnosis and management and outcomes for solid cancers in Tamil Nadu- Multicentric mixed method study

Background:

Oral cavity (14%), lung (10.4%) and Gastro intestinal tract (around 20%) cancers form major proportion of the cancer burden in India and Tamil Nadu. Delays in diagnosis and management of these cancers also has a significant impact on the outcomes. The main goals of this project are to identify delays in the diagnosis and management of these cancers, along with its causes and how these delays impact cancer outcomes.

This is an academic research study conducted at **PSG Hospital** funded by **Tamil Nadu Health Systems Research Project (TNHSRP), Ministry of Health and Family Welfare, Government of Tamil Nadu** and led by **PSG Hospitals, Coimbatore**. We expect to include around 2000 cancer patients from multiple cancer centres across Tamil Nadu.

You are being invited to participate in this research study because you are a native of Tamil Nadu and you or your family member has been diagnosed with one of the above cancers (oral cancer, lung, food pipe, stomach, bowel, liver, gall bladder, pancreas, etc.)

What is this study about?

In the study, we will collect data about social and economic background, where you live, your disease, the treatment you received, including where you received treatment and how much it cost for you, any difficulties or delays that you faced during the treatment or follow up and your opinions regarding the causes for such delays or difficulties. This information will be collected in the form of a questionnaire which you will fill with the help of our field investigators. We may also ask for your medical records from you or your hospital for collecting this information. We will collect data about your disease onset, first GP contacted before diagnosis and the time of treatment initiated. You will be asked to fill a survey with some details about your income, education and occupation. If any questions make you uncomfortable, you do not have to answer them.

Participation in this study will have no impact on your treatment or follow up. No changes to your treatment will be made whether you decide to participate or not.

An interpreter/translator will be provided if you have any difficulty in understanding the questions during taking part in the study.

Time commitment:

The time commitment for you is very low (about 20 minutes). Whilst you are in hospital we will invite you to answer the survey and we will support you in any questions you have about it. After this, your participation will be over and nothing further will need to be done.

Risks and Benefits:

There are no direct risks or benefits of participating in the study for you. The indirect benefit is that the results from the study can help the Govt. of Tamil Nadu to provide better cancer care services by updating their policies.

Confidentiality:

Information about you will be kept confidential. You will be given the choice to share your email in case you want to get feedback about the study results. If you don't wish to share it or don't hold an e-mail account, you can always ask the local research partners (respective site PI) for this information, if you are interested. The least possible information about you that is needed for the research will be sent to the Government of Tamil Nadu (TNHSRP) which is coordinating this study. It will be stored for 10 years but will then be destroyed. We will keep

the data as safely and less detailed as possible; no records of your name e-mail or telephone will be kept in the study central files.

Consent:

It is up to you to decide to join the study. If you agree to take part, we will ask you to sign (or fingerprint) a consent form. If you are uncomfortable in answering any of our questions during the course of the interview, you have the right to withdraw from the interview / study at any time. You have the freedom to withdraw from the study at any point of time. Kindly be assured that your refusal to participate or withdrawal at any stage, if you so decide, will not result in any form of compromise or discrimination in the services offered nor would it attract any penalty. You will continue to have access to the regular services offered to a patient. Withdrawing from the study will not affect the care you receive.

You will NOT be paid any remuneration for the time you spend with us for this interview / study. The information provided by you will be kept in strict confidence. Under no circumstances shall we reveal the identity of the respondent or their families to anyone. The information that we collect shall be used for approved research purposes only. You will be informed about any significant new findings - including adverse events, if any, – whether directly related to you or to other participants of this study, developed during the course of this research which may relate to your willingness to continue participation.

You can contact the study team at any time for further details:

Principal Investigator Details:

Dr. K S Rajkumar – Principal Investigator
Professor
Department of Surgical Oncology
PSGIMSR, Coimbatore
Email: rajkumarks@psgimsr.ac.in

IEC Details:

Member Secretary,
Institutional Human Ethics Committee (IHEC),
Academic Block, 1st Floor,
PSG Institute of Medical Sciences and Research,
Avinashi Road, Peelamedu,
Coimbatore – 641 004, India.
Phone: +91 422 4345818
Fax: +91 422 2594400
Email: ihec@psgimsr.ac.in

PSG Institute of Medical Sciences & Research
Peelamedu, Coimbatore 641 004, India
Phone: +91-0422-4345818 Fax: +91-422-2594400

INFORMED CONSENT FORM (Adults)

Study Title:
Understanding correlation between social determinants of delays in diagnosis and management and outcomes for solid cancers in Tamil Nadu- Multicentric mixed method study

Patient/Participant Name: _____

Address: _____

_____

I have been given a copy of information sheet giving details of the study. I volunteer to participate in the above-mentioned study.

The details of the study has been provided to me in writing and explained to me in my own language. I confirm that I have understood the above study and had the opportunity to ask questions. I confirm that I have understood about the compensation and the risks and benefits involved in this research. I understand that my participation in the study is voluntary and that I am free to withdraw at any time without giving any reason, and without my routine medical care in this hospital being affected. I understand that confidentiality of my identity will be maintained during the research period, after its completion as well as during publication of the results.

I also consent to be contacted over telephone for study purposes/ knowing the results

Having understood the same, I hereby give my consent to them to interview me. I am affixing my signature / left thumb impression to indicate my consent and willingness to participate in this study (i.e., willingly abide by the study requirements).

Name and Signature / Left thumb impression of the Patient / Legal Representative with date:

Name and Signature of the Interviewer/Investigator with date:

Name and Signature of Witness/Interpreter with date:

PSG Institute of Medical Sciences & Research
Peelamedu, Coimbatore 641 004, India
Phone: +91-0422-4345818 Fax: +91-422-2594400

PARENTAL ASSENT FORM
(For children between 13-18 years old)

Study Title:
Understanding correlation between social determinants of delays in diagnosis and management and outcomes for solid cancers in Tamil Nadu- Multicentric mixed method study

Patient/Participant Name: _____

Parent Name: _____

Address: _____

_____

We have been given a copy of information sheet giving details of the study. We (my child and I) volunteer to participate in the above-mentioned study.

The details of the study has been provided to us in writing and explained to us in our own language. We (my child and I) confirm that we have understood the above study and had the opportunity to ask questions. We (my child and I) confirm that we have understood about the compensation and the risks and benefits involved in this research. We (my child and I) understand that participation in the study is voluntary and that we are free to withdraw at any time without giving any reason, and without my routine medical care in this hospital being affected. We (my child and I) understand that confidentiality of my identity will be maintained during the research period, after its completion as well as during publication of the results.

We (my child and I) also consent to be contacted over telephone for study purposes/ knowing the results

Having understood the same, we hereby give my consent to them to interview us. I am affixing my signature / left thumb impression to indicate my consent and willingness for my child to participate in this study (i.e., willingly abide by the study requirements).

Name and Signature / Left thumb impression of the Parent / Legal Representative with date:

Name and Signature of Person Conducting Assent Discussion with date:

Name and Signature of the child with date (if child assents):

Name and Signature of Witness/Interpreter with date:

PSG Institute of Medical Sciences & Research
Peelamedu, Coimbatore 641 004, India
Phone: +91-0422-4345818 Fax: +91-422-2594400

Participant Information Sheet (Doctors)

Study Title:

Understanding correlation between social determinants of delays in diagnosis and management and outcomes for solid cancers in Tamil Nadu- Multicentric mixed method study

Background:

Oral cavity (14%), lung (10.4%) and Gastro intestinal tract (around 20%) cancers form major proportion of the cancer burden in India and Tamil Nadu. Delays in diagnosis and management of these cancers also has a significant impact on the outcomes. The main goals of this project are to identify delays in the diagnosis and management of these cancers, along with its causes and how these delays impact cancer outcomes.

This is an academic research study conducted at **PSG Hospital** funded by **Tamil Nadu Health Systems Research Project (TNHSRP), Ministry of Health and Family Welfare, Government of Tamil Nadu** and led by **PSG Hospitals, Coimbatore**. We expect to include around 2000 cancer patients from multiple cancer centres across Tamil Nadu

You are being invited to participate in this research study because you are a doctor who treats patients with one of the above cancers (oral cancer, lung, food pipe, stomach, bowel, liver, gall bladder, pancreas, etc.) or are a primary care or specialist doctor who regularly sees patients with the above cancers

What is this study about?

In the study, we will collect your opinions regarding the social and economic background of your patients, any difficulties or delays that they face(d) during the treatment or follow up and your opinions regarding the causes for such delays or difficulties. This information will be collected in the form of an interview with the help of our field investigators. If any questions make you uncomfortable, you do not have to answer them. The interviews will be recorded for qualitative analysis.

An interpreter/translator will be provided if you have any difficulty in understanding the questions during taking part in the study.

Time commitment:

The time commitment for you is very low (about 20 minutes After this, your participation will be over and nothing further will need to be done.

Risks and Benefits:

There are no direct risks or benefits of participating in the study for you. The indirect benefit is that the results from the study can help the Govt. of Tamil Nadu to provide better cancer care services by updating their policies.

Confidentiality:

Information about you will be kept confidential. You will be given the choice to share your email in case you want to get feedback about the study results. If you don't wish to share it or don't hold an e-mail account, you can always ask the local research partners (respective site PI) for this information, if you are interested. The least possible information about you that is needed for the research will be sent to the Government of Tamil Nadu (TNHSRP) which is coordinating this study. It will be stored for 10 years but w1then be destroyed. We will keep the data as safely and less detailed as possible; no records of your name e-mail or telephone will be kept in the study central files.

Consent:

It is up to you to decide to join the study. If you agree to take part, we will ask you to sign (or fingerprint) a consent form. If you are uncomfortable in answering any of our questions during the course of the interview, you have the right to withdraw from the interview / study at any time. You have the freedom to withdraw from the study at any point of time. Kindly be assured that your refusal to participate or withdrawal at any stage, if you so decide, will not result in any form of compromise or discrimination in the services offered nor would it attract any penalty. You will continue to have access to the regular services offered to a patient. Withdrawing from the study will not affect the care you receive.

You will NOT be paid any remuneration for the time you spend with us for this interview / study. The information provided by you will be kept in strict confidence. Under no circumstances shall we reveal the identity of the respondent or their families to anyone. The information that we collect shall be used for approved research purposes only. You will be informed about any significant new findings - including adverse events, if any, – whether directly related to you or to other participants of this study, developed during the course of this research which may relate to your willingness to continue participation.

You can contact the study team at any time through this email:

Principal Investigator Details:

Dr. K S Rajkumar – Principal Investigator
Professor
Department of Surgical Oncology
PSGIMSR, Coimbatore
Email: rajkumarks@psgimsr.ac.in

IEC Details:

Member Secretary,
Institutional Human Ethics Committee (IHEC),
Academic Block, 1st Floor,
PSG Institute of Medical Sciences and Research,
Avinashi Road, Peelamedu,
Coimbatore – 641 004, India.
Phone: +91 422 4345818
Fax: +91 422 2594400
Email: ihec@psgimsr.ac.in

PSG Institute of Medical Sciences & Research
Peelamedu, Coimbatore 641 004, India
Phone: +91-0422-4345818 Fax: +91-422-2594400

INFORMED CONSENT FORM (Doctors)

Study Title:

Understanding correlation between social determinants of delays in diagnosis and management and outcomes for solid cancers in Tamil Nadu- Multicentric mixed method study

Participant Name: _____

Address: _____

_____

I have been given a copy of information sheet giving details of the study. I volunteer to participate in the above-mentioned study.

The details of the study has been provided to me in writing and explained to me in my own language. I confirm that I have understood the above study and had the opportunity to ask questions. I confirm that I have understood about the compensation and the risks and benefits involved in this research. I understand that my participation in the study is voluntary and that I am free to withdraw at any time without giving any reason, and without my routine medical care in this hospital being affected. I understand that confidentiality of my identity will be maintained during the research period, after its completion as well as during publication of the results.

I also consent to be contacted over telephone for study purposes/ knowing the results

Having understood the same, I hereby give my consent to them to interview me. I am affixing my signature / left thumb impression to indicate my consent and willingness to participate in this study (i.e., willingly abide by the study requirements).

Name and Signature of the study participant with date:

Name and Signature of the Interviewer/Investigator with date:

Name and Signature of Witness/Interpreter with date:

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பங்கேற்பாளர் தகவல் தாள் (மருத்துவர்கள்)

தலைப்பு:

தமிழ்நாட்டில் புற்றுநோய் கண்டறிதல் மற்றும் சிகிச்சையில் ஏற்படும் தாமதங்களின் மற்றும் அதன் விளைவுகளில் சமூக நிர்ணயிப்பாளர்களுக்கு இடையே உள்ள தொடர்பைப் புரிந்துகொள்வது- மல்டிசென்ட்ரிக் கலப்பு முறை ஆய்வு

பின்னணி:

வாய்வழி குழி (14%), நுரையீரல் (10.4%) மற்றும் இரைப்பை குடல் (சுமார் 20%) புற்றுநோய்கள் இந்தியாவிலும் தமிழகத்திலும் புற்றுநோய் சுமையின் பெரும்பகுதியை உருவாக்குகின்றன. இந்த புற்றுநோய்களைக் கண்டறிதல் மற்றும் நிர்வகிப்பதில் ஏற்படும் தாமதங்களும் விளைவுகளில் குறிப்பிடத்தக்க தாக்கத்தை ஏற்படுத்துகின்றன. இந்தத் திட்டத்தின் முக்கிய குறிக்கோள்கள், இந்த புற்றுநோய்களைக் கண்டறிதல் மற்றும் நிர்வகிப்பதில் ஏற்படும் தாமதங்கள், அதன் காரணங்கள் மற்றும் இந்த தாமதங்கள் புற்றுநோய் விளைவுகளை எவ்வாறு பாதிக்கின்றன என்பதைக் கண்டறிவதாகும்.

இது தமிழ்நாடு சுகாதார அமைப்புகள் ஆராய்ச்சித் திட்டம் **(TNHSRP)**, தமிழ்நாடு அரசின் சுகாதாரம் மற்றும் குடும்ப நல அமைச்சகம் மூலம் PSG மருத்துவமனையில் நடத்தப்படும் கல்வியியல் ஆராய்ச்சி ஆய்வாகும். தமிழகம் முழுவதும் உள்ள பல்வேறு புற்றுநோய் மையங்களில் இருந்து சுமார் 2000 புற்றுநோயாளிகளை சேர்க்க எதிர்பார்க்கிறோம்.

மேற்கூறிய புற்றுநோய்களில் (வாய் புற்றுநோய், நுரையீரல், உணவுக் குழாய், வயிறு, குடல், கல்லீரல், பித்தப்பை, கணையம் போன்றவை) நோயாளிகளுக்கு சிகிச்சை அளிக்கும் மருத்துவராக நீங்கள் இருப்பதால், இந்த ஆராய்ச்சி ஆய்வில் பங்கேற்க அழைக்கப்படுகிறீர்கள். மேற்கூறிய புற்றுநோயால் பாதிக்கப்பட்ட நோயாளிகளை தொடர்ந்து பார்க்கும் முதன்மை சிகிச்சை அல்லது சிறப்பு மருத்துவர்.

இந்த ஆய்வு எதைப் பற்றியது?

ஆய்வில், உங்கள் நோயாளிகளின் சமூக மற்றும் பொருளாதாரப் பின்னணி, சிகிச்சையின் போது அவர்கள் எதிர்கொள்ளும் ஏதேனும் சிரமங்கள் அல்லது தாமதங்கள் அல்லது பின்தொடர்தல் மற்றும் அத்தகைய தாமதங்கள் அல்லது சிரமங்களுக்கான காரணங்கள் குறித்த உங்கள் கருத்துகள் ஆகியவற்றை நாங்கள் சேகரிப்போம். இந்தத் தகவல்கள் எங்கள் கள ஆய்வாளர்களின் உதவியுடன் நேர்காணல் வடிவில் சேகரிக்கப்படும். ஏதேனும் கேள்விகள் உங்களுக்கு சங்கடமானதாக இருந்தால், அதற்கு நீங்கள் பதிலளிக்க வேண்டியதில்லை. நேர்காணல்கள் தரமான பகுப்பாய்விற்காக பதிவு செய்யப்படும்.

ஆய்வில் பங்கேற்கும் போது கேள்விகளைப் புரிந்துகொள்வதில் உங்களுக்கு ஏதேனும் சிரமம் இருந்தால் மொழிபெயர்ப்பாளர்/மொழிபெயர்ப்பாளர் வழங்கப்படும்.

நேர அர்ப்பணிப்பு:

உங்களுக்கான நேர அர்ப்பணிப்பு மிகக் குறைவு (சுமார் 20 நிமிடங்களுக்குப் பிறகு, உங்கள் பங்கேற்பு முடிந்துவிடும், மேலும் எதுவும் செய்ய வேண்டியதில்லை.

அபாயங்கள் மற்றும் நன்மைகள்:

உங்களுக்கான ஆய்வில் பங்கேற்பதால் நேரடியான அபாயங்கள் அல்லது நன்மைகள் எதுவும் இல்லை. மறைமுகமான பலன் என்னவென்றால், ஆய்வின் முடிவுகள் அரசாங்கத்திற்கு உதவும். தமிழ்நாடு அவர்களின் கொள்கைகளை மேம்படுத்துவதன் மூலம் சிறந்த புற்றுநோய் சிகிச்சை சேவைகளை வழங்க வேண்டும்.

இரகசியத்தன்மை:

உங்களைப் பற்றிய தகவல்கள் ரகசியமாக வைக்கப்படும். ஆய்வு முடிவுகளைப் பற்றிய கருத்தைப் பெற விரும்பினால், உங்கள் மின்னஞ்சலைப் பகிர்வதற்கான தேர்வு உங்களுக்கு வழங்கப்படும். நீங்கள் அதைப் பகிர விரும்பவில்லை அல்லது மின்னஞ்சல் கணக்கை வைத்திருக்கவில்லை என்றால், நீங்கள் ஆர்வமாக இருந்தால், இந்தத் தகவலை உள்ளூர் ஆராய்ச்சி கூட்டாளர்களிடம்

(அந்தந்த தளம் PI) எப்போதும் கேட்கலாம். உங்களைப் பற்றிய ஆராய்ச்சிக்குத் தேவைப்படும் குறைந்தபட்ச தகவல் இந்த ஆய்வை ஒருங்கிணைக்கும் தமிழ்நாடு அரசுக்கு (TNHSRP) அனுப்பப்படும். இது 10 ஆண்டுகள் சேமிக்கப்படும், ஆனால் பின்னர் அழிக்கப்படும். தரவை முடிந்தவரை பாதுகாப்பாகவும் குறைவான விவரமாகவும் வைத்திருப்போம்; உங்கள் பெயர் மின்னஞ்சல் அல்லது தொலைபேசி பற்றிய பதிவுகள் ஆய்வு மைய கோப்புகளில் வைக்கப்படாது.

ஒப்புதல்:

படிப்பில் சேருவது உங்கள் விருப்பம். நீங்கள் பங்கேற்க ஒப்புக்கொண்டால், ஒப்புதல் படிவத்தில் கையொப்பமிட (அல்லது கைரேகை) உங்களிடம் கேட்போம். நேர்முகத் தேர்வின் போது எங்களின் ஏதேனும் கேள்விகளுக்குப் பதிலளிப்பதில் உங்களுக்கு அசௌகரியம் இருந்தால், எந்த நேரத்திலும் நேர்காணலில் இருந்து / படிப்பிலிருந்து விலக உங்களுக்கு உரிமை உண்டு. எந்த நேரத்திலும் படிப்பிலிருந்து விலக உங்களுக்கு சுதந்திரம் உள்ளது. நீங்கள் எந்த நிலையிலும் பங்கேற்க மறுப்பது அல்லது திரும்பப் பெறுவது, நீங்கள் அவ்வாறு முடிவு செய்தால், வழங்கப்படும் சேவைகளில் எந்தவிதமான சமரசம் அல்லது பாரபட்சம் ஏற்படாது அல்லது அபராதம் விதிக்கப்படாது என்பதை தயவுசெய்து உறுதியளிக்கவும். நோயாளிக்கு வழங்கப்படும் வழக்கமான சேவைகளை நீங்கள் தொடர்ந்து அணுகுவீர்கள். படிப்பில் இருந்து விலகுவது நீங்கள் பெறும் கவனிப்பைப் பாதிக்காது.

இந்த நேர்காணல்/படிப்புக்காக நீங்கள் எங்களுடன் செலவழித்த நேரத்திற்கு எந்த ஊதியமும் உங்களுக்கு வழங்கப்படாது. நீங்கள் வழங்கிய தகவல்கள் கடுமையான நம்பிக்கையுடன் வைக்கப்படும். எந்தச் சூழ்நிலையிலும், பதிலளிப்பவர் அல்லது அவர்களது குடும்பத்தினரின் அடையாளத்தை நாங்கள் யாருக்கும் தெரிவிக்க மாட்டோம். நாங்கள் சேகரிக்கும் தகவல்கள் அங்கீகரிக்கப்பட்ட ஆராய்ச்சி நோக்கங்களுக்காக மட்டுமே பயன்படுத்தப்படும். ஏதேனும் குறிப்பிடத்தக்க புதிய கண்டுபிடிப்புகள் - பாதகமான நிகழ்வுகள், ஏதேனும் இருந்தால் - உங்களுக்கு அல்லது இந்த ஆய்வின் பிற பங்கேற்பாளர்களுடன் நேரடியாக தொடர்புடையதாக இருந்தாலும், இந்த ஆராய்ச்சியின் போது உருவாக்கப்பட்ட, தொடர்ந்து பங்கேற்பதற்கான உங்கள் விருப்பத்துடன் தொடர்புடையதாக இருக்கலாம்.

இந்த மின்னஞ்சல் மூலம் எந்த நேரத்திலும் ஆய்வுக் குழுவைத் தொடர்புகொள்ளலாம்:

முதன்மை ஆய்வாளர் விவரங்கள்:

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தகவலறிந்த ஒப்புதல் படிவம் (டாக்டர்கள்)

தலைப்பு:
தமிழ்நாட்டில் புற்றுநோய் கண்டறிதல் மற்றும் சிகிச்சையில் ஏற்படும் தாமதங்களின் மற்றும் அதன் விளைவுகளில் சமூக நிர்ணயிப்பாளர்களுக்கு இடையே உள்ள தொடர்பைப் புரிந்துகொள்வது- மல்டிசென்ட்ரிக் கலப்பு முறை ஆய்வு

பங்கேற்பாளர் பெயர்: _____

முகவரி: _____

_____

ஆய்வு விவரங்கள் அடங்கிய தகவல் தாளின் நகல் என்னிடம் கொடுக்கப்பட்டுள்ளது. மேற்கூறிய ஆய்வில் பங்கேற்க நான் முன்வந்துள்ளேன்.
ஆய்வின் விவரங்கள் எனக்கு எழுத்துப்பூர்வமாக வழங்கப்பட்டு எனது சொந்த மொழியில் எனக்கு விளக்கப்பட்டுள்ளது. மேற்கூறிய ஆய்வைப் புரிந்துகொண்டு கேள்விகளைக் கேட்கும் வாய்ப்பைப் பெற்றுள்ளேன் என்பதை உறுதிப்படுத்துகிறேன். இழப்பீடு மற்றும் இந்த ஆராய்ச்சியில் உள்ள அபாயங்கள் மற்றும் நன்மைகள் பற்றி நான் புரிந்துகொண்டேன் என்பதை உறுதிப்படுத்துகிறேன். இந்த ஆய்வில் எனது பங்கேற்பு தன்னார்வமானது என்பதையும், எந்த காரணமும் கூறாமல், இந்த மருத்துவமனையில் எனது வழக்கமான மருத்துவச் சேவை பாதிக்கப்படாமல், எந்த நேரத்திலும் நான் விலகிக்கொள்ள சுதந்திரமாக இருக்கிறேன் என்பதையும் புரிந்துகொள்கிறேன். எனது அடையாளத்தின் ரகசியத்தன்மை ஆராய்ச்சிக் காலத்திலும், அது முடிந்த பிறகும், முடிவுகளை வெளியிடும் போதும் பராமரிக்கப்படும் என்பதை நான் புரிந்துகொள்கிறேன்.

ஆய்வு நோக்கங்களுக்காக/முடிவுகளைத் தெரிந்துகொள்வதற்காக தொலைபேசியில் தொடர்புகொள்ளவும் சம்மதிக்கிறேன்

இதைப் புரிந்துகொண்டு, அவர்கள் என்னை நேர்காணல் செய்ய என் சம்மதத்தைத் தெரிவித்துக் கொள்கிறேன். இந்த ஆய்வில் பங்கேற்பதற்கான எனது சம்மதத்தையும் விருப்பத்தையும் குறிக்க எனது கையொப்பம் / இடது கட்டைவிரல் பதிவை ஒட்டுகிறேன் (அதாவது, படிப்புத் தேவைகளுக்கு விருப்பத்துடன் இணங்குகிறேன்).

பங்கேற்பாளர் பெயர் மற்றும் கையொப்பம் தேதியுடன்:

நேர்காணல் செய்பவரின் பெயர் மற்றும் கையொப்பம் தேதியுடன்:

சாட்சியின் பெயர் மற்றும் கையொப்பம் தேதியுடன்:

PSG Institute of Medical Sciences & Research
Peelamedu, Coimbatore 641 004, India
Phone: +91-0422-4345818 Fax: +91-422-2594400

Understanding correlation between social determinants of delays in diagnosis and management and outcomes for solid cancers in Tamil Nadu- Multicentric mixed method study

Interview guide for Doctors

About you

1. Could you please tell me a little bit about yourself and your practice?- (Name, Gender, qualification, Years of practice, Specialty)

About early diagnosis of cancer

2. From your perspective, what is the role of family physicians in diagnosing cancer as early as possible? What is the role of cancer specialists in diagnosing cancer as early as possible?
3. Can you please help me understand how you generally proceed when a patient presents to you with signs/symptoms that might be related to cancer?
4. Once patients present to you with signs/symptoms, what challenges have you faced in getting to a cancer diagnosis as quickly as possible? What things influence the time it takes to get to that diagnosis?

Expediting the diagnostic process

5. In your experience, what are some facilitators or enablers of making a cancer diagnosis as early as possible?
6. Given your experience, what are some opportunities for streamlining the pathways from the time a patient presents to a family physician to diagnosis of cancer?

Improving patient and family experiences

7. We know from a previous study that the diagnostic period can be a time of high anxiety for patients and families. What, in your opinion, could be done to better support them during this period?

Anything else?

8. Is there anything else you wish to say?

Thank you

PSG Institute of Medical Sciences & Research
Peelamedu, Coimbatore 641 004, India
Phone: +91-0422-4345818 Fax: +91-422-2594400

நிபுணர்களுக்கானநேர்காணல்வழிகாட்டி

உங்களைப்பற்றி

1. உங்களைப்பற்றியும்உங்கள்பயிற்சியைப்பற்றியும்கொஞ்சம்சொல்லமுடியுமா? - (பெயர், பாலினம், தகுதி, பயிற்சிஆண்டுகள், சிறப்பு)

புற்றுநோயைமுன்கூட்டியேகண்டறிதல்பற்றி

2. உங்கள்பார்வையில்,
புற்றுநோயைகூடியவிரைவில்கண்டறிவதில்குடும்பமருத்துவர்களின்பங்குஎன்ன? கூடியவிரைவில்புற்றுநோயைக்கண்டறிவதில்புற்றுநோய்நிபுணர்களின்பங்குஎன்ன?
3. புற்றுநோயுடன்தொடர்புடையஅறிகுறிகள்/அறிகுறிகளுடன்ஒருநோயாளிஉங்களிடம்முன்வைக்கும்போதுநீங்கள்பொதுவாகஎப்படிநடந்துகொள்கிறீர்கள்என்பதைப் புரிந்துகொள்ளதயவுசெய்துஎனக்குஉதவமுடியுமா?
4. நோயாளிகள்உங்களிடம்அறிகுறிகள்/அறிகுறிகளுடன்முன்வைத்தவுடன், முடிந்தவரைவிரைவாகபுற்றுநோயைக்கண்டறிவதில்நீங்கள்என்னசவால்களைஎதிர்கொண்டீர்கள்?
அந்தநோயறிதலைப்பெறஎடுக்கும்நேரத்தைஎன்னவிஷயங்கள்பாதிக்கின்றன?

நோயறிதல்செயல்முறையைவிரைவுபடுத்துதல்

5. **உ**ங்கள்அனுபவத்தில்,
முடிந்தவரைசீக்கிரம்புற்றுநோயைக்கண்டறிவதற்கானசிலவசதிகள்அல்லதுஉதவியாளர்கள்என்ன?
6. உங்கள்அனுபவத்தின்அடிப்படையில்,
ஒருநோயாளிஒருகுடும்பமருத்துவரிடம்புற்றுநோயைக்கண்டறிவதுவரையிலான பாதைகளைஒழுங்குபடுத்துவதற்கானசிலவாய்ப்புகள்என்ன?

நோயாளிமற்றும்குடும்பஅனுபவங்களைமேம்படுத்துதல்

7. நோயறிதல்காலம்நோயாளிகள்மற்றும்குடும்பங்களுக்குஅதிகஅழுத்தத்தையேற்படுத்தும்ஒருமுந்தையஆய்வில்இருந்துநாம்அறிவோம்.
இந்தகாலகட்டத்தில்அவர்களைசிறப்பாகஆதரிக்கஎன்னசெய்யமுடியும்என்பதுஉங்கள்கருத்து?

வேறுஎதாவது?

8. நீங்கள்வேறுஏதாவதுசொல்லவிரும்புகிறீர்களா?

நன்றி

Institutional Human Ethics Committee
PSG Institute of Medical Sciences & Research

Recognized by The Strategic Initiative for Developing Capacity in Ethical Review (SIDCER, WHO)
POST BOX NO. 1674, PEELAMEDU, COIMBATORE 641 004, TAMIL NADU, INDIA
Phone : +91 422 - 4345818, Fax : +91 422 2594400, Email : ihec@psgimsr.ac.in

Ref. No : PSG/IHEC/2023/Appr/FB/005

January 07, 2023

To
Dr Rajkumar K S
Professor
Department of Surgical Oncology
PSG IMS & R
Coimbatore

Co-investigators: Dr Saranya Rajamanickam / Dr Sudha Ramalingam / Dr Arulmurugan Ramalingam
Dr Sandhiya Venkatesan

Ref: Project No. 22/335

Dear Sir,

Institutional Human Ethics Committee, PSG IMS&R reviewed and discussed your application dated 02.12.2022 to conduct the research study entitled "*Understanding correlation between social derminants of delays in diagnosis and management and outcomes for solid cancers in Tamilnadu – Multicentric mixed method study*" during the IHEC review meeting held on 16.12.2022.

The following documents were reviewed and approved:

1. Project submission form
2. Study protocol (Version 1 dated 02.12.2022)
3. Informed consent forms
4. Assent and Parental consent forms
5. Data collection tool
6. Project sanction letter
7. Authorship Agreement
8. Current CVs of Principal investigator, Co-investigators
9. Budget

The full board review meeting was convened on 16.12.2022 between 2.30 pm and 4.45 pm. The following members of the Institutional Human Ethics Committee (IHEC) were present for the discussions:

Sl. No.	Name of the Member of IHEC	Qualification	Area of Expertise	Gender	Affiliation to the Institution Yes/No	Present at the meeting Yes/No
1	Mr Antony Raj B	MA	Social Sciences	Male	No	Yes
2	Dr Bhuvaneswari K	MD	Clinical Pharmacology	Female	Yes	Yes

PSG IMS&R COIMBATORE INSTITUTIONAL HUMAN ETHICS COMMITTEE SECRETARY

3	Mr Gowpathy Velappan	BA, BL	Legal Advisor	Male	No	Yes
4	Dr Karthikeyan S (Member – Secretary, IHEC)	MD	Epidemiologist, Ethicist	Male	Yes	Yes
5	Mr Manigandan B	B Com, LLB	Lay Person	Male	No	Yes
6	Mrs Nirmala M (Alternate Member-Secretary, IHEC)	M Sc	Nursing	Female	Yes	Yes
7	Dr Parag K Shah (Vice-Chairperson, IHEC)	DNB	Clinician (Ophthalmology)	Male	No	Yes
8	Dr Rajani Sundar (Chairperson, IHEC)	MD, DA	Clinician	Female	No	Yes
9	Dr Ramesh S	MD	Clinician	Male	Yes	Yes
10	Dr Senthurselvi R	MD	Pharmacology	Female	No	No
11	Dr Sivakumar V	M Pharm, Ph D	Pharmacy	Male	Yes	No
12	Dr Sujatha R	MD	Biochemistry	Female	Yes	No
13	Mrs Sweety Subha P	MPT	Physiotherapy	Female	Yes	Yes

The study is approved in its presented form for the stated sample size. The decision was arrived at through consensus. Neither PI nor any of proposed study team members were present during the decision making of the IHEC. The IHEC functions in accordance with New Drugs and Clinical Trials Rules, 2019. The approval is valid until one year from the date of sanction. You may make a written request for renewal / extension of the validity, along with the submission of status report as decided by the IHEC.

Following points must be noted:

1. IHEC should be informed of the date of initiation of the study
2. Status report of the study should be submitted to the IHEC every 12 months
3. PI and other investigators should co-operate fully with IHEC, who will monitor the trial from time to time
4. At the time of PI's retirement/intention to leave the institute, study responsibility should be transferred to a colleague after obtaining clearance from HOD, Status report, including accounts details should be submitted to IHEC and extramural sponsors
5. In case of any new information or any SAE, which could affect any study, must be informed to IHEC and sponsors. The PI should report SAEs occurred for IHEC approved studies within 24 hours of the occurrence
6. In the event of any protocol amendments, IHEC must be informed and the amendments should be highlighted in clear terms as follows:
   a. The exact alteration/amendment should be specified and indicated where the amendment occurred in the original project. (Page no. Clause no. etc.)
   b. Variation in the proposed sample size
   c. Alteration in the budgetary status should be clearly indicated and the revised budget form

SECRETARY PSG IMSR COIMBATORE-641004 INSTITUTIONAL HUMAN ETHICS COMMITTEE

should be submitted

d. If the amendments require a change in the consent form, the copy of revised Consent Form should be submitted to Ethics Committee for approval

e. If the amendment demands a re-look at the toxicity or side effects to patients, the same should be documented

f. If there are any amendments in the trial design, these must be incorporated in the protocol, and other study documents. These revised documents should be submitted for approval of the IHEC and only then can they be implemented

g. Any deviation-Violation/waiver in the protocol must be informed to the IHEC within the stipulated period for review

7. Final report along with summary of findings and presentations/publications if any on closure of the study should be submitted to IHEC

Thanking You,

Yours Sincerely,

SECRETARY
PSG IMS&R
COIMBATORE-641004
INSTITUTIONAL HUMAN ETHICS COMMITTEE

7/1/2023

Dr S Karthikeyan
Member - Secretary
Institutional Human Ethics Committee

Institutional Human Ethics Committee
PSG Institute of Medical Sciences & Research

Recognized by The Strategic Initiative for Developing Capacity in Ethical Review (SIDCER, WHO)
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Ref. No. PSG/IHEC/2023/Appr/FB/005

January 07, 2023

To
Dr Rajkumar K S
Professor
Department of Surgical Oncology
PSG IMS & R
Coimbatore

Co-investigators: Dr Saranya Rajamanickam / Dr Sudha Ramalingam / Dr Arulmurugan Ramalingam
Dr Sandhiya Venkatesan

Ref: Project No. 22/335

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2	Dr Bhuvaneswari K	MD	Clinical Pharmacology	Female	Yes	Yes

GSTIN : 33AAACT3400E1Z4

CIN : U85110TN1994SGC027939

TAMILNADU MEDICAL SERVICES CORPORATION LTD.,

(A Government of Tamil Nadu Undertaking)
ISO 9001 : 2015 Certified Organisation

No. 417, Pantheon Road, Egmore,
Chennai - 600 008.
Phone : 044 - 2819 1890, 2819 0259
FAX : 044 -2819 0636

Ref. 0803/TNMSC/MAINT/2023

08.03.2023

Date : .....

To

The Head of the Institutions
RGGGH(Chennai),SMC(Chennai),TNGMSSH(Chennai),GRH(Chennai),
GMCH-Coimbatore,Madurai,Tirunelveli,
Trichy,Thanjavur,Salem,Sivagangai,Villupuram,Theni,The Nilgris,Tiruvarur,ESI-Coimbatore.
GH-Melur,Srirangam,Pattukottai,Mettur,Karaikudi,Tindivanam,Periyakulam,
Conoor.

Sir/Madam,

Sub: Operational Research Program (ORP) implemented by TNHSRP – sharing of particulars to investigators–reg.

Ref: Copy of TNHSP ltr.ref.no. 1806/TNHSRP/PMU/2021 Dt.23.02.2023

As per reference cited, It has been informed by the Project Director, TNHSRP that an Operational Research Program (ORP) has been implemented by TNHSRP to study the existing services and performances of Govt.Hospitals in Tamil Nadu through Indian Institute of Technology ,Mumbai and for this a MoU has been executed between the IIT(M) and TNHSRP.

As it has been proposed to perform study related to Equipment Utilization and cancer management in the above mentioned Government Medical College Hospitals and as the activities of TNMSC are restricted to CT/MRI/RT centres, it is informed that the HoDs of Radiology/Radiotherapy centres may permit the investigators to conduct the study in the specified area and share necessary details to the team with a copy marked to TNMSC.

Sd/-
Managing Director.

\\True copy\by order

General Manager (S) I/c

Copy to

1) The PD TNHSP
2) The Director of Medical Education,Chennai
3) The Director of Medical & Rural Health Services
4) The HoDs of respective Radiology/Radiotherapy centres.

Directorate of Public Health and Preventive Medicine
Scientific Advisory Committee
No. 359, Anna Salai, DMS Campus, Teynampet, Chennai – 06.

S.No. : DPHPM/SAC/2023/109

R.No.011575/HEB/A2/2023

Date : 13-02-2023

Sub:	Scientific Advisory Committee - Health Education Bureau (HEB) – Study Permission – Dr. Rajkumar K.S - "Understanding correlation between social determinants of delays in diagnosis and management and outcomes for solid cancers in Tamil Nadu – Multicentric mixed method study"– Regarding.
Ref:	Individual's Application Dated : 23.01.2023

With reference to the above Dr. Rajkumar K.S, Professor, Department of Surgical Oncology, PSG Institute of Medical Sciences & Research, Coimbatore – 641 004, is permitted to conduct a study on "Understanding correlation between social determinants of delays in diagnosis and management and outcomes for solid cancers in Tamil Nadu – Multicentric mixed method study"

Institutional Ethics Committee Approval Date	07.01.2023
Institution	Institutional Human Ethics Committee, PSG Institute of Medical Sciences & Research, Coimbatore – 641 004.

Subject to the following conditions:

- Data Collected should not be published in the newspaper or in any media without the prior permission of Government of Tamil Nadu / DPH&PM, Chennai – 06.
- The data on the survey should not be shared with any other 3rd party and inference arising on analysis of the data should not be disseminated without the written permission of Director of Public Health and Preventive Medicine / Government of Tamil Nadu.
- The analytical findings are to be shared to this office for useful inputs.
- The outcomes of the proposed study, policy and its implications in the Public Health may be shared with this department.

13/2/23

Dr. T.S. Selvavinayagam,
Director of Public Health and
Preventive Medicine,
Chennai – 06.

To:	Copy To:
Dr. Rajkumar K.S, Professor, Department of Surgical Oncology, PSG Institute of Medical Sciences & Research, Coimbatore – 641 004,	**The Project Director,** Tamil Nadu Health System Reform Program (TNHSRP) Chennai – 06.

GSTIN : 33AAACT3400E1Z4

CIN : U85110TN1994SGC027939

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Trichy,Thanjavur,Salem,Sivagangai,Villupuram,Theni,The Nilgris,Tiruvarur,ESI-Coimbatore.
GH-Melur,Srirangam,Pattukottai,Mettur,Karaikudi,Tindivanam,Periyakulam,
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Sd/-
Managing Director.

\\True copy\by order

General Manager (S) I/c

Copy to

1) The PD TNHSP
2) The Director of Medical Education,Chennai
3) The Director of Medical & Rural Health Services
4) The HoDs of respective Radiology/Radiotherapy centres.

From **02 December 2022**

Professor V R Muraleedharan,
Indian Institute of Technology (Madras),
Chennai - 600036.
[Coordinator, ORP – TNHSRP]

To
Dr. K.S. Rajkumar,
Professor of Surgical Oncology,
PSG Institute of Medical Sciences & Research (PSGIMSR),
Coimbatore – 641 004

Dear Dr. K.S. Rajkumar,

Subject: Your research proposal **"Understanding the correlation between social determinants of delays in diagnosis and management and outcomes for solid cancers in Tamil Nadu using a multicentric mixed method study"** submitted to the **Operational Research Programme-Tamil Nadu Health System Reform Programme (ORP-TNHSRP)**

We are happy to announce that your proposal has been approved with financial support by the Selection Committee of the ORP – TNHSRP. The total amount sanctioned for the above study is **Rs. 24,36,000/-.**

The draft MoU to be executed between IIT Madras and PSG Institute of Medical Sciences & Research (PSGIMSR), is attached for your reference. We request you to kindly consult with your legal cell and let us know if you need any clarification/modification or further information in this regard. We shall then prepare the final version of the MoU and forward you the same for signature.

In the meanwhile, we request you to get the approval of your Ethics Committee for your proposal to enable us to transfer the funds to your account and complete other formalities.

We request you to furnish details of the Bank Account (of your Institution) in order to release the funds.

We thank you for your interest in being part of this pioneering initiative of the Dept. of Health and Family Welfare of the Govt of Tamil Nadu.

Sincerely,

V.R.Muraleedharan
Coordinator, ORP-TNHSRP

FULL DETAILS (Read-only) -> Click Here to Create PDF for Current Dataset of Trial

CTRI No	**CTRI/2023/03/050660** [Registered on: 14/03/2023] **Trial Registered Prospectively**
Acknowledgement Number	REF/2023/03/064243
Last Modified On:	03/06/2023
Post Graduate Thesis	No
Type of Trial	Observational
Type of Study	Mixed Methods - Qualitative and Quantitative Cohort Study
Study Design	Single Arm Study
Public Title of Study	A study to understand the reasons for delays in the diagnosis and management of solid cancers in Tamil Nadu
Scientific Title of Study Clarification(s) with Reply Modification(s)	Understanding correlation between social determinants of delays in diagnosis and management and outcomes for solid cancers in Tamil Nadu- Multicentric mixed method study
Trial Acronym	

Secondary IDs if Any

Secondary ID	Identifier
NIL	NIL

Details of Principal Investigator or overall Trial Coordinator (multi-center study)

Name	Dr K S Rajkumar
Designation	Professor of Surgical Oncology
Affliation	PSG Institute of Medical Sciences and Research
Address	Department of Surgical Oncology PSG Institute of Medical Sciences and Research Peelamedu Coimbatore 641004 Coimbatore TAMIL NADU 641004 India
Phone	9940155250
Fax	
Email	drksrajkumar@gmail.com

Details Contact Person Scientific Query

Name	Dr K S Rajkumar
Designation	Professor of Surgical Oncology
Affliation	PSG Institute of Medical Sciences and Research
Address	Department of Surgical Oncology PSG Institute of Medical Sciences and Research Peelamedu Coimbatore 641004 TAMIL NADU 641004 India
Phone	9940155250
Fax	
Email	drksrajkumar@gmail.com

Details Contact Person Public Query

Name	Dr K S Rajkumar
Designation	Professor of Surgical Oncology
Affliation	PSG Institute of Medical Sciences and Research
Address	Department of Surgical Oncology PSG Institute of Medical Sciences and Research Peelamedu Coimbatore 641004 TAMIL NADU 641004 India

Phone	9940155250
Fax	
Email	drksrajkumar@gmail.com

Source of Monetary or Material Support

Tamil Nadu Health Systems Reforms Project Operational Research Grant

Primary Sponsor

Name	Tamil Nadu Health Systems Reforms Program
Address	TNHSRP 3rd Floor DMS Annex Building 359, Anna Salai, Teynampet Chennai 600006
Type of Sponsor	Government funding agency

Details of Secondary Sponsor

Name	Address
NIL	NIL

Countries of Recruitment

India

Sites of Study
Clarification(s) with Reply
Modification(s)

No of Sites = **1**

Name of Principal Investigator	Name of Site	Site Address	Phone/Fax/Email
Dr K S Rajkumar	PSGIMSR	Department of Surgical Oncology PSG Superspeciality Hospital PSGIMR Avinashi Road Peelamedu Coimbatore TAMIL NADU	9940155250 drksrajkumar@gmail.com

Details of Ethics Committee
Clarification(s) with Reply
Modification(s)

No of Ethics Committees= **1**

Name of Committee	Ethics Committee registered with DHR /CDSCO or not	Ethics Committee Registration No.	Approval Status	Date of Approval	Approval Document	Is IEC?
PSG Institute of Medical Sciences and Research IHEC	Yes	ECR/252/INST/TN/2013/RR-19	Approved	07/01/2023	Approval File	No

Regulatory Clearance Status from DCGI

Status	Date	Aproval Document
Not Applicable	No Date Specified	No File Uploaded

Health Condition / Problems Studied

Health Type	Condition
Patients	**(1) ICD-10 Condition:** C00-D49||Neoplasms,

Intervention / Comparator Agent

Type	Name	Details

Inclusion Criteria

Age From	18.00 Year(s)
Age To	99.00 Year(s)
Gender	Female
Details	1. Resident of Tamil Nadu (resided in Tamil Nadu for atleast 1 year at the time of diagnosis of cancer) 2. Known to have oral cavity (including lip) cancers, lung cancers and cancers of the Gastro intestinal tract (any age and any stage). 3. Diagnosed on or after January 1 2020

	4. On treatment or have received treatment (at least some part) or on follow-up at one of the hospitals (study centers) in Tamil Nadu. Efforts will be made to include patients who have died or lost to followup. 5. Able and willing to give consent for participation in the study
Exclusion Criteria	**Details**: 1. Patients with other cancers, hematological cancers, second cancers or multiple cancers (synchronous or metachronous). 2. Not willing to participate in the study. 3. Patients who are not residents of Tamil Nadu 4. Patients (including residents of Tamil Nadu) who have received whole of their treatment in a hospital outside Tamil Nadu
Method of Generating Random Sequence	
Method of Concealment	
Blinding/Masking	

Primary Outcome
Clarification(s) with Reply
Modification(s)

Outcome	TimePoints
1.Socioeconomic and demographic determinants contributing to delay 3. Delays in cancer diagnosis (Time durations): a. Actual Delays (rounded to the nearest week) b. Patient-reported reason for the delay in treatment c. Significant delays 4. Cancer Outcomes: a. Adherence to Treatment – completed/delayed/not completed/modified b. Adherence to Follow up - Regular/irregular c. Recurrence and Survival data	1 & 3 years

Secondary Outcome

Outcome	TimePoints
None	1 year

Target Sample Size	**Total Sample Size=**"2000" **Sample Size from India=**"2000" **Final Enrollment numbers achieved (Total)=** "Applicable only for Completed/Terminated trials" **Final Enrollment numbers achieved (India)=**"Applicable only for Completed/Terminated trials"
Phase of Trial	N/A
Date of First Enrollment (India)	15/03/2023
Date of Study Completion (India)	Applicable only for Completed/Terminated trials
Date of First Enrollment (Global)	If country of recruitment is only India, global date would be not applicable.
Date of Study Completion (Global)	Applicable only for Completed/Terminated trials
Estimated Duration of Trial	**Years=**"1" **Months=**"0" **Days=**"0"
Recruitment Status of Trial (Global) Modification(s)	If country of recruitment is only India, global status would be not applicable.
Recruitment Status of Trial (India)	Open to Recruitment

Publication Details Clarification(s) with Reply Modification(s)	None yet
Individual Participant Data (IPD) Sharing Statement	**Will individual participant data (IPD) be shared publicly (including data dictionaries)?** **Response** - NO
Result Disclosure	**Do you wish to upload results?** **Response** - Summary results have not yet been disclosed
Brief Summary	Despite increased access to healthcare and the establishment of Oncology departments in various medical colleges, Tertiary cancer care centers and Regional cancer centers by Govt. of Tamil Nadu and an increased number of private cancer hospitals, there are still gaps and barriers in access to healthcare in some geographical locations within Tamil Nadu.. Geographical and social barriers to healthcare contribute to the diagnosis and treatment delays and therefore to cancer outcomes in patients with solid tumors especially in oral cavity (including lip) cancers, lung cancers and cancers of the Gastro intestinal tract. Identifying these determinants will help address health care gaps in Tamil Nadu, decrease delays and improve cancer outcomes. Aim of the study is to understand the correlation between social determinants of delays in cancer diagnosis and management and cancer outcomes for patients with oral cavity (including lip) cancers, lung cancers and cancers of the Gastro intestinal tract in Tamil Nadu. **Study Design:** Mixed Methods Research study with convergent parallel design (Quantitative and Qualitative) The study will have 2 components: 1. Quantitative component: Observational ambispective cohort study 2. Qualitative component: In-depth interviews of doctors **Study Duration:** 10 months **Study Population:** 1. Patients with known with oral cavity (including lip) cancers, lung cancers and cancers of the Gastro intestinal tract residing in Tamil Nadu and who are on treatment or follow-up at one of the eligible hospitals in Tamil Nadu. 2. Doctors involved in cancer care in Tamil Nadu **Inclusion Criteria for patients:** 1. Resident of Tamil Nadu (resided in Tamil Nadu for atleast 1 year at the time of diagnosis of cancer) 2. Known to have oral cavity (including lip) cancers, lung cancers and cancers of the Gastro intestinal tract (any age and any stage). 3. Diagnosed on or after January 1 2020 4. On treatment or have received treatment (at least some part) or on follow-up at one of the hospitals (study centers) in Tamil Nadu. Efforts will be made to include patients who have died or lost to followup. 5. Able and willing to give consent for participation in the study **Exclusion Criteria for patients:** 1. Patients with other cancers, hematological cancers, second cancers or multiple cancers (synchronous or metachronous). 2. Not willing to participate in the study. 3. Patients who are not residents of Tamil Nadu 4. Patients (including residents of Tamil Nadu) who have received whole of their treatment in a hospital outside Tamil Nadu **Inclusion Criteria for Doctors (qualitative part):** 1. Oncologist (Radiation or Medical or Surgical Oncology) directly involved in the care of cancer patients

2. Primary care doctors (primary care clinician/GP/ any specialist other than oncologist) not directly involved in the care of cancer patients but who usually refer patients to specialists

Study area:

1. Government Hospitals within the state of Tamil Nadu with Oncology departments (Radiation or Medical or Surgical Oncology)
2. Private cancer centers/hospitals within the state of Tamil Nadu with oncology departments (Radiation or Medical or Surgical Oncology)
3. Primary care centre (Qualitative part)

Study Approvals:

PSGIMSR, Coimbatore will be the coordinating institute and will be responsible for overall study approvals (regulatory and ethical), financial approvals, MoU with TNHSRP/IIT Madras, manpower recruitment and training, project oversight, reporting and publications.

Kilpauk Medical College (Govt. Royapettah Hospital) will be the nodal centre for the North zone, Thanjavur Medical College will be the nodal centre for the East zone and Madurai Medical College will be the nodal centre in the South zone.

Ethical approval will be obtained from IEC of PSGIMER, nodal centres & other hospitals as required. Since this is an observational ambispective cohort study with no impact on patient management, we expect expedited IEC approvals/waivers from most hospitals/centres. Administrative approval will be obtained from all hospitals/proposed study centres. If required, a Clinical Trial Agreement or Material Transfer Agreement can be signed between PSGIMSR and individual hospitals.

The proposed study centres and the number may change depending on approvals and permissions. Individual Hospital leads will be included as site/local Principal Investigators. Additional co-investigators can be included as per hospital needs and guidelines for IEC or administrative approval purposes. However, it the responsibility and discretion of Individual Hospital leads to include co-investigators who they think will contribute substantially to the study.

Consent:

Written informed consent (for adults aged 18 and above – hard or soft copy) and parental consent (for pediatric patients < 18 years– hard or soft copy) will be obtained. We estimate that only a small number of the patients with the above cancers will be under the age of 18 years for whom a parental assent/consent will be used. Consent Waivers/permission for oral consent will be obtained from individual IECs if required and used wherever applicable. ICMR guidelines regarding informed consent will be followed. Informed consent will be taken from the doctors for participation in the qualitative study.

DATA COLLECTION:

Qualitative Study:

The qualitative component of the study will include an in-depth interview of 20 doctors of whom 10 would be oncologists directly involved in the care of cancer patients and 10 would be primary care doctors not directly involved in the care of cancer patients but who usually refer patients to specialists.

Interviews will be recorded and transcribed for qualitative analysis. Interview questions will be structured based on previous literature and government reports so that we can gather doctors' opinions on what they think the delay in cancer diagnosis and management is and how they think it affects the outcome of patients with solid cancer.

Quantitative study:

Patients will be identified from hospital records and cancer registries. After obtaining consent, the data collected will be from the patients and caregivers' records/memory and if available, hospital records. Strict confidentiality of patients will be maintained. The management of

patients will be at the discretion of their doctors as per their hospital policy. Data regarding the sociodemographic profile, causes of delay in treatment, follow-up duration, and recurrence details will be collected (using a structured questionnaire) by interviewing the participants.

OUTCOME MEASURES

1. **Social determinants contributing to delay**
    a. Demographic factors
    b. Socioeconomic factors
2. **Geographical determinants contributing to delay**
    a. Distance between nearest GP/PHC to whom/which the patient usually goes and his or her home
    b. Distance between nearest Government Hospital or Specialty Hospital with > 50 beds to whom/which the patient usually goes and his or her home
    c. Distance between nearest Cancer Center (Government or Private) and his or her home
    d. Distance between home and current treating hospital
3. **Delays in cancer diagnosis (Time durations):**
    a. Actual Delays (rounded to the nearest week)
    b. Patient-reported reason for the delay in treatment
    c. Significant delays

        > 4 weeks => significant delay

4. **Cancer Outcomes:**
    a. Adherence to Treatment – completed/delayed/not completed/modified
    b. Adherence to Follow up - Regular/irregular
    c. Recurrence and Survival data

CANCER INSTITUTE (WIA)

(REGIONAL CANCER CENTRE)

INSTITUTIONAL ETHICS COMMITTEE- NABH ACCREDITED

NABH Accreditation No: EC-CT-2020-0141

Re-Registration No. ECR/235/Inst/TN/2013/RR-19

IEC/ 2023/ Aug 06

23/08/2023

To,

Dr. Arvind Krishnamurthy

Principal Investigator

Professor & Head, Department of Surgical Oncology

Cancer Institute (WIA)

38, Sardar Patel Road Adyar, Chennai-600 036

Subject: Ethics Committee Approval Letter

Reference: "Understanding correlation between social determinants of delays in diagnosis and management and outcomes for solid cancers in Tamil Nadu- Multicentric mixed method study"

Dear Dr. Arvind Krishnamurthy,

Institutional Ethics Committee reviewed and discussed your application dated 13 July 2023 to conduct the study titled "Understanding correlation between social determinants of delays in diagnosis and management and outcomes for solid cancers in Tamil Nadu- Multicentric mixed method study" during the Institutional Ethics Committee meeting held on 05 August 2023 at 9.00 am in the Board Room 2nd Floor, Lions Cancer Support Centre (IORT building) Dr. S. Krishnamurthy Campus, Cancer Institute (WIA), Chennai 600 036.

At the IEC meeting held on 05 August 2023, the committee, after due consideration had raised certain queries and IEC query letter dated 14 August 2023 was issued.

Responses to the queries received on 22 Aug 2023 and the supporting documents were reviewed and approved on 23 August 2023

Phone: 044-22209150 Extn: 135/219, Fax: 044-24912085

E-mail: iec@cancerinstitutewia.org

The following documents were reviewed and approved.

1. Covering Letter dated 13th July 2023
2. Title Page
3. Certificate from Investigator
4. Protocol with Annexures
5. Patient Information Sheet- Adult & Paediatric- English & Tamil
6. Parental Assent Form - English & Tamil
7. Informed Consent Adult- English
8. Institutional Ethics Committee Approval letter- PSG Institute of Medical Sciences

The following members of the ethics committee were present at the Ethics Committee Meeting held on 05 August 2023 at 9.00 am in the Board Room 2nd Floor, Lions Cancer Support Centre (IORT building) Dr. S. Krishnamurthy Campus, Cancer Institute (WIA), Chennai 600 036

S. No	Name of the member	Role/ Designation in Ethics Committee	Affiliation of the Member with Institution
1	Dr. J.S. Sathyanarayana Murthy	Chairman	No
2	Dr. R. Swaminathan	Member Secretary	Yes
3	Dr. Manoj Murhekar	Clinician	No
4	Dr. C. Suthakaran	Medical Scientist/ Pharmacologist	No
5	Dr. J. C. Bose	Clinician	No
6	Dr. S. Lakshminarasimhan	Clinician	No
7	Dr. B. Ananthi	Clinician	Yes
8	Dr. S. Padma	Legal Expert	No
9	Mrs. Sudha Ganapathy*	Social Scientist	No
10	Mrs. Lata Ramakrishnan	Lay Person	No

*Participated through Virtual video conferencing platform.

The Quorum requirements as per New Clinical Trial Rules 2019 was fulfilled.

The study protocol and documents were reviewed and approved by the ethics committee to be conducted in its presented form. The decision was taken unanimously. Principal Investigator should conduct the study in accordance to the IEC approved protocol

The Institutional Ethics Committee, Cancer Institute (WIA) functions in accordance with:

The New Drugs and Clinical Trials Rules 2019,Good Clinical Practice Guidelines for Clinical Trials in India issued by CDSCO and Ministry of Health and Family Welfare, Government of India, National Ethical Guidelines for Bio-Medical and Health Research involving Human Participants issued by ICMR and ICH-GCP Guidelines.

The ethics committee expects to be informed about the progress of the study. Please note that it is the responsibility of the Principal Investigator to inform the IEC if there is any changes in the protocol and patient information sheet /informed consent form, if applicable. You are also requested to provide a copy of final report to IEC.

Yours Sincerely,

Dr. R. Swaminathan

Member Secretary

Ref.No: 5067/ME3/2023

Office of the Dean
Coimbatore Medical College,
Coimbatore-14.
Dated:15.07.2023.

Sub: Medical Education – Coimbatore Medical College, Coimbatore – TNHSRP –Operational Research Program (ORP) 4th year (2022-2023) research proposals approved and study to be initiated Permission Order Issued -Regarding.

Ref: 1. Ref.No: 1806/TNHSRP/PMU/2021 dated: 17.02.2023 of the Project Director, Tamil Nadu Health system Reform Program, Chennai
2. Ref.No.017181/ME1/1/2023 dated: 20.02.2023 of the Directorate of Medical Education and Research Kilpauk, Chennai -10
3. Dr.K.S.Rajkumar, Professor of Surgical Oncology PSG Hospital, Peelamedu Coimbatore-04 letter dated: 03.06.2023.

As per the above reference cited, I[st] and II[nd] cited above, the Dr.K.S.Rajkumar, Professor of Surgical Oncology PSG Hospital is permitted to conduct the study in this Institution.

The above Individual

DEAN
DEAN
Coimbatore Medical College
Coimbatore - 641 014.

To

Dr.K.S.Rajkumar, Professor of Surgical Oncology PSG Hospital, Avinashi Road Peelamedu, Coimbatore-04.

Copy to the Head of the department Surgical Oncology /Radio oncology/Ethical Committee Member Coimbatore Medical Coimbatore-18.

Copy to the Project Director Tamil Nadu Health System Reform Program, Teynampet, Chennai -600 006.

OFFICE OF RESEARCH
INSTITUTIONAL REVIEW BOARD (IRB)
CHRISTIAN MEDICAL COLLEGE, VELLORE, INDIA

CDSCO - Ethics Committee Registration No: ECR/326/INST/TN/2013/RR-2019, DHR Registration No: EC/NEW/INST/2023/TN/0211

Dr. J. Amalorpavanathan, M.S. Dip. NBE. M. Ch.,
Chairperson, Ethics Committee

Dr. Prasanna Samuel, M.Sc., Ph.D.,
Secretary, Research Committee

Prof. Keith Gomez, MA (S.W), M.Phil.,
Deputy Chairperson, Ethics Committee.

Dr. Jacob John, MD., Ph D.,
Chairperson, Research Committee

Dr. Suceena Alexander, MD, DM (Nephrology), FRCP (Lon), FASN., Ph.D.
Secretary, Ethics Committee, IRB
Additional Vice-Principal (Research)

November 02, 2023

Dr. Rohin Mittal,
Professor,
Department of Surgery - 2,
Christian Medical College,
Vellore – 632 004.

Sub: Understanding correlation between social determinants of delays in diagnosis and management and outcomes for solid cancers in Tamil Nadu- Multicentric mixed method study.
Dr. Rohin Mittal, Professor, Employment Number: 28639, Department of General Surgery Unit 2, Dr. Royson Jerome Dsouza, Employment number: 21407, Fellow-Colorectal Surgery.

Ref: IRB Min. No. 15578 [OBSERVE] dated 26.07.2023

Dear Dr. Rohin Mittal,
The Institutional Review Board (Silver, Research and Ethics Committee) of the Christian Medical College, Vellore, reviewed and discussed your project titled "Understanding correlation between social determinants of delays in diagnosis and management and outcomes for solid cancers in Tamil Nadu- Multicentric mixed method study" on July 26, 2023.

The Committee reviewed the following documents:

1. IRB application
2. Information Sheet and Informed Consent forms
3. Case Report Form
4. GCP Certificate
5. CVs of Drs. Mark Ranjan, Rohin, Vidya, Inian Samarasam, Samuel Paul, Royson.
6. No of documents 1- 5.

The following Institutional Review Board (**Silver**, Research & Ethics Committee) members were present at the meeting held on July 26, 2023 at 8.45 am in NEW IRB ROOM, ADJACENT TO CARMAN BLOCK, CMC, BAGAYAM CAMPUS, Vellore-632002. 1 of 4

Dr. J. Amalorpavanathan, M.S. Dip. NBE, M. Ch.,
Chairperson, Ethics Committee

Dr. Prasanna Samuel, M.Sc., Ph.D.,
Secretary, Research Committee

Prof. Keith Gomez, MA (S.W), M.Phil.,
Deputy Chairperson, Ethics Committee.

Dr. Jacob John, MD., Ph D.,
Chairperson, Research Committee

Dr. Suceena Alexander, MD, DM (Nephrology), FRCP (Lon), FASN., Ph.D.
Secretary, Ethics Committee, IRB
Additional Vice-Principal (Research)

ETHICS COMMITTEE MEMBERS			
Name	**Qualification**	**Designation**	**Affiliation**
Dr. J. Amalorpavanathan	M.S (Gen. Surg), Dip. NBE (Gen. Surg), M. Ch (Vascular Surgery)	Chairperson, Ethics Committee, IRB, CMC Vellore, Vascular Surgeon, Retired Faculty, Chennai.	External, Clinician
Dr. Suceena Alexander	M.D, D.M (Nephro), FRCP (Lon.), FASN, Ph.D.	Secretary – (Ethics Committee), IRB, Addl. Vice Principal (Research), Professor of Nephrology, CMC, Vellore	Internal, Clinician
Prof. Keith Gomez	M.A (S.W), M. Phil (Psychiatry Social Work)	Deputy Chairperson, Ethics Committee, IRB, Student counselor, Loyola College, Chennai.	External, Social Scientist
Dr. Jayaprakash Muliyil	M.D, MPH, Dr. PH (Epid), DMHC	Retired Professor, CMC, Vellore	External, Scientist & Epidemiologist
Dr. Blessed Winston	M.D Pharmacology	Associate Professor, Clinical Pharmacology, CMC, Vellore	Internal, Pharmacologist
Mrs. Anne Jarone	M. Sc (Nursing)	Professor, Associate Nursing Superintendent, CMC, Vellore	Internal, Nurse
Mrs. Shandrila Immanuel	M. Sc (Nursing)	Deputy Dean, College of Nursing, CMC, Vellore	Internal, Nurse
Mr. C. Sampath	B.Sc, BL	Sr. Legal Officer, Vellore	External, Legal Expert
Mrs. B. Scholastica Mary Vithiya	M. Phil, Ph. D.	Assistant Professor, Auxilium College, Vellore	External, Layperson

RESEARCH COMMITTEE MEMBERS			
Dr. D. J. Christopher	DTCD DNB, FRCP(Glasg), FCCP(USA)	Professor, Pulmonary Medicine, CMC, Vellore	Internal, Clinician
Dr. Jacob John	MD, MPH	Chairperson, Research Committee, Professor, Community Medicine, CMC, Vellore	Internal, Clinician
Dr. Prasanna Samuel	M. Sc, Ph.D.	Secretary, Research Committee, Associate Professor of Biostatistics, CMC, Vellore	Internal, Statistician
Dr. Rajdeep Ojha	M. Tech, PhD	Associate Professor of Physical Medicine and Rehabilitation, CMC, Vellore	Internal, Basic Medical Scientist
Dr. RV. Shaji	M.Sc, Ph.D.	Professor, Hematology, CMC, Vellore	Internal, Basic Medical Scientist
Dr. Winsely Rose	MD (Paed)	Professor, Paediatrics, CMC Vellore	Internal, Clinician
Dr. Nihal Thomas	MD MNAMS DNB (Endo) FRACP (Endo) FRCP (Edin) FRCP (Glas) FRCP (London) FACP Ph.D. (Copenhagen)	Professor & Head Department of Endocrinology, Diabetes, and Metabolism	Internal, Clinician
Dr. Christhunesa S. Christudass	M.Sc., Ph.D	Professor, Neurochemistry, Department of Neurological Sciences	Internal, Basic Medical Scientist
Dr. Rohin Mittal	MS, DNB	Professor, Department of General Surgery, CMC Vellore	Internal Clinician
Dr. Elizabeth Vinod	MBBS, MD,	Associate Professor, Department of Physiology, CMC Vellore	Internal Basic Medical Scientist

We approve the project to be conducted as presented for the duration 10 months.

Kindly provide the total number of patients enrolled in your study and the total number of Withdrawals for the study entitled: "Understanding correlation between social determinants of delays in diagnosis and management and outcomes for solid cancers in Tamil Nadu- Multicentric mixed method study". Please send copies of this to the Research Office (research@cmcvellore.ac.in).

The Institutional Ethics Committee expects to be informed about the progress of the project. Any adverse events occurring in the course of the project, any amendments in the protocol and the patient information / informed consent. On completion of the study, you are expected to submit a copy of the final report. Respective forms can be downloaded from the following link: http://172.16.11.136/Research/IRB_Polices.html in the CMC Intranet and in the CMC website link address: http://www.cmch-vellore.edu/static/research/Index.html.

Yours sincerely,

Dr. Suceena Alexander,
Secretary (Ethics Committee)
Institutional Review Board

Dr. SUCEENA ALEXANDER
MD, DM(Nephrology), FRCP(Lon), FASN, PhD.
Secretary - (Ethics Committee),
Institutional Review Board, Christian Medical College,
Vellore - 632 002, Tamil Nadu, India.

IRB Min. No. 15578 [OBSERVE] dated 26.07.2023

Ethics Committee Silver, Office of Research, Ist Floor, Carman Block, Christian Medical College, Vellore, Tamil Nadu 632 002
Tel: 0416 – 2284294, 2284289, 3075645 Fax: 0416 – 2262788 E-mail: research@cmcvellore.ac.in

Ref.No.017181/ME1/1/2023

Directorate of Medical Education
Kilpauk, Chennai -10.
Dated :23.02.2023.

Sub: Medical Education – TNHSRP – Operational Research Program (ORP) – 4th year (2022-2023) research proposals – approved and study to be initiated – Permission requested – communicated - Regarding

Ref: Ref.No.1806/TNHSRP/PMU/2021 of the Project Director, Tamil Nadu Health System Reform Program, Chennai dated:17.02.2023.

****

A copy of letter in the reference cited received from the Project Director, Tamil Nadu Health System Reform Program, Chennai, is enclosed and the Deans / Head of the Institution's are directed to permit the investigators to conduct the study in the specified area at their respective Institution.

Encl: As in the ref. cited.

for Director of Medical Education

To:

1. The Dean, Rajiv Gandhi Government General Hospital, Chennai
2. The Dean, Government Stanley Medical College Hospital, Chennai
3. The Dean, Government Medical College and Hospital, Omandurar Government Estate, Chennai
4. The Dean, Coimbatore Medical College Hospital, Coimbatore
5. The Dean,Government Rajaji Hospital and Madurai Medical College, Madurai
6. The Dean, Tirunelveli Medical College and Hospital, Tirunelveli
7. The Dean, Mahatma Gandhi Memorial Government Hospital and KAP Vishwanatham Government Medical College, Trichy
8. The Dean, Thanjavur Medical College Hospital, Thanjavur
9. The Dean, Government Mohan Kumaramanagalam Medical College and Hospital, Salem

10. The Dean, Government Sivagangai Medical College and Hospital Sivagangai
11. The Dean, Government Villupuram Medical College and Hospital, Villupuram
12. The Dean, Government Theni Medical College and Hospital, Theni
13. The Dean, Government Medical College and Hospital,The Nilgiris
14. The Dean, Government Thiruvarur Medical College and Hospital, Thiruvarur

Copy to:

1. The Project Director,
   Tamil Nadu Health System Reform Program,
   Chennai

2. The Mission Director,
   National Health Mission – Tamil Nadu,
   Chennai

Dr. GVN Cancer Institute

(A UNIT OF GVN HOSPITAL (P) LTD)

INSTITUTIONAL ETHICS COMMITTEE

To:
Dr.Rajkumar K.S
Professor & Surgical Oncologist,
PSG Institute of Oncology,
PSG IMSR & Hospitals,
Coimbatore- 641004.

Ref: Proposal dated 23/06/2023

Sub: Ethical Clearance

Dear Dr.Rajkumar,

As our Institutional Human Ethics Committee has reviewed your proposal to the conditions placed upon

The ethical approval and also which is based upon your presentation dated 23rd June 2023. The Committee concluded that there was no aspect of human violation in this project. The committee recommended to consider the participants privacy during data collection.

Project Title: **Understanding correlation between social determinants of delays in diagnosis and management and outcomes for solid cancers in Tamilnadu -multicentric mixed method study**

TNHSRP – ORPTamilnadu Health System Reform Programme-Operational Research Programme.

We approve the study conducted in its presented form

GVN- IEC excepts be informed about the progress of the study, the final report, any Changes in the protocol.

Yours sincerely,

M. Shakthi Yathev

Member Secretary GVN-IEC

MEENAKSHI MISSION HOSPITAL & RESEARCH CENTRE
MADURAI | TAMIL NADU

INSTITUTIONAL ETHICS COMMITTEE

The following members of MMHRC - IEC were present at the meeting conducted on 20 Jul 2023 between 15:20 to 16:50 hrs at 6th Floor, Video Conference Hall, MMHRC, Madurai.

Name of the Member	Designation & Role at MMHRC - IEC
Dr.G.Kumaresan	Chairperson
Dr.Ramesh Ardhanari	Member Secretary
Dr.M.Malathi	Pharmacologist & Basic Medical Scientist
Dr.P.Krishnamoorthy	Clinician
Mr.M.Panneerselvam	Legal Expert
Mrs.R.Amuthaselvi	Lay Person
Dr.M.Kannan	Social Scientist

MMHRC - IEC approves this project to be conducted in its presented form

With Regards,

Dr.Ramesh Ardhanari,
Member Secretary,
MMHRC - IEC.

Member Secretary
Institutional Ethics Committee
Meenakshi Mission Hospital and Research Centre
Lake Area, Melur Road, Madurai-625 107.
DCG (I) Reg. No. ECR/398/Inst/TN/2013/RR-19
IORG Reg. No. IORG0007720

INSTITUTIONAL ETHICS COMMITTEE

Date: 27 Jul 2023

To

Dr.VijayaBhaskar.R,
Senior Consultant & Head,
Department of Surgical Oncology,
Meenakshi Mission Hospital and Research Centre,
Lake Area, Melur Road,
Madurai – 625107.

Sub: MMHRC-IEC Approval for the Academic thesis entitled: " Understanding correlation between social determinants of delays in diagnosis and management and outcomes for solid cancers in Tamil Nadu- Multicentric mixed method study_ Operational Research Program 2022-2023; Tamil Nadu Health System Reform Program (TNHSRP)"

Dear Dr.VijayaBhaskar.R,

The Institutional Ethics Committee MMHRC - IEC reviewed and discussed your application for the approval of Academic Study Entitled: " Understanding correlation between social determinants of delays in diagnosis and management and outcomes for solid cancers in Tamil Nadu- Multicentric mixed method study_ Operational Research Program 2022-2023; Tamil Nadu Health System Reform Program (TNHSRP)" on 20 Jul 2023.

The following documents were reviewed:

S. No.	Name of the Document	Version No.	Date of Version
1.	Protocol	NA	NA
2.	Study Proforma	NA	NA
3.	Informed Consent From - English & Tamil	NA	NA

*** NA - Not Applicable**

Nadu, INDIA. P: 0452-4263000/254 3000. F: 0452-258 6353, mmhrciec@yahoo.com / www.mmhrc.com

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INSTITUTIONAL ETHICS COMMITTEE

Date: 27th July 2023

To,

Dr. B.Sivanesan
Chairman – Department of Oncology
GKNM Hospital
Coimbatore

Subject : Approval to conduct the below mentioned study.

EC Reference Number: 2023/IEC/042

Study Title: ***Understanding Correlation between Social determinants of delays in Diagnosis & Management and Outcomes for Solid cancers in Tamil Nadu - Multicentric Mixed Method Study***

Dear **Dr. B.Sivanesan,**

Your study titled ***"Understanding Correlation between Social determinants of delays in Diagnosis & Management and Outcomes for Solid cancers in Tamil Nadu - Multicentric Mixed Method Study."*** proposal has been reviewed and accepted by the Institutional Ethics Committee and herewith grant permission to conduct the study.

The IEC functions in accordance with Indian GCP, ICH GCP, ICMR guidelines and other applicable regulatory requirements.

Yours sincerely,

Chairman/ Member Secretary, Ethics committee

MEMBER SECRETARY
INSTITUTIONAL ETHICS COMMITTEE
G. KUPPUSWAMY NAIDU MEMORIAL HOSPITAL
PAPPANAICKEN PALAYAM
COIMBATORE 641 037