
**Addis Ababa University**

**College of Health Sciences, School of Medicine**

**Department of Pediatrics and Child Health**

**Pediatric Hematology and Oncology Unit**

# Time to Diagnosis and Factors Associated with Delayed Diagnosis in Children with Solid Cancer at a Tertiary Referral Hospital in Ethiopia: A Prospective Study

A Research Paper to be submitted to the Pediatric Hematology and Oncology Unit, Department of Pediatrics and Child Health, School of Medicine, College of Health Sciences, Addis Ababa University in Partial Fulfillment of the Requirements for the Sub-Specialty Certificate in Pediatrics Hematology and Oncology

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## Declaration form

This is to certify that the thesis prepared by Dr. Gashaw Arega, entitled **'Time to Diagnosis and Factors Associated with Delayed Diagnosis in Children with Solid Cancer at a Tertiary Referral Hospital in Ethiopia: A Prospective Study"** original research submitted to the Pediatric Hematology and Oncology Unit, Department of Pediatrics and Child Health, School of Medicine, College of Health Sciences, Addis Ababa University in Partial Fulfillment of the Requirements for the Sub-Specialty Certificate in Pediatrics Hematology and Oncology complied with the regulations of the university and met the accepted standards concerning originality and quality. This thesis has not been presented for a degree in any other university, and all sources of materials used for the thesis have been duly acknowledged.

**Assurance of principal investigator**

I, the undersigned, declare that this postgraduate degree thesis is my original work which has not been presented for a degree in any other university, and that all sources of materials used for the thesis have been duly acknowledged.

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**Approval of the advisor**

This thesis has been submitted with my approval as university advisor.

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**Time to Diagnosis and Factors Associated with Delayed Diagnosis in Children with Solid Cancer at a Tertiary Referral Hospital in Ethiopia: A Prospective Study**


## ABSTRACT

**Background**: Only one-third of children with cancer can survive in developing countries in Africa. Timely diagnosis, early treatment initiation, and access to cancer treatment are integral components of pediatric oncology to improve the outcomes of children with cancer.

**Objectives**: The primary aim of this study was to assess the time to diagnosis (TD), and patterns of delay among newly diagnosed pediatric solid cancer patients and to investigate associated factors affecting time to diagnosis and treatment in a tertiary referral hospital in Ethiopia,

**Materials and Methods:**

This prospective study was conducted in the Pediatric Hematology and Oncology (PHO) unit, Department of Pediatrics and Child Health, Tikur Anbessa Specialized Hospital, Addis Ababa University from May 2023 to May 2024. All newly diagnosed solid cancers under the age of 15 were included in the study. The pretreatment diagnostic time intervals were classified into Time to Presentation (TP), Time to Referral (TR), Time to Registration (Tr), Time to Definitive Diagnosis (TDD), and Time to Diagnosis (TD) from the onset of symptoms and signs to the confirmed diagnosis at the oncology treatment center. The parental delay, referral delay, physician delay, health care system delay, treatment delay, and total delay, and the factors associated were also investigated.

**Results**: A total of 250 children with solid cancers (excluding hematolymphoid cancers) were prospectively studied with a male-to-female ratio of 1.3:1, and 49.2% of children were between 1-5 years old. Central nervous tumors, renal tumors, retinoblastoma, and soft tissue sarcoma were the most common solid cancers accounting for 24%, 17.2%, 16.8%, and 15.2% respectively. The median times for TP, TR, Tr, TDD, and TD were 30, 30, 2, 5, and 99 days respectively. The median physician, healthcare system, treatment, and total time delay were 40, 5, 46, and 112 days respectively. The shortest total delay was seen in patients with germ cell tumors, neuroblastoma, and Wilms tumor, and the longest total delay was in patients with retinoblastoma, and endocrine tumors. About 63.6% of children with cancer had a referral delay to the oncology center of more than two weeks, and the factors associated were misdiagnosis of cancer and patient management for non-oncologic diseases. The longer time of diagnosis (TD) was correlated with parental education status ($p=0.007$), types of solid cancers ($p=0.005$), and sites of the tumor ($p=0.003$).

**Conclusion**s: Educating the caregivers, training about the symptoms and signs of childhood cancer presentations to the primary care physicians, and designing policies and strategies for early diagnosis, referral and treatment of childhood cancer are crucial for better outcomes.

# CHAPTER ONE INTRODUCTION

## 1.1 Background

Globally, around 400,000 children and adolescents under the age of 19 are diagnosed with cancer every year. The most common types of solid malignancies in this age group include Central Nervous Tumors (CNS), neuroblastoma, soft tissue sarcoma, renal tumors, and bone sarcomas (1,2). Unfortunately, only a small proportion of children and adolescents with cancer in Low and Middle-Income countries (LMICs) can survive (2,3).

Parental health-seeking behavior, diagnosis delay, lack of cancer treatment centers, unavailability of trained pediatric oncologists, the high incidence of severe acute malnutrition, and treatment-related mortality are the factors influencing the survival of children in LMICs. (3,4)

Early diagnosis and prompt initiation of cancer therapy are crucial for reducing morbidity and mortality in pediatric cancer patients. This is especially important for pediatric solid cancer patients, who require timely diagnosis and multidisciplinary tumor board treatment that includes loco-regional control therapy through surgery, radiotherapy, or both (4,5,6). However, several factors influence the timely diagnosis of cancer in children and adolescents, making it a complex process. These factors include parental factors, the child's age, the type of childhood cancer, geographical location, socioeconomic status, the health referral system, and health infrastructure. These factors can have a significant impact on the time it takes to diagnose the cancer and can lead to delays in treatment. (6,7,8).

Therefore, this prospective study aims to assess childhood solid cancer patterns, investigate time to diagnosis, and identify factors associated with delayed diagnosis at a tertiary referral hospital in Ethiopia. Prompt diagnosis and treatment initiation are crucial for improving survival rates in pediatric cancer patients.

## 1.2 Statements of the Problem

Cancer is the leading non-accidental cause of death for children and adolescents. The likelihood of surviving a diagnosis of childhood cancer is lower in LMICs. Owing to the differences in the sociocultural factors, facilities, and outcomes between the developed and developing countries, a study of factors associated with delayed diagnosis and treatment in developing countries like Ethiopia is warranted. Therefore, in this study, we aimed to determine the time to diagnosis, the parental and physician delay, and the factors associated with them to improve patient care and outcomes for childhood cancers. Hence, this study will lay the foundation for designing a strategic plan for an effective timely intervention and health program in the country and the continent.

## 1.3 Significance of the study

As Tikur Anbessa Specialized Hospital represents a big catchment area receiving children with cancer from every corner of the country for investigation and treatment, this study will give a clear understanding of the late detection and diagnosis of children with solid tumors. This prospective study is helpful to improve care and to design strategic interventions and policies to improve survival in children with cancer. The investigator observed that there are patient-specific, physician-specific, and disease-specific risk factors contributing to diagnosis delay and late treatment initiation. Lack of access to care, medication shortages, and inadequate access to medical equipment fuel these disparities. Such factors contribute to delays in access to care and increased mortality risk for children suffering from cancer. The situation will continue unless action to improve access to quality care is taken at national and international levels.

## Chapter TWO: LITERATURE REVIEW

Central Nervous Tumors (CNS), neuroblastoma, soft tissue sarcoma, renal tumors, and bone sarcomas, are the most common childhood solid malignancies (1,2). Early diagnosis and prompt initiation of cancer therapy are crucial for reducing morbidity and mortality in pediatric cancer patients. This is especially important for pediatric solid cancer patients, who require timely diagnosis and multidisciplinary tumor board treatment that includes loco-regional control therapy through surgery, radiotherapy, or both (4,5,6). However, several factors influence the timely diagnosis of cancer in children and adolescents, making it a complex process. These factors include parental factors, the child's age, the type of childhood cancer, geographical location, socioeconomic status, the health referral system, and health infrastructure. These factors can have a significant impact on the time it takes to diagnose the cancer and can lead to delays in treatment. (6,7,8).

The Time to Diagnosis (TD) is the total time from the onset of symptoms to the confirmed cancer diagnosis. It includes Time to Presentation (TP), Time to Referral (TR), Time to Registration (Tr), and Time to Definitive Diagnosis (TDD). The total delay can be further categorized into parental delay, referral delay, definitive diagnosis delay, physician delay (referral delay + definitive diagnosis delay), treatment delay, and healthcare system delay (physician delay + treatment delay). The diagnosis delay is the sum of parental and physician delays. (9,10,11,12,13)

A population-based study in Singapore found that the median diagnosis delay for pediatric solid tumors was 5.3 weeks. Shorter diagnosis delays were associated with younger age, tumor site, incidental diagnosis by healthcare professionals, and pediatric emergency unit visits (14). In India, a study showed that the median time to diagnosis, referral, presentation, and definitive diagnosis for pediatric solid tumors were 76, 43, 7, and 16 days, respectively. The study found that delays in diagnosis were influenced by factors such as maternal educational status, state of residence, lesion site, disease stage, and tumor type (15,16).

Similarly, studies conducted in Egypt, Peru, and Indonesia revealed median diagnosis times of 6.7, 8.8, and 10 weeks, respectively. Factors associated with delayed diagnosis included the child's age, parents' educational status, use of alternative treatment, tumor type, and tumor site. Children with central nervous system tumors experienced the longest median time to diagnosis (17, 18, 19). In Sub-Saharan Africa, the majority of pediatric cancer cases are diagnosed at an advanced stage. A study in Northern Tanzania showed that the median referral delay was 89 days, with patients visiting a median of two facilities before being referred to the cancer center. Referral to a higher-level facility resulted in shorter referral times (20).

A retrospective study in Northern Ethiopia found that the child's age, residency, family's socioeconomic status, parental education, health insurance, use of holy water, and caregivers' perception of cancer curability influenced the timeliness of cancer diagnosis. The median delay in diagnosis at a public hospital in Gondar, Ethiopia was 68 days (21, 22).

Therefore, this prospective study aims to assess childhood solid cancer patterns, investigate time to diagnosis, and identify factors associated with delayed diagnosis at a tertiary referral hospital in Ethiopia. Prompt diagnosis and treatment initiation are crucial for improving survival rates in pediatric cancer patients.

## 2.1 Operational Definitions

The Time to Diagnosis (TD) is the total time from the onset of symptoms to the confirmed cancer diagnosis. It includes Time to Presentation (TP), Time to Referral (TR), Time to Registration (Tr), and Time to Definitive Diagnosis (TDD). The total delay can be further categorized into parental delay, referral delay, definitive diagnosis delay, physician delay (referral delay + definitive diagnosis delay), treatment delay, and healthcare system delay (physician delay + treatment delay). The diagnosis delay is the sum of parental and physician delays. (9,10,11,12,13)

# Chapter Three: Objectives

## 3.1 General objectives

To assess the time to diagnosis (TD) and factors associated with delayed diagnosis in children with solid cancers at a tertiary referral hospital in Ethiopia

## 3.2 Specific objectives

• To describe the demographic profile and pattern of solid tumors at Tikur Anbessa Hospital

• To assess the time to presentation (TP) to the cancer treatment center at TASH

• To describe the time to diagnosis (TD) in children with solid tumors

• To identify the associated risk factors for lag time to diagnosis (TD) in children with solid tumors

• To assess the stage of the disease at presentation (Local vs advanced)

• To assess the time to definitive diagnosis (TDD) at the cancer treatment center in children with solid tumors

# Chapter 4: Methods

## 4.1 Study setting

Ethiopia, is a low- and middle-income country in East Africa, the 12$^{th}$ most populous country in the world and the second most populous in Africa. The population density in Ethiopia is 115 per Km$^2$ (298 people per m$^2$) with an estimated of more than 120 million people. The median age is 19.5 years; the pediatric population accounts for almost half of the population. Tikur Anbessa Specialized Hospital, established in 1974, is the largest tertiary hospital in the country and is administered by Addis Ababa University, the hospital offers diagnosis and treatment for approximately half a million patients a year. A separate pediatric haemato-oncology treatment center in the Department of Pediatrics and Child Health at Tikur Anbessa Specialized Hospital began in March 2013. The pediatric haemato-oncology ward has 41 beds, and more than 20 beds were allocated for pediatric hematology-oncology patients at the pediatric emergency unit. There are 3 pediatric haemato-oncologists, 8 pediatric hematology-oncology fellows, and 20 pediatric nurses working in the pediatrics hematology- unit. Apart from these more than 25 pediatrics residents and 10 pediatric interns attach and work at the in-patient ward and outpatient haemato-oncology clinic every month. The pediatric haemato-oncology unit provides both inpatient and outpatient services to more than 800 patients every month and an estimated 8,000-10,000 patients are seen per year.

## 4.2 Study design

This prospective study was conducted at Tikur Anbessa Specialized Hospital, Pediatric Hematology-Oncology (PHO) unit from March 2023 to March 2024. This study aimed to assess the patterns and the different types of delay in children with newly diagnosed solid cancers and to describe the factors influencing delayed diagnosis in our setup. Data were collected by trained second-year pediatric residents using a structured questionnaire supervised by the principal investigator (PI), senior pediatric hematology and oncology fellow. The study questionnaires had informed consent and three parts: Part I was about the socio-demographic profile of the study participants and caregivers, Part II was about the different time intervals in children with solid cancers; assessing the time to presentation (TP), time to referral (TR), Time to registration, time definitive diagnosis (TDD), and time to diagnosis (TD). Part III was about assessing the six different types of delay in children with solid cancers in days; assessing the time interval and factors influencing parental delay, referral delay, physician delay, diagnosis delay, treatment delay, health care system delay, and total delay. Caregivers of children with solid cancers were interviewed to assess the various pre-diagnostic time intervals from the onset of symptoms and delays at the time of registration to the pediatric oncology center. The definitive diagnosis and treatment delay were assessed prospectively from registration to the oncologic center, and the factors contributing to these delays were evaluated. Part IV was about the anatomic site of the tumor and confirmed diagnosis, investigating the stage of the disease (localized or metastatic), and the treatment intent (curative or palliative intent). A pilot test was performed on 5% of the sample to assure content and language clarity. Problems highlighted during the pre-test were revised before the actual data collection. The collected data were checked for completeness and consistency by the principal investigator. The study was approved by the Research Ethics Committee of the Department of Pediatrics and Child Health, and the Institutional Review Board (IRB) of the College of Health Sciences of Addis Ababa University.

## 4.3 Sampling

All pathologically and clinical-radiologically confirmed new solid cancers in children under 15 years at the pediatric hematology and oncology unit of Tikur Anbessa Specialized Hospital, were included from May 2023 to May 2024. Children with hematolymphoid malignancies, and tissue biopsies revealing benign tumors were excluded. A total of 250 childhood solid cancer patients who met the inclusion criteria were prospectively evaluated and included in the study.

## 4.4. Inclusion and exclusion criteria

### 4.4.1 Inclusion Criteria

• All pathologically and clinical-radiologically confirmed new solid cancers in children under 15 years

### 4.4.2. Exclusion criteria

- Children diagnosed with hematolymphoid cancers (Acute Leukemia, Lymphoma, Chronic leukemia)
- Children who already started treatment for pediatric solid cancers at another center

## 4.5 Study Variables

The primary objective of this study was to assess the time to diagnosis (TD) and factors associated with delayed diagnosis in children with solid cancers at a tertiary referral hospital in Ethiopia.

The time interval from the onset of disease symptoms to the treatment initiation is classified into Time to Presentation (TP); the duration of illness from the onset of symptoms to the first healthcare visit, Time to Referral (TR); the time interval from the first healthcare visit to the final referral to the oncologic center with a suspicion of childhood cancer, Time to Registration (Tr); the time interval from the referral center to the arrival and enrollment to the Tikur Anbessa oncology center, Time to Definitive Diagnosis (TDD); the time interval from the registration to the pediatric oncology center to the confirmation of cancer diagnosis and the Time to Diagnosis (TD), the sum of time to presentation, time to referral, time to registration, and Time to Definitive diagnosis, is the total time duration from the onset of diseases symptoms and signs till the confirmation of cancer diagnosis. Parental time is the sum of the time of presentation and time to registration. [**Figure 1**] The various delays can be classified into parental delay, referral delay, definitive diagnosis delay, physician delay (referral delay + definitive diagnosis delay), treatment delay, Healthcare system delay (physician delay treatment delay), and total delay. [**Figure 2**]

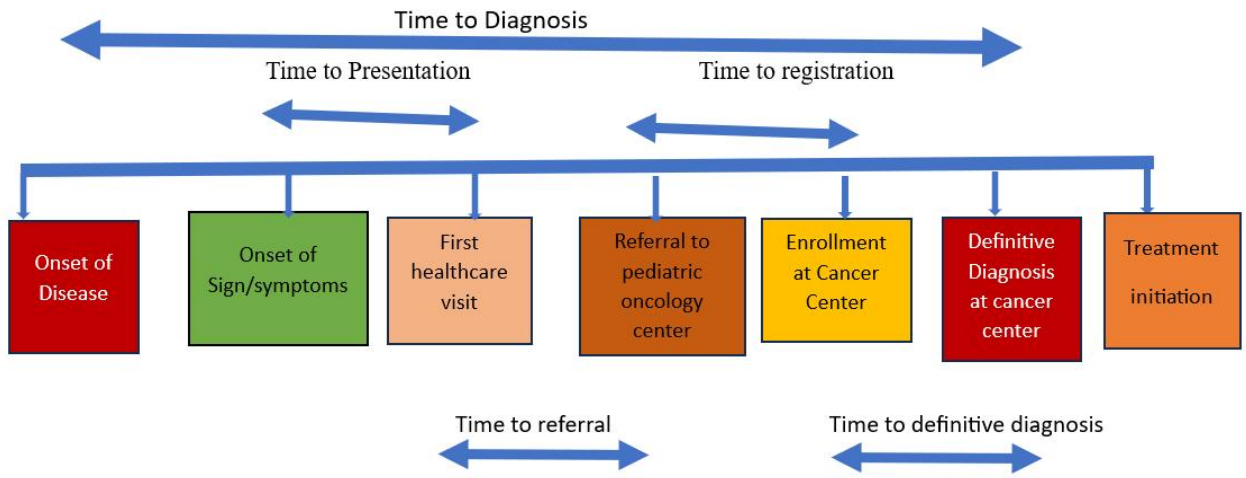



*Figure 1: The different time intervals from the onset of disease symptoms to treatment initiation in children with solid cancers*

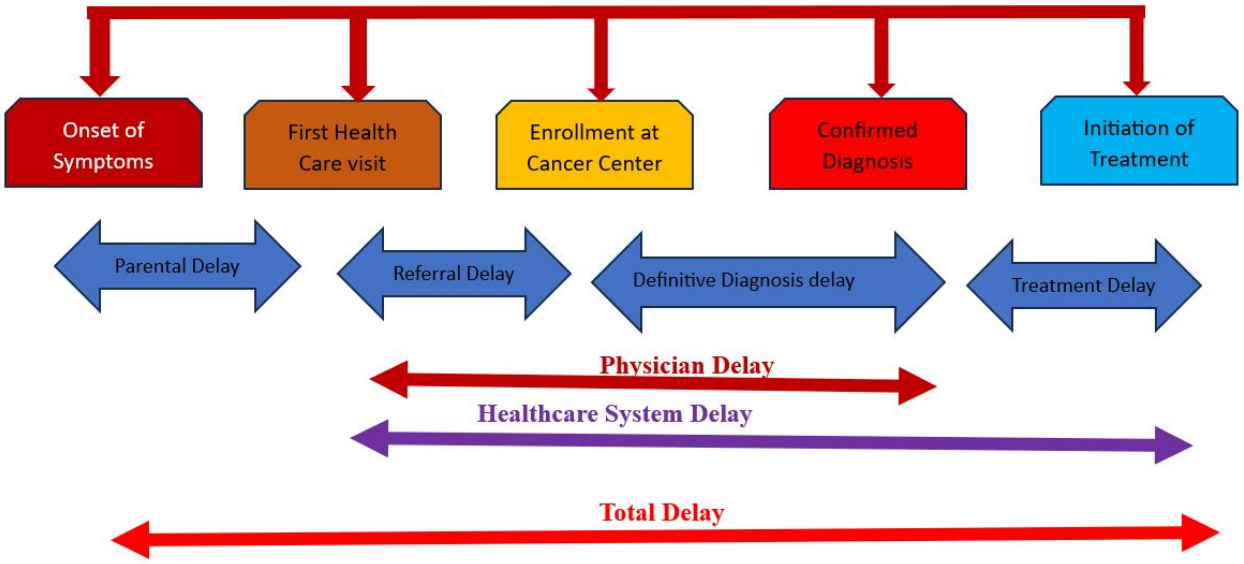



***Figure 2*: The various delays from the onset of disease symptoms to treatment initiation in children with solid cancers**

## 4.6 Data Collection and Data Analysis

Data were collected by trained second-year pediatric residents using a structured questionnaire supervised by the principal investigator (PI), senior pediatric hematology and oncology fellow. The study questionnaires had informed consent and three parts: Part I was about the socio-demographic profile of the study participants and caregivers, Part II was about the different time intervals in children with solid cancers; assessing the time to presentation (TP), time to referral (TR), Time to registration, time definitive diagnosis (TDD), and time to diagnosis (TD). Part III was about assessing the six different types of delay in children with solid cancers in days; assessing the time interval and factors influencing parental delay, referral delay, physician delay, diagnosis delay, treatment delay, health care system delay, and total delay. Caregivers of children with solid cancers were interviewed to assess the various pre-diagnostic time intervals from the onset of symptoms and delays at the time of registration to the pediatric oncology center. The definitive diagnosis and treatment delay were assessed prospectively from registration to the oncologic center, and the factors contributing to these delays were evaluated. Part IV was about the anatomic site of the tumor and confirmed diagnosis, investigating the stage of the disease (localized or metastatic), and the treatment intent (curative or palliative intent.

After selecting the study cases, the data was collected from the registration log book, the patient card, and the follow-up chart by the data collectors. The administered questionnaire encompasses the socio-demography profile, clinical profile, and outcome. ODK version 2022.3.3 software was used to collect the data along with the Kobo Toolbox server to store the collected data. Data was entered into Epi data version 3.1 and exported to SPSS version 25 for analysis. P-value $<0.05$ was considered to be statistically significant.

## 4.7 Data Quality control and management

To ensure data quality, the structured questionnaire checklists were tested on 5% of the sample. Problems highlighted during the pre-test were revised before the actual data collection. The collected data were checked for completeness and consistency by the principal investigator.

## 4.8 Ethical Approval and Informed Consent

The study was approved by the Research and Publication Committee of the Pediatrics and Child Health Department (DRCP), School of Medicine, College of Health Sciences, Addis Ababa University, and the College Institutional Review Board (IRB). Confidentiality was fully maintained during data collection and analysis, and participants would be anonymous during the dissemination of results.

## 4.9 Dissemination of Findings

The results of the study were presented on the Pediatric Hematology and Oncology Research Defense Day (July 18, 2024); attended by professors in pediatrics and child health, consultant pediatric hematologists and oncologists, experts in Public Health, Pediatric Hematology and Oncology Fellows, Guest from Ministry of Health, and pediatric residents and a formal report was submitted to the Department of Pediatrics and Child Health, the School of Medicine, College of Health Sciences Registrar on July 19, 2024. The research will be published in international peer-reviewed high-impact factor scientific journals and will be shared with the hospital, governmental agencies, and the scientific community to allow for improvements and to provide essential care and support for children with cancers.

## 4.10 Statistics

This was a prospective study, we included all the newly diagnosed solid cancer patients within the time frame of the study. The data were recorded in an Excel sheet and analyzed statistically using the Statistical Program for the Social Sciences (IBM SPSS Statistics for Windows, Version 25.0). The categorical variables were described with frequency, and percentage and plotted with bar and pie charts. The time to presentation, time to referral, time to registration, time to diagnosis, and time to treatment were calculated in days; the median, minimum, maximum, and interquartile ranges were evaluated. The various time intervals of diagnosis and treatment delay and the factors associated with the delayed diagnosis were assessed. A p-value of $\leq 0.05$ was considered statistically significant.

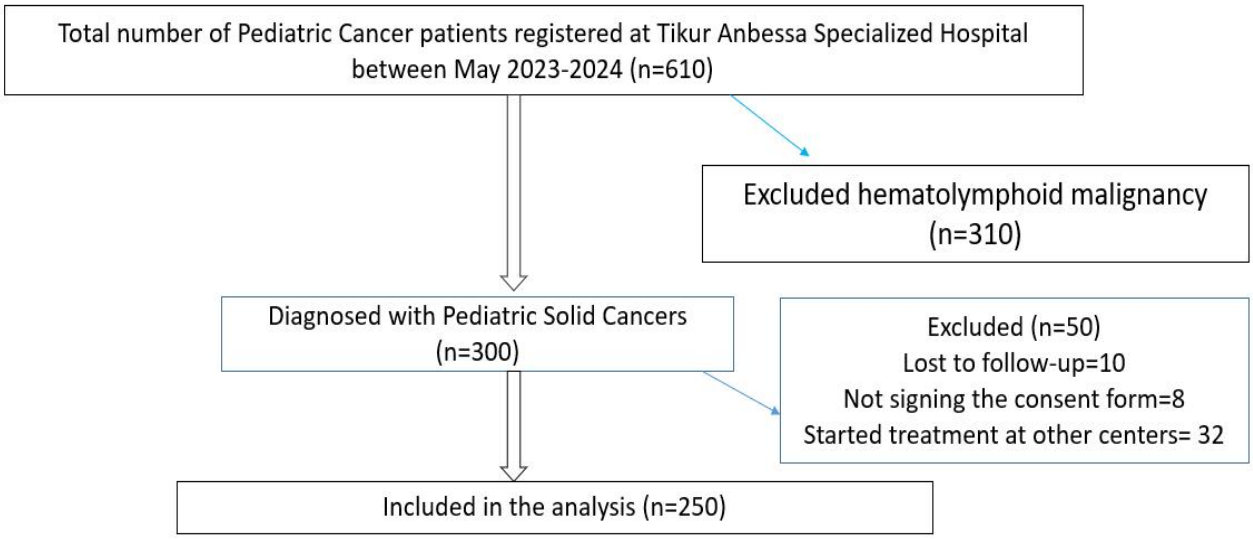



***Figure 3***: Flow diagram of newly diagnosed pediatric solid cancer patients

# Chapter Five: Results

**Socio-demographic characteristics of Children with Solid Cancers**

A total of two hundred fifty (n=250) children with solid cancers were included in the study. The majority of children were males; 55.2% (n=138) with a male-to-female ratio of 1.3:1. Nearly half of the children were between 1-5 years of age accounting for 49.2% (n=123), and 21.2 % (n=53) were between 6-10 years. Children under five years of age constituted 56.4% (n=139) of children with solid cancers in the study. Most of the children came from the Oromia region; 32.8 % (n=82), Amhara; 20% (n=50%), Southern Region; 17.6% (n=43), and Addis Ababa; 16.8%(n=42) as shown in **Table 1**, **Figure 4 and 5**. Most caregivers were parents; 95.6% (n=239), and both parents were the caregivers for 31.2% (n=31) of children with solid cancers. More than three-fourths of the caregivers had a formal education; 77.2% (n=193), and one-fifth (19.2%) had a college-level education. The majority of them; 71.6% (n=179) had community-based health insurance (CBHI), and most of them were referred from General Hospital (51.2%) and Tertiary Referral Hospitals (31.2%).

| *Table 1*. Socio-demographic profile of pediatric solid cancer patients at Tikur Anbessa Specialized Hospital, Addis Ababa, Ethiopia, 2023–2024 (n=250) | | |
|---|---|---|
| Variable | Frequency | Percent (%) |
| **Age category** | | |
| < 1 year | 18 | 7.2 |
| 1-5 years | 123 | 49.2 |
| 6-10 years | 53 | 21.2 |
| 11–15 years | 56 | 22.4 |
| **Sex** | | |
| Male | 138 | 55.2 |
| Female | 112 | 44.8 |
| **Residence** | | |
| Oromia | 78 | 37.5 |
| Amhara | 55 | 26.4 |
| South West and Central Ethiopia | 35 | 16.8 |
| Addis Ababa | 13 | 6.3 |
| Tigray | 8 | 3.8 |
| Other regions | 19 | 9.2 |
| **Primary Caregivers of Children** | | |
| Father | 88 | 35.2 |
| Mother | 73 | 29.2 |
| Both Parents | 78 | 31.2 |
| Adult Relative | 10 | 4.0 |
| Non-relative Adult | 1 | 0.4 |
| **Caregiver's Educational Status** | | |
| Primary education | 74 | 29.6 |
| No formal education | 57 | 22.8 |
| Secondary education | 48 | 19.2 |
| College level | 48 | 19.2 |
| Can read and write | 23 | 9.2 |
| **Community-Based Health Insurance** | | |
| Yes | 179 | 71.6 |
| No | 71 | 28.4 |
| **Source of Referral** | | |
| Health Center | 1 | 0.4 |
| District Hospital | 4 | 1.6 |
| General Hospital | 128 | 51.2 |
| Tertiary Referral Hospital | 78 | 31.3 |
| Private clinic/hospital | 38 | 15.2 |
| Self-referred | 1 | 0.4 |

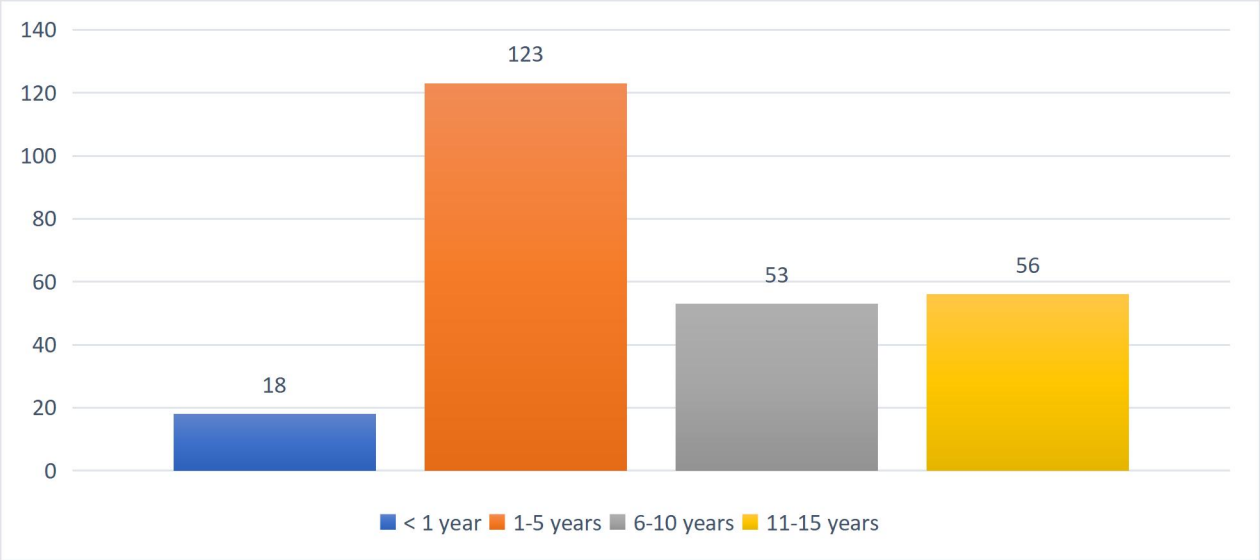



***Figure 4*- Age distribution of solid cancers in Children and Adolescents at Tikur Anbessa Specialized Hospital, Ethiopia, 2023-2024**

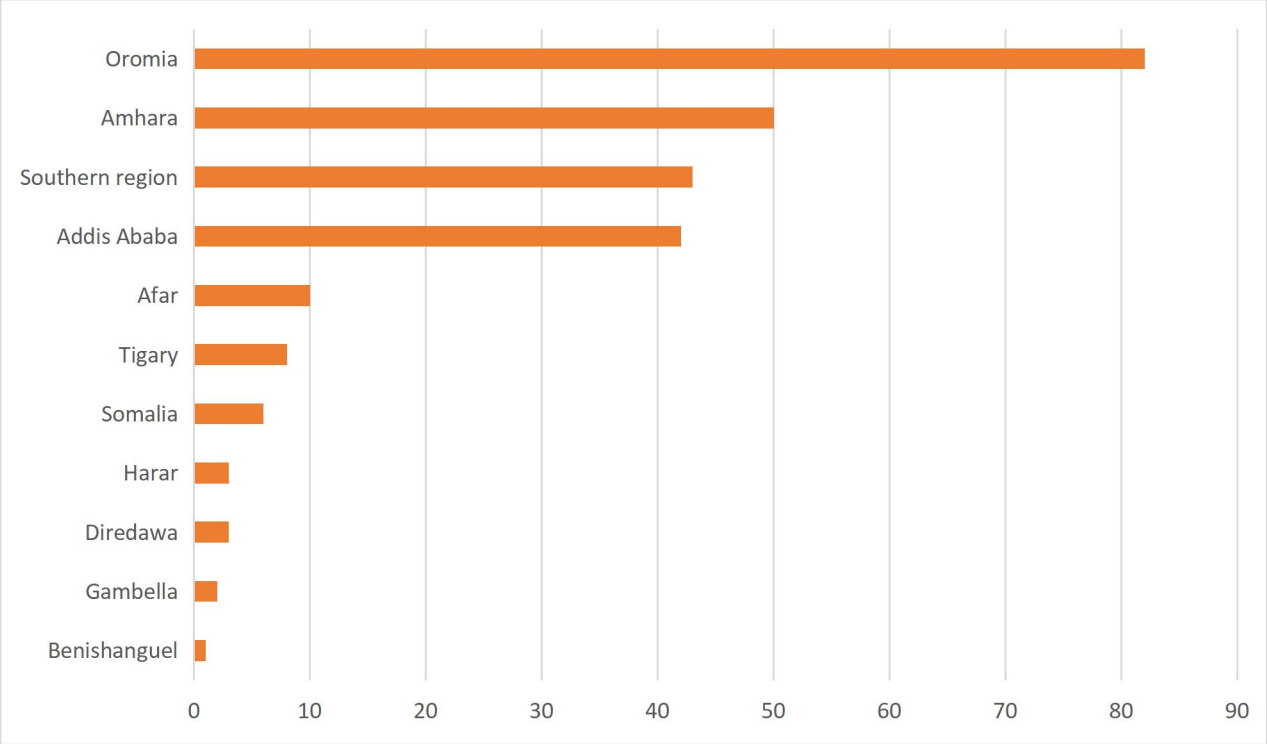



***Figure 5*- Residence of children with newly diagnosed solid cancer patients at Tikur Anbessa Specialized Hospital, Pediatric Hematology-Oncology Unit, 2023-202**

**Patterns, Primary Anatomic Sites and the Incidence of Metastasis in Children with Solid Cancers**

Central Nervous System (CNS) tumors were the most common childhood solid cancers in our study accounting for 24% (n=60) followed by renal tumors (17.2%), retinoblastoma (16.8), soft tissue sarcoma (15.2%), neuroblastoma (12.4%), and bone tumors (5.2%) as shown in **Figure 6**. The abdomen, head-neck region, and central nervous system were the most common anatomic sites of the tumor contributing 30% (n=75), 29 (n=74), and 23% (n=57) respectively [**Figure 7].** About 74.6 % (n=191) of children with solid cancers presented with localized diseases, and 23.4 % (n=59) presented with distant metastasis (stage IV disease). Curative treatment intent was started for 78.8% (n=197) of children with solid cancers at the time of diagnosis, and 21.2 % (n=53) of children were put on palliative care treatment.

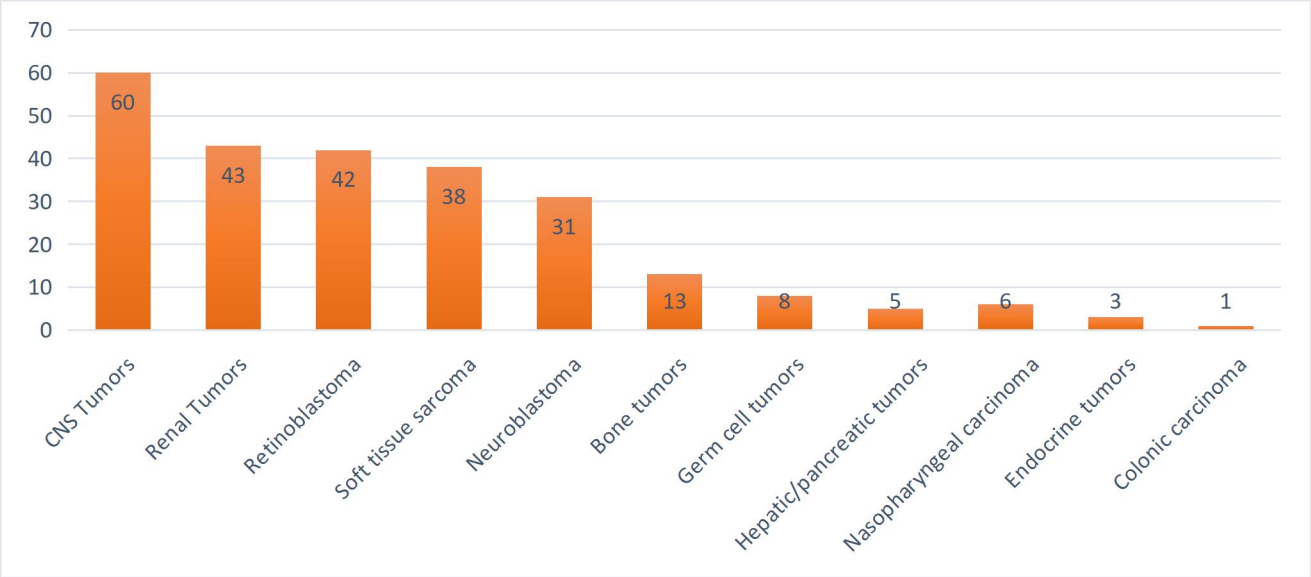



*Figure 6*- Patterns of Childhood Solid Cancers at Tikur Anbessa Specialized Hospital, Ethiopia, (n=250)

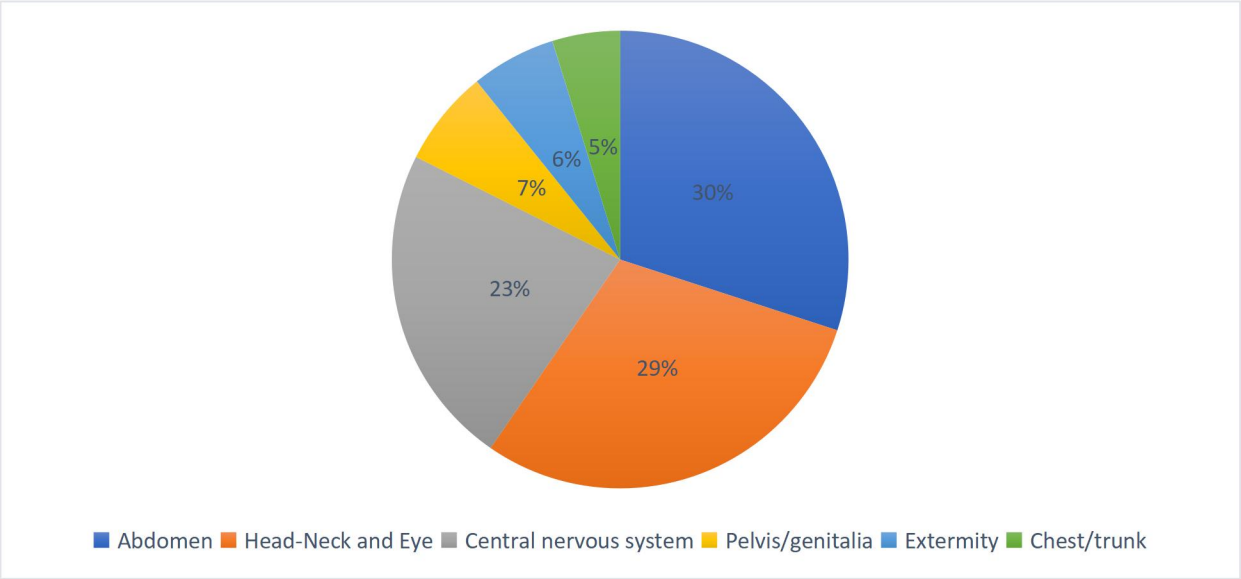



*Figure 7*- Primary Anatomic Sites of Childhood Solid Cancers at Tikur Anbessa Specialized Hospital, Ethiopia (n=250)

**Time to Presentation, Time to Referral, Time to Registration, and Time to Diagnosis (TD) in Children with Solid Cancers**

The median duration of Time to Presentation (TP) was 30 days (IQR of 7-120); the median time to Referral (TR) was 30 days (IQR 8-80). The median duration of Time to Registration was 2 days (IQR 1-7), Time to Definitive Diagnosis was 5 days (IQR 1-10), and Time to Treatment (TT) was 5 days (IQR 1-10). The median duration of Time to Diagnosis (TD) in children with solid cancers was 99 days (IQR 47-254). The median time of diagnosis (TD) of renal tumors and neuroblastoma were 62 and 64 days respectively. The median time of diagnosis was beyond three months for children with bone tumors (107 days), CNS tumors (119 days), retinoblastoma (284 days), Nasopharyngeal Carcinoma (181 days), and endocrine tumors (587 days) (Table 2 and Table 3)

| **Variables** | **Range** | **Median (IQR: 25th–75th) in days** | |
|---|---|---|---|
| Time to Presentation (TP) | 1-1825 | 30± (8-121) | |
| Time to Referral (TR) | 1-930 | 30± (8-78) | |
| Time to Registration | 1-340 | 2± (1-6) | |
| Time to Definitive Diagnosis | 1-120 | 5±16 (1-10) | |
| Time to Diagnosis (TD) | 4-2549 | 99± (46-253) | |
| Time to Treatment | 1-90 | 5± (2-10) | |
| **Time to Diagnosis (TD) in Children with Various Solid Cancers** | **Range** | **Median ±SD** | **P** |
| CNS Tumors | 17-1222 | 119± 184 | 0.005 |
| Renal Tumors | 4-340 | 62± 86 | |
| Retinoblastoma | 4-1221 | 284± 186 | |
| Soft Tissue Sarcoma | 10-979 | 83± 124 | |
| Neuroblastoma | 8-349 | 64± 55 | |
| Bone Tumors | 23-739 | 107± 98 | |
| Germ cell Tumors | 4-1590 | 39± 545 | |
| Hepatic and Pancreatic Tumors | 19-212 | 65± 78 | |
| Nasopharyngeal Carcinoma | 42-547 | 181± 190 | |
| Endocrine Tumors | 57-890 | 587± 422 | |

*Table 2*: **Time to Diagnosis (Median and Range)**

| Types of Solid Cancers (Frequency) | Time to Presentation Median (IQR: $25^{th}$–$75^{th}$) | Time to Referral Median (IQR: $25^{th}$–$75^{th}$) | Time to Registration Median (IQR: $25^{th}$–$75^{th}$) | Time to Definitive Diagnosis Median (IQR: $25^{th}$–$75^{th}$) | Time to Diagnosis Median (IQR: $25^{th}$–$75^{th}$) | Time to Treatment Median (IQR: $25^{th}$–$75^{th}$) |
|---|---|---|---|---|---|---|
| CNS Tumors (n=60) | 30(7-120) | 74(21-1200 | 2 (1-7) | 4(1-10) | 119 (70-277) | 7(2-21) |
| Renal Tumors (n=43) | 30(5-60) | 14(2-43) | 1(1-7) | 2(1-5) | 62(30-116) | 3(1-7) |
| Retinoblastoma (n=42) | 105(22-326) | 30(10-120) | 3 (2-124) | 3(1-7) | 284 (66-399) | 3(1-6) |
| Soft Tissue Sarcoma (n=38) | 18(7-60) | 28(7-62) | 2 (1-7) | 9 (1-21) | 83(45-130) | 9(2-14) |
| Neuroblastoma (n=31) | 30(7-90) | 20(10-41) | 2(1-4) | 7(4-12) | 64(34-177) | 4(1-8) |
| Bone Tumors (n=13) | 60(23-120) | 28(3-109) | 1(1-3) | 10(2-38) | 107(59-301) | 4(2-8) |
| Germ Cell Tumors (n=8) | 9(2-279) | 18(2-63) | 1(1-11) | 4(1-10) | 39(11-328) | 14(5-15) |
| Hepatic and Pancreatic Tumors (n=5) | 14(5-90) | 30(5-48) | 1(1-6) | 6(5-11) | 65(23-155) | 5(2-10) |
| Nasopharyngeal Carcinoma (n=6) | 44(18-249) | 75(10-108) | 2(1-3) | 20(6-53) | 181(50-371) | 12(5-20) |
| Endocrine Tumors (n=3) | 365 | 60 | 5 | 39 | 587 | 5 |
| Colonic cancer (n=1) | 7 | 160 | 1 | 2 | 169 | 5 |
| All Solid Cancers (n=250) | 30(7-120) | 30(8-80) | 2(1-7) | 5(1-10) | 99(47-254) | 5(1-10) |
| The median and the IQR (interquartile range) in days | | | | | | |

***Table 3***: The different time intervals of diagnosis in children with solid cancers (n=250)

**Factors Associated with Delayed Diagnosis in Children with Solid Cancers**

The median parental delay was 38 days (IQR13-135). Children with germ cell tumors, hepatic/pancreatic tumors, and renal tumors had the shortest delay with a median parental delay of 15, 18, and 31 days respectively. In contrast, children with bone tumors, retinoblastoma, and endocrine tumors had the longest parental delay.

The median referral delay to the pediatric oncology center was 30 days (IQR 7-76). Referral delay was shortest for children with Wilm's tumors (12 days), and longest for CNS tumors (74 days), and nasopharyngeal carcinoma (75 days).

The median definitive diagnosis delay once the patient enrolled in the oncologic center was five days (IQR 1-10 days). Children with renal tumors and germ cell tumors (GCT) had the shortest definitive diagnosis time (2 days), whereas children with nasopharyngeal carcinoma and endocrine tumors had the longest definitive diagnosis delay of 20 and 39 days respectively.

The median physician delay (referral plus definitive diagnosis delay) was 40 days with an IQR of 15-92 days. The median treatment delay in children with solid cancers at the pediatric oncology center was 5 days and the shortest for children with Wilm's tumors. The median healthcare system delivery for all solid cancer was 46 days (IQR 21-100) and the shortest duration was in children with Wilms' tumors, GCT, and hepatic/pancreatic tumors. The median total delay for all pediatric solid cancers was 112 days (IQR 53-277). The shortest total delay was seen in patients with germ cell tumors (54 days), neuroblastoma (68 days), Wilms tumor (72 days), and soft tissue sarcoma (101 days). The longest total delay was in patients with retinoblastoma and pediatric endocrine tumors as described in Table 4.

| Types of Solid Cancers | Parental Delay Median (IQR: 25th–75th) | Referral Delay Median (IQR: 25th–75th) | Definitive Diagnosis Delay Median (IQR: 25th–75th) | Physician Delay Median (IQR: 25th–75th) | Treatment Delay Median (IQR: 25th–75th) | Health Care System Delay Median (IQR: 25th–75th) | Total Delay Median (IQR: 25th–75th) |
|---|---|---|---|---|---|---|---|
| CNS Tumors | 32(12-147) | 74(21-120) | 4(1-10) | 77(33-127) | 7(2-21) | 86(41-146) | 125(79-294) |
| Renal Tumors | 31(8-92) | 12(3-43) | 2(1-5) | 17(6-51) | 3(1-7) | 31(9-52) | 72(34-23) |
| Retinoblastoma | 138(31-354) | 30(10-98) | 3(1-7) | 37(13-202) | 3(1-6) | 43(17-1030 | 277(69-402) |
| Soft Tissue Sarcoma | 33(14-87) | 28(7-62) | 10(1-21) | 45(18-83) | 9(2-14) | 47(30-94) | 101(57-212) |
| Neuroblastoma | 33(10-93) | 20(10-41) | 7(4-14) | 35(17-59) | 4(1-8) | 41(26-63) | 68(40-161) |
| Bone Tumors | 63(24-122) | 28(3-109) | 10(2-38) | 47(11-148) | 4(2-8) | 48(21-172) | 112(65-340) |
| Germ Cell Tumors (GCTs) | 15(4-307) | 18(2-28) | 2(1-9) | 24(5-35) | 14(5-15) | 37(19-48) | 54(26-342) |
| Hepatic and Pancreatic Tumors | 18(6-109) | 30(5-48) | 7(5-38) | 37(10-81) | 5(2-10) | 38(16-88) | 99(29-169) |
| Nasopharyngeal Carcinoma | 45(19-253) | 75(10-108) | 20(6-53) | 96(33-179) | 12(5-20) | 116(46-186) | 186(61-400) |
| Endocrine Tumors | 368 | 60 | 39 | 140 | 5 | 150 | 589 |
| Colonic cancer | 8 | 160 | 2 | 262 | 5 | 267 | 275 |
| All Solid Cancers | 38(12-152) | 30(7-76) | 5(1-10) | 40(15-92) | 5 (1-10) | 46(21-100) | 112(53-277) |
| The median and the IQR (interquartile range) in days | | | | | | | |

***Table 4***- The median delay of the various components of delays in children with solid cancers (n=250)

Nearly 74.4 % (n=186) of children went to their first health visit two weeks after the onset of symptoms and signs of the disease. The perceiver barriers for the caregiver's delay were a lack of parental awareness about childhood cancers (86%), a preference for the traditional way of treatment (cultural/religious beliefs), and financial constraints to seek medical care. Nearly two-thirds of children; 63.6% (n=159) had a referral delay to the oncology center of more than two weeks, and the main factors for delayed referral were misdiagnosis of cancer (83.6% of solid cancer patients were initially misdiagnosed), and patient management for non-oncologic diseases (47.2%) [**Figure 8**]. About 38 % (n=95) had a treatment delay of more than two weeks. The reason for the delay was waiting for metastatic(staging) workup investigations (77.8%), and waiting for multidisciplinary treatment (MDT) tumor board decision (73.6%). The factors associated with the time of diagnosis were parental education status (p=0.032), the presence of CBHI (P=0.022), types of solid cancers (p=0.04), and sites of the tumor (p=0.035). The time of diagnosis was shortest in parents with secondary and college level education, and the median time of diagnosis was shortest in children with renal, and neuroblastic tumors as shown in **Table 5**.

| *Table 5*. **Perceived barriers and Factors associated with delay in children with solid cancers at Tikur Anbessa Hospital, Ethiopia** | | |
|---|---|---|
| **Variables** | **Frequency** | **Percent (%)** |
| **Reasons for Caregiver Delay (n=186)** | | |
| Lack of Parents' Awareness of Cancer | 160 | 86.0 |
| Traditional way of treatment | 80 | 43.0 |
| Financial Constraints | 66 | 35.5 |
| Family members disagree about treatment | 12 | 6.4 |
| Poor general condition of the patient | 2 | 1.2 |
| Other reasons | 8 | 4.3 |
| **Factors for Referral Delay (n=159)** | | |
| Doubt/misdiagnosis of Cancer | 133 | 83.6 |
| The patient managed for non-oncologic disease | 75 | 47.2 |
| Multiple referrals | 66 | 41.2 |
| Investigation workup | 27 | 17.0 |
| Family members disagree about child referral | 11 | 6.9 |
| Poor general condition of the patient for referral | 10 | 6.3 |
| **Reasons for Treatment Delay (n=95)** | | |
| Waiting for metastatic and staging workup | 74 | 77.8 |
| Waiting for MDT decision | 70 | 73.6 |
| On the waiting list for bed admission | 32 | 33.6 |
| Financial constraints for treatment | 6 | 6.3 |
| Parents not decided on Child's treatment | 2 | 2.3 |
| Chemotherapy medications unavailability | 1 | 1.1 |
| Others | 8 | 8.4 |
| **Factors Affecting Time of Diagnosis (TD)** | **Median TD in days** | **P** |
| Age | | 0.149 |
| 1-5 years | 190 | |
| 6-10 years | 205 | |
| 11-15 years | 263 | |
| Sex | | 0.535 |
| Male | 104 | |
| Female | 95 | |
| Parental education | | 0.032 |
| No formal education | 140 | |
| Can read and write | 137 | |
| Secondary education | 59 | |
| College level Education | 82 | |
| Types of Solid Cancers | | 0.04 |
| Renal tumors | 62 | |
| Neuroblastoma | 64 | |
| CNS tumors | 119 | |

| | | |
|---|---|---|
| Nasopharyngeal | 181 | |
| Retinoblastoma | 286 | |
| Endocrine tumors | 589 | |
| Sites of the tumour | | 0.035 |
| Lower back | 28 | |
| Pelvis/genitalia | 60 | |
| Abdomen | 65 | |
| Chest/trunk | 115 | |
| Head and neck | 157 | |
| Community-Based Health Insurance (CBHI) | (n=179) | 0.022 |

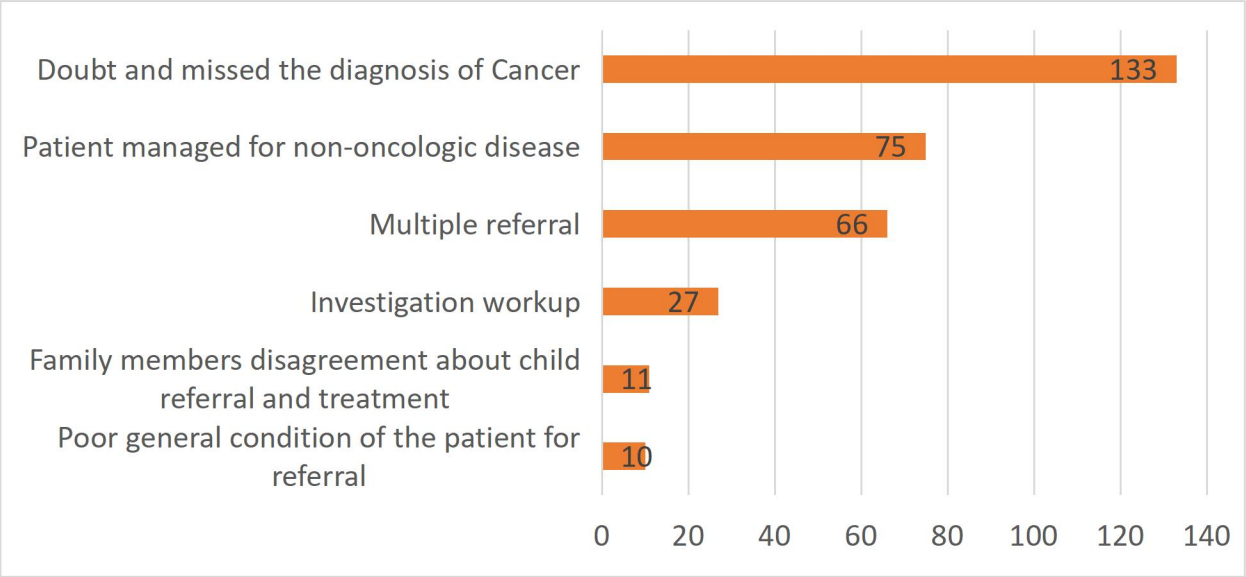



***Figure 8***- Reasons for Referral Delay in Children with Solid Cancers at Tikur Anbessa Specialized Hospital, Ethiopia

## Chapter six: DISCUSSION

Solid Cancers are the most common cause of mortality and morbidity in children and adolescents with cancers. However, the epidemiology and patterns of pediatric solid cancers, time to presentation, time to diagnosis, factors associated with delayed referral, and diagnosis were not well studied in Low and Middle-Income Countries (LMICs) who carries the highest burden of childhood cancers. Ethiopia, a country in East Africa, the second most populous country in Africa, has an estimated population of more than 120 million and more than half of the population are in the pediatric age group. Our study revealed solid cancers were more common in children under five years with a male sex predominance. Central Nervous System (CNS) tumors, renal tumors, retinoblastoma, soft tissue sarcoma, and neuroblastoma were the most common childhood solid cancers; retinoblastoma was more common in our setup compared to other studies. (1,2) Nearly one-fourth of children presented with distant metastasis (stage IV disease), and more than one-fifth of children were put on palliative care treatment at the time of diagnosis.

The various time intervals related to time diagnosis were longer than those studies from the developed nations, and our study showed the median Time to Presentation (TP), Time to Referral (TR), Time to Registration (Tr), Time to Definitive Diagnosis (TDD), and Time to Diagnosis (TD) were 30, 30, 2, 5, and 99 days (14.2 weeks) respectively. The median time to diagnosis (TD) in our study was the longest compared to other studies in Egypt (6.7 weeks), Singapore (5.3 weeks), Peru (8.8 weeks), India (9.5 weeks), and Gondar, North West Ethiopia (9.7 weeks), and Indonesia (10 weeks) (14,15,16,17,18,22). The median time to presentation and time to definitive diagnosis were also longer than other studies in India (15,16). The shortest time of diagnosis was for renal tumors and neuroblastoma, and the longest time of diagnosis was for children with endocrine tumors, nasopharyngeal carcinoma, retinoblastoma, and CNS tumors; the median time of diagnosis was beyond three months, and children with retinoblastoma and CNS tumors had a delayed diagnosis similar to other studies. (16,17,18)

Children with bone tumors, retinoblastoma, and endocrine tumors had the longest parental delay with a median of 9, 19.7, and 77 weeks respectively. The perceived factors for parental delay were lack of parental awareness, preference for the traditional way of treatment, and financial constraints to seek medical care and these factors were also a significant contributor to the lag time to diagnosis in children with cancer. (18,20,21,22)

Our study revealed that the median Referral delay was 30 days; the shortest for children with Wilm's tumors (12 days), and longest for CNS tumors (74 days), and nasopharyngeal carcinoma (75 days), and the referral delay was shorter than other studies in Tanzania (89 days) and India (43 days). (15,16,20) Doubt and missed diagnosis of cancer at the initial health facility visit and patient management for non-oncologic diseases (47.2%) were the contributing factors for delayed referral to the oncologic center, with a similar finding with other studies in Low- and Middle-Income Countries (LMICs). (17,18,20,21,22). The physician delay was significant in our study with a median of 40 days with an IQR of 15-92 days, longer than parental delay with a similar finding in Israel. (23).

In our study, the median definitive diagnosis and treatment delay once the patient enrolled at the pediatric oncology center was 5 days, and the reasons contributing to treatment delay of more than 7 days were metastatic workup investigations, waiting for multidisciplinary tumor board decisions, and waiting list for inpatient bed admission.

The factors associated with the time of diagnosis (TD) in our study were parental education status, the presence of community-based health insurance, types of solid cancers, and sites of the tumor; the time to diagnosis was shortest in parents with secondary and college level education, and the median time of diagnosis was shortest in children with renal, and neuroblastic tumors, these factors also significantly affect the diagnosis delay in other studies done in India and Egypt. (15,16,19)

The diagnosis of CNS and retinoblastoma tumors was significantly delayed. This delay may be due to a lack of awareness of symptoms and signs among caregivers and physicians, as well as the indolent nature of the tumor. While tumor biology does play a role, healthcare professionals need to have awareness and early detection of clinical symptoms and signs of pediatric solid cancers to facilitate timely diagnosis and early referral to pediatric oncology treatment centers. To minimize diagnosis delays in children with retinoblastoma, it is recommended to design policies and strengthen the screening system for children under five years old. Based on our findings, we recommend encouraging parents to seek early medical care for their children when they are sick, rather than relying on traditional methods of treatment. Additionally, we suggest shortening the time to diagnosis through the implementation of continuing professional and institutional development (CPID) certification courses, as well as focused specialty medical training on the signs and symptoms of childhood cancers. This will improve the diagnostic capabilities of healthcare professionals and foster a high index of suspicion, facilitating early referral of children with suspected cancer.

## Chapter 7: Strengths and limitations of the study

This prospective study was conducted in one of the largest tertiary referral hospitals in Ethiopia, which served as the only pediatric hematology and oncology center until recently. Our study highlighted the patterns and time to diagnosis in children with solid cancers. This prospective study focused on the overall picture of diagnosis and treatment delay in children with cancer, and the factors associated with delayed diagnosis in children and adolescents with solid cancers. The results can be generalized to other setups with similar settings. The time intervals of diagnosis, the various diagnosis delays, and the perceived barriers and associated factors were investigated in the study. However, this study does not assess the effect of diagnosis delay on the treatment outcomes and survival status of children with cancer. Another limitation of this study is that it did not specifically investigate the socioeconomic status and psychosocial issues among caregivers, which can significantly affect the time to diagnosis.

## Chapter 8: Conclusion

Diagnosis delay is a significant concern for children and adolescents with cancer in Ethiopia. To tackle this issue, it is essential to establish a sustainable program that prioritizes early detection, prompt referral, and timely initiation of cancer treatment for pediatric patients. Moreover, it is crucial to raise awareness among caregivers and provide education to physicians and healthcare professionals regarding the symptoms and signs of childhood and adolescent cancers. Collaboration between governmental and non-governmental organizations, societies of pediatric hematology and oncology, and other stakeholders is essential to ensure access to cancer care and the decentralization of treatment.

# Chapter 9: Declarations

## 9.1 Ethics approval

The study received approval from the Research and Ethics Committee (REC) of the Pediatrics and Child Health Department at the School of Medicine, and the College Institutional Review Board (IRB) of the College of Health Sciences, Addis Ababa University.

## 9.2 Availability of data and materials

The datasets used and analyzed are available upon reasonable request from the corresponding author.

## 9.3 Competing interests

We have no competing interests.

## 9.4 Funding: This research has no funding source

## Annex I: የስምምነት ቅጽ ፡ የጥናቱ የመረጃና ስምምነት ሰነድ

ይህ የመረጃና የስምምነት ሰነድ በጥቁር አንበሳ ስፔሻላይዝድ ሆስፒታል ሕክምናና ትምህርት ክፍል በ Solid tumors ካንሰር በሽታ ለሚታመሙ ሕጻናትና ልጆች በሽታቸዉ ታዉቆ ፡ ህክምና እስከሚጀምሩ ደስታ ድረስ ያለዉን የጊዜ ሂደት ያጠናል። ህመሙ ከጀመረበት እስከ የመጀመሪያ የጤና ማዕከል ጉብኝት ፡ ከጤና ጣቢያ እስከ አጠቃላይ

ሆስፒታል፤ ከአጠቃላይ ሆስፒታል እስከ ካንሰር ሚዕከል እስከሚደርሱ ያለዉን የጊዜ መጉላላትና ምክንያቶች በጥልቀት ይዳሰሳል። በጥቁር አንበሳ ሆስፒታል የህፃናትና የልጆች ህክምና ትምህርት ክፍል ከደረሱ በኋላ

በሽታዉን ለማወቅና ህክምና ለመጀመር የሚፈጅባቸዉን ጊዜና ምክንያት በጥልቀት ይመረምራል።

**የጥናቱ መነሻ ሐሳብ እና አላማ**

ይህ ጥናት ጥቁር አንበሳ ሆስፒታል በህፃናት የካንሰር ትምህርት ክፍል ሚታከሙ ህፃናት

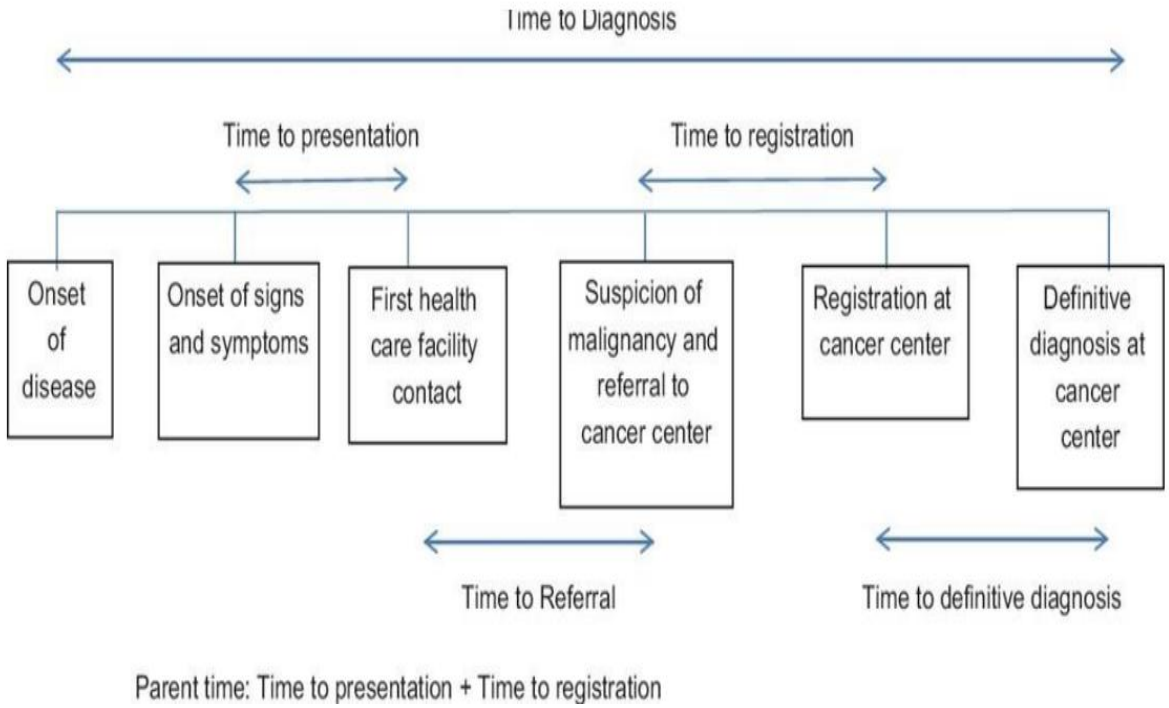
ከበሽታው ጋር ተያይዞ የሚደርስባቸውን የህክምና መጉላላትና ተያያዥ ምክንያቶች

ያጠናል። የጥናቱ አላማ ታካሚዎች ላይ የሚደርሰውን ጫና በመረዳት አስፈላጊው ድጋፍ

እና ትብብር የሚያገኙበትን ሁኔታ መፍጠር ነዉ።።

(እባክዎትን ከዚህ በታች ያለዉን ሰዕል ለአስታሚሚዉ በማስረዳት የጥናቱን ዓላማ

ያስረዷቸዉ።)



ከእርሶ ምን ይጠበቃል?

በጥናቱ ለመሳተፍ ከፈቀዱ ስለእርስዎ የማህበራዊ ሁኔታና ስለ ልጅዎ የጤና ሁኔታ መረጃ ይሰጣሉ። በጥናቱ ላይ በመሳተፍ የሚያጋጥሙ ስጋቶች ልጅዎ ወይም እርሶ በዚህ ጥናት በመሳተፋችሁ የሚደርስባችሁ አንዳችም ጉዳት አይኖርም፡፡

ምሥጢር ስለመጠበቅ የጥናቱ የተሳታፊዎችን መረጃም ሆነ ማንነት በምሥጢር የሚጠበቅ ይሆናል በመሆኑም የተሳታፊዉ ስም በጥናቱ መጠይቅ ላይ አይካተትም።

በጥናቱ ለመሳተፍ ስላለመፈለግ ወይም ተሳትፎን ስለማቋረጥ

በጥናቱ እንዲሳተፉ አይገደዱም፡፡ እንዲሁም ተሳትፎዎን በማንኛውም ጊዜ ማቋረጥ ይችላሉ፡፡ በመሳተፎ ራስዎን ወይም ልጅዎን በተመለከተ መግለፅ የማይፈልጉት መረጃ ካለ እንዲገልፁ አይገደዱም። በጥናቱ መሳተፍ ባይፈልጉ በልጅዎ የህክምና ክትትል ላይ የሚያሳድረው ምንም ዓይነት ተጽእኖ አይኖርም፡፡

የጥናቱ ጥቅም ከዚህ ጥናት የሚገኘው መረጃ በጥቁር አንበሳ ስፐሻላይዝድ ሆስፒታል ለሚታከሙ የሕጻናት የካንሰር ህመምተኞች የሚደረገውን ህክምና እና ክትትል ለማሻሻል ይጠቅማል። በጥናቱ ወቅት ጥያቄ ቢኖሮት ማንኛውም ጥያቄ ካሎት ከዚህ በታች በተገለፀው የዋና ተመራማሪ አድራሻ በመጠቀም መጠየቅ ይችላሉ። የስምምነት ሰነድ ልጁ/ ልጅቱ በዚህ ጥናት እንዲሳተፍ (እንድትሳተፍ) ፈቃደኛ ስለሆኑ ለትብብርዎ በቅድሚያ እያመሰገንን ከበታች በተዘጋጀው ቦታ ላይ እንዲፈርሙ በትህትና እንጠይቃለን፡፡ከዚህ በታች ስምና ፊርማዬ የተገለፀው ግለሰብ ከላይ የተገለፁትን መረጃዎች በማንበብ እና በመረዳት የጥናቱ ተሳታፊ ለመሆን ተስማምቻለሁ፡፡

ፊርማ:_____ ቀን፡_____

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## Annex II: Study Questionnaire: TIME TO DIAGNOSIS (TD) AND FACTORS ASSOCIATED WITH DELAYED DIAGNOSIS IN CHILDREN WITH SOLID CANCER AT TERTIARY REFERRAL HOSPITAL, ADDIS ABABA, ETHIOPIA

I. **Socio-demographic data of the patients**

1. Age of child at diagnosis (Years/Months) ———— MRN= _____ Phone number= ———
2. Sex of the child 1. Male 2. Female

3. Birth order (First, second, third……. child)= ———— 4.

Family size (Total number of children) = ————

5. The region from which the child referred

A. Amhara B. Oromia C. SNNPR D.Tigray E. Addis Ababa F.Afar

G. Harar H. Gamblla I. Benishangul J. Somali K. Others (specify) _____

6. Religion A. Orthodox Christian☐ Muslim ☐ Protestant ☐ Catholic☐ Other

specify_____

7. Primary Caregiver Mother ☐ Father ☐ Both parents ☐ Adult relative☐ Non-relative adult☐

Orphanage ☐

8. Primary caregiver's highest level of education No formal education ☐ Can read and write☐

Primary education (attended grades 1-8) ☐

Secondary education (attended grades 9-12) ☐

College level education☐

9. Income per month= _____

**II. Medical History and delay of the patient with childhood cancers**

10. Date of first symptom noticed/detected (DD/MM/YY)= ———

11. Duration of illness in days before an initial visit to nearby health ——— 12. Date of

the initial visit to the nearby health care facility (DD/MM/YY) ———

13. Reasons for delay provided by parents/caregivers:

1. Lack of parent awareness of at initial presentation or association the disease with some

accidental events

2. Financial constraints leading to delayed seeking referral or workup

3. The patient took alternative treatment (traditional ways)

4. Poor general condition of the patient

5. Disagreement among family members about the Child treatment

6. Others (Specify)

14. Number of health-care facility visits before TASH ———

15. Date of referral to TASH (DD/MM/YY) ———

16. Days stayed before coming to TASH after the referral ———

17. Travel time in (Days) to reach to TASH ———

18. Reasons for delay referral from the primary visiting health institution

1. Financial constraints leading to delayed seeking referral or workup

2. Patient took alternative treatment (traditional ways)

3. Children managed for wrong diagnosis

4. Multiple referral

5. Poor general condition of the patient

6. Patients dissatisfied, wanting early response to treatment

7.Disagreement among family members about the Child treatment

8. Diagnosis doubt in the visiting primary center

9. Others (Specify)

19. Date of enrolment to TASH /registration at TASH (DD/MM/YY)———

20. Working diagnosis at referral center_____

21. Source of referral to TASH

1. Health center

2. District hospital

3. General hospital

4. Private clinic/hospital

5. Tertiary referral Hospital 6. Self-referred

22. Length of stay - admitted at Hospital(in-patient) before referral to TASH ———

23. Date of final diagnosis confirmed (DD/MM/YY) ——— 24. Date of treatment initiation

[DD/MM/YY]= _____

25. Gaps between the date of final confirmed diagnosis and initiation of treatment in days ——

26. Reasons for delaying initiation of treatment once the patient is enrolled at TASH

Waiting for diagnostic work-up ☐ Bed not available ☐ Waiting for Biopsy result ☐

Decision not given ☐ Waiting for MDT decision ☐ Financial reasons ☐

Parents not decided on treatment ☐ Chemotherapy medications not available ☐

Others ☐ specify_____

27. Major presenting symptoms: _____

Fever☐ bone pain☐ epistaxis☐ easy fatigability☐

Abdominal swelling☐ Leucorrhea ☐ Back swelling ☐ Swelling over the extremity ☐ Neck swelling☐

Visual loss ☐ Gait disturbance ☐ cough ☐ shortness of breath☐ others_____

28. Sites of tumor:

1.Brain/Spinal cord 2.Head and Nec 3.Chest/trunk 4.Abdomen 5.Pelvic/genitalia 6.Extremity

7. Lower back swelling 8. Other (Specify) : _____

29. Anthropometry: Weight _____ Height/length _____
MUAC_____W/H_____H/A_____BMI_____

Index=

30. Did they present with Oncologic emergencies while presenting at TASH? yes ☐ No ☐

31. If they present with which oncologic emergencies (choose)

A. Tumor Lysis Syndrome B. Infection [specify the focus] _____

C. Superior mediastinal syndrome/SVCS D. Abdominal compartment syndrome E. Acute Kidney Injury F.

Raised ICP / Hypertension G. Seizure H.Body weakness (paralysis)

I. Bowel/Bladder incontinence J. Others (Specify) _____

32. Confirmed Diagnosis=_____

33. Means of Diagnosis confirmation:

A.Tissue diagnosis B. FNAC C. MRI D. CT SCAN E. U/SOUND F. X -RAY

G. Immunohistochemistry H. Cytology I. Biochemical (VMA,HVA/AFP and B-HCG I.

Others (Specify

34. Metastatic Work up:

A. Bone marrow Aspiration /Bone Marrow Biopsy _____

B. CHEST CT SCAN _C. CXR _____ D. U/sound _____ E. Brain/Spinal MRI_____

F.CSF Cytology (CSF1/2/3) ____

35. Stage of the disease=

Stage I ☐ II ☐ III ☐ IV ☐ localized ☐ Metastatic ☐

36. Treatment Intent Curative Intent ☐ Palliative intent ☐

37. Do they have 'Tena Medhin' or social insurance? A. Yes B. No

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