

ADDIS ABABA UNIVERSITY
COLLEGE OF HEALTH SCIENCE
SCHOOL OF NURSING AND MIDWIFERY

**FACTORS INFLUENCING DELAY TO DIAGNOSIS AND
TREATMENT AMONG PEDIATRIC ONCOLOGY
PATIENTS AT BLACK LION SPECIALIZED HOSPITAL,
ADDIS ABABA ETHIOPIA 2019.**

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A THESIS SUBMITTED TO THE SCHOOL OF GRADUATE STUDIES
OF ADDIS ABABA UNIVERSITY COLLEGE OF HEALTH SCIENCE,
DEPARTMENT OF NURSING AND MIDWIFERY IN PARTIAL
FULFILMENT OF THE REQUIREMENTS FOR THE DEGREE OF
MASTER OF SCIENCES IN NURSING SPECIALITY IN CLINICAL
ONCOLOGY

JUNE, 2019

ADDIS ABABA, ETHIOPIA

Acknowledgements

First and for most, I would like to say thank you to the almighty God for his endless help throughout my life. Next, my special thanks go to my Advisors, Dr. Hussen Mekonnen and Ms. Nete Tewfik for devoting their precious time in providing constructive comments and advice which finally helped me to prepare this thesis.

I would like to express my sincere gratitude to the parents of children Cancer patient dedicated their time to respond to these questions because without their participation, this study would not have been possible.

I would like to thank Mr. Negalign Getahun coordinator of oncology department for his valuable support and advice, from start of topic selection to end of proposal development.

I would like to extend my deepest gratitude to AAU College of health science and my heartfelt thanks also go to black lion specialized hospital oncology department staff members, data collectors, friends and those helped me by collecting and analyzing data throughout this thesis.

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Abbreviations and Acronyms

ALL	Acute Lymphoblastic Leukemia
CI	Confidence Interval
FMOH	Federal Minister of Health
GLOBOCAN	Global Cancer Incidence Mortality and Prevalence
HCS	Health Care System
IQR	Inter Quartile Range
LMIC	Low And Middle Income Countries
LICs	Low Income Countries
MICs	Middle Income Countries
MOH	Ministry Of Health
NHL	Non-Hodgkin Lymphoma
QOL	Quality Of Life
STAT4	Signal Transducers and Activators of Transcription
BLSH	Black lion Specialized Hospital
WHO	World Health Organization

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SUMMARY

Background: The worldwide incidence of childhood cancer is increasing and has become the leading cause of disease-related mortality in the developed countries. In high-income countries, more than 80% of children with cancer are cured, but in many low and middle-income countries only 20% are cured, including Ethiopia. Delay in diagnosis and treatment of cancer patients may impact on poor prognosis and quality of life. In this study delay as classified in factors related to the patient and health care systems.

Objective: The aim of this study was to assess factors influencing delay to diagnosis and initiation of treatment among pediatric oncology patients attending at black lion specialized hospital oncology unit, Addis Ababa, Ethiopia, 2019.

Methods: This study was an institutional based cross-sectional study conducted on 244 pediatric cancer patients from February to April, 2019. Data was collected using structured questionnaire from parents or caregiver of the children through interview and supported from medical reviews. Bivariate and multivariate analysis using Odds ratio (OR) was utilized to evaluate association between dependent and independent variables. All statistical analysis was performed using STATA (Version 14), and statistical significance was set at $P < 0.05$.

Result: In this study 244 children participated in which the response rate was 100%. The mean age of child was 6.4 years ($SD \pm 3.2$). With regards to prevalence of delay, 127(52.0%) were patient delay (> 30 days) and 104(42.6%) were having health system delay (>30 days). Factors that were the predictor of patient delay include: age, place of residence, diagnosis of the child and visit to traditional hillers showed significantly associated ($P < 0.05$). Similarly, factors that were predictor of health system delay which were health insurance and child first seen in health center showed significantly associated ($p < 0.05$).

Conclusion and Recommendations: The median Health care system related delay in our study was longer than patient-related delay. Design health education strategies to increase the level of awareness of the early signs of cancer among parents and the importance of early presentation at health facilities is recommended to condense patient delay. As a result, the education of health professionals on the symptoms suspicious of childhood cancer and timely investigation of suspicious clinical features for early diagnosis and initiation of definitive treatment is strongly indicated.

Keywords: pediatric oncology, cancer, delay to diagnosis, delay to treatment.

1. INTRODUCTION

1.1. Background

Cancer is a term used for the malignant, autonomous and uncontrolled growth of cells and tissues. According to the World Health Organization (WHO) Global cancer (GLOBOCAN) statistics report an estimated 18.1 million new cancer cases and 9.6 million deaths occurred in 2018. Accounting for more than 70% of these cancer deaths occur in low and middle-income countries (1).

Childhood cancer is one of the most common health problems in the world and Childhood cancer is the second cause of death in the world (2). It is estimated that around 250,000 children are diagnosed with cancer every year and 80,000 deaths annually from childhood cancer worldwide(3). Higher incidence of childhood cancer occurred in the low and middle income countries compared to the developed countries (4). There was wide international variation on the survival of childhood cancer, currently the survival rate of childhood cancer is around 80% in high-income countries while in low and middle-income countries (LMICs), survival rates are currently 10% in low income countries (LICs) and 30% in middle-income countries (MICs). Ninety percent of childhood cancer death occurs in low and middle income countries because of delay in diagnosis, and no or inadequate treatment. However, More than 80% of children with cancer worldwide live in LMI countries (5, 6).

In the United States in 2017, Approximately 1.69 million new cases of invasive cancers are diagnosed annually. It is estimated 10,590 new cases children are diagnosed with cancer among children from birth to 14 years, and about 1,180 children are expected to die from the disease (7). In Africa, an estimated 70,000 new cases of children with cancer are diagnosed every year (8), and the incidence varies across the continent ranges from 45 per million in South Africa and 29.4 per million in Namibia (9, 10).The most common childhood malignancies in Africa are Burkitt lymphoma, non-Hodgkin lymphoma (NHL), retinoblastoma, rhabdomyosarcoma and Wilms tumor (11).

Studies in Ethiopia on the epidemiology of childhood cancer in particular are scarce. According to GLOBOCAN report, cancer incidence in Ethiopia is up to 150,000 cases

per year and currently cancer accounts for 4% of all deaths (12). In Ethiopia about 3,707 new cases of pediatric cancer diagnosed every year. The most common childhood cancers in Ethiopia are leukemia, lymphoma, Wilm's tumor and retinoblastoma (13). A majority of childhood cancers are diagnosed at an advanced stage of disease because of late presentation and mortality rates account close to 90% in developing countries including Ethiopia (14).

Factors contribute to diagnosis and initiation of treatment delay is due to patient-related, health care systems and disease related factors. Patient-related factors to early diagnosis and initiation of treatment includes sex of the child, age of the child and socioeconomic background of the child and parents. Health care system factors include access to services, skill of health service providers, waiting time and availability of diagnostic and treatment capabilities and disease related factors are cancer type, symptom, cancer stage mainly related to its clinical presentation and progression (15, 16).

Early diagnosis and timely start of treatment can improve survival and quality of life (QOL) of children with cancer. Early diagnosis of childhood cancer is a key factor in improving the outcomes of cancer treatment because it gives opportunity for timely initiation of appropriate treatment. Many childhood cancers have a high chance of cure if diagnosed early and treated adequately (15, 17).

1.2. Statement of the Problem

Every year, around 160,000 new cases and 90,000 deaths occur in children under the age of 15 due to cancer worldwide and 90 % deaths of children with cancer occurs in low and middle income countries(18). In Sub-Saharan Africa, there are high mortality rates of childhood cancer; survival rate of children with cancer being less than 10%. Several specific challenges to improving survival include advanced-stage of the disease at presentation, misdiagnosis, and failure to start or complete treatment, inadequate hospital infrastructure and medications, lack of trained health care providers (19).

In south Africa, The main reason for delay in diagnosis of childhood cancer is the failure of health care practitioners to identify the warning signs (20). In Morocco, patient related factors for delay of early diagnosis of childhood cancer was residential area, contacting non-medical person, lack of awareness about the disease, economical problem, and poor knowledge of pediatric cancer, symptoms, and causes (21).

In Kenya childhood cancer patient related factor , more than 65% patients associated with advanced stage due to Late presentation and 70 % of healthcare system factors associated with advanced stage at diagnosis (22).

The majority of children with cancer in developing countries are diagnosed too late because of economical problem, low education status of parents , belief in traditional medicine, lack of referral pathways and lack of knowledge among the health-care workers provides a barrier to the ultimate diagnosis resulting in reduced survival, more aggressive disease state and fewer treatment options (23, 24).

Early diagnosis immediately followed by initiation of effective treatment is essential in the care of children with cancers. Most children seek consultation only when the disease is already at an advanced stage. In Ethiopia showed that more than 68.8% diagnosed at advanced stage of the disease indicating delay in seeking diagnosis and treatment (25). The key strategy in reducing childhood cancer related mortality, improving parent's awareness about childhood cancer early detection methods. This is very important because an excellent prognosis is directly associated with the stage at which the tumor is initially detected and how the tumor is localized .This all show the need of information on

identifying the factors influencing to late diagnosis of childhood cancer may help the community to reduce the chance of getting the disease and for better outcome of cancer treatment. If not there will be increase morbidity and mortality in the country. The major health problem not yet given priority, cancer control programs, the provision of early diagnosis and treatment services are limited. In Ethiopia where there is a limited oncology diagnosis and treatment service, trained medical personnel, adequate facilities, and a sufficient supply of essential anticancer drugs. Those have a great contribution for late diagnosis and treatment of cancer in Ethiopia (26).

During the search of literature, there is no published data from Ethiopia; and no document particularly relevant studies on the factors that affect late diagnosis and initiation of treatment in pediatric oncology patients. Therefore, the findings from this study help to identify the factors that influence delay to diagnoses and treatments among pediatric oncology patients.

1.3. Significance of the study

The results from this study will help in awareness creation programs among communities about childhood cancer. Member of communities at different level must be aware of specific cancer symptoms, understand the urgency of these symptoms to minimize mortality and morbidity due to delay for diagnosis and treatment. The findings from this study will also have importance at healthcare level and may help as key information in order to improve early symptom recognition and timely diagnosis and initiation of definitive treatment with symptoms suspicious of childhood cancer that might down stage the diseases cost effectively to improve the overall survival and quality of life of patients and families.

The results of the study will help to improve effective strategies to shorten delays in childhood cancer diagnosis and timely initiation of appropriate treatment. Successful shortening delay of the diagnosis and treatment periods will ultimately lead to improved prognosis of childhood cancer in Ethiopia. It will also helpful in providing information as baseline for future studies.

2. LITERATURE REVIEW

2.1. Childhood Cancer and Classification

Cancer is one of the main causes of morbidity and mortality worldwide, especially in developing countries. Worldwide, around 160,000 new cases and 90,000 deaths occur in children under the age of 15 due to cancer every year. Childhood cancer is the second cause of death in the world that overcomes only accidents(18).

According to the global Classification of cancer in children, leukemia, (34%), brain tumors, (23%), and lymphoma (12%) are the three most common diagnoses in children under the age of 15 (27).Several patterns of pediatric malignancy distributions have been reported in LMIC. Burkitt lymphoma, non-Hodgkin lymphoma, retinoblastoma, rhabdomyosarcoma and Wilms tumor are the most common malignancies in children in Africa, compared to Asian countries, such as India and Pakistan, where leukemia is the most common malignancy(11).

1.2 Incidence and Mortality of Childhood Cancer

In the United States in 2017, Approximately 1.69 million new cases of invasive cancers are diagnosed annually. It is estimated 10,590 new cases children are diagnosed with cancer among children from birth to 14 years, and about 1,180 children are expected to die from the disease (7).

The study conducted in Denmark In 2015, the annual incidence ranged from 15.5 to 22.2 cases per 100,000 children under the age of 15 years. The survival rate of 5 years for all types of cancer diagnosed between 2003 and 2014 was 74% and the survival rate of 5 years increased significantly from 72% in 1985 to 86% in 2014(28).

On the other hand a study in Iran, the incidence of childhood cancer was 48 upto 112 and in girls and boys 51 upto 144 million. The most common cancer in children aged 0 to 14 years was leukemia (incidence rate 8 to 62 million), lymphoma (3 to 23) and brain tumors (3 to 22). Cancer mortality among children in 2004 was 42 and 49 million for girls and boys(29).

Study done in India was the incidence rates for boys ranged from 18.6 to 159.6 per million and among girls from 11.3 to 112.4. Leukemia and lymphoma were the most common malignant tumors in boys, while leukemia and brain tumors were more common in girls. In India, cancer is the ninth leading cause of death among children between 5 to 14 years of age(30).

The current incidence of childhood cancer in many other African countries is not known. But Study done in Namibia was the incidence of childhood cancer was 29.4 per million. Leukemia (22.5%) and retinoblastoma (16.2%) were the most common tumors, with renal tumors, soft tissue sarcomas and lymphomas following in frequency(9).

In Ethiopia approximately 3,707 new cases of pediatric cancer every year with leukemia being the commonest cancer (29%), followed by NHL, Wilms tumor, and retinoblastoma. Acute leukemia accounted for 89% (of which 91% was acute lymphocytic leukemia and 9% was acute myeloid leukemia) of all the leukemia cases in children(13). Mortality rates for most pediatric cancers are close to 90% in developing countries, including Ethiopia(14).due to a low level of awareness about cancer among clinicians and the population, inadequate access to health care, cost of care, lack of diagnostic equipment and availability of cancer treatment (31).

2.3. Factors affecting delay to diagnosis and treatment Related to Patient

2.3.1. Socio Demographic Characteristics

Socio demographic data is the most important factor influencing in diagnosing cancer in children. Most studies time to diagnosis was older patients have a significantly higher risk for a delay of diagnosis than younger patients.

A study done in Mexican showed that there was a statistically significant association between patient delay and age; found that children between ages 10 and 14 had about 1.8 times more likely to be delayed as compared to the children under 1 year of age(32).This result is similar with a research done from Peru the retrospectively study done in 2016 with sample size of 284 children showed that age of the patient was found as a risk factor for patient delay (33).

The study done in Egypt retrospective with sample size 172 children there was a significant association between age and patient delays showed a significant difference between the age group of less than 5 years (49.4%), followed by 5 and 10 years of age (41.3%) and the lowest among greater than 10 years of age (9.3), larger patient delay was found for the patients 5–10 years of age are longer patient delay as compared children's of the age group of 0-5 years. Other statistically significant association was shown for lower parental education status and socioeconomic level also showed a significant statistical association with patient delay. Other factors such as family size, residence were not statistically significant associated (34).

The other cross sectional study done in Canada with sample size of 1360 Children showed that there was a significant association between age of the patient and patient delay. Children older children are longer patient delay than younger children but not associated with Health care system delay. Other factors such as sex, education level and occupation and residence were not statistically significant associated (35).

A Crosse sectional study in Nigeria showed that it was found that children's the age group 15-17 are longer patient delay as compared children's of the age group of 5-9 year. Other factors such as sex, education level and occupation and socioeconomic groups were not statistically significant associated (36).

Statistically significant differences in diagnosis delay between male and female patients was observed in only 2 of 9 studies (15). For example Hospital based retrospective study in Singapore showed that Out of the 146 patients found a slightly higher risk for delayed diagnosis was significantly longer for male patients as compared to female patients. Other factors such as patient age, diagnosis or parental education had no significant (37).

Study done in Canada a prospective cohort study showed that There was a statistically significant association between Family income with patient and health care system(HCS) delay, although the effects different by disease. For example leukemia patients, there was a greater risk of patient delay in the two higher income groups compared to the lowest income group. In contrast to these findings, leukemia patients of families in the highest income category had a lower risk of physician delay than those in lowest income families.

Age was positively associated with patient delay for both leukemia and lymphoma patients, but not with HCS delay (35).

A study done in Israel a Retrospective Study of 315 Children showed that there was a significant association between the father's age and patient delay. Children of younger fathers were diagnosed earlier. Diagnosis was also achieved earlier in children of younger mothers ($p < .01$). The mean and median delay times were longer as the mother's age was higher (38).

The burden of traveling from the patient's place of residence to health professionals is a significant problem that can affect access to diagnosis and treatment of cancer (39). Study done in Southeastern Turkey showed that, place of residence was the only demographic or socioeconomic factor significantly associated with a patient delay (40).

2.3.2. Awareness of parent's

2.3.2.1. Awareness about the disease

Parents may wrongly believe cancer is incurable or associate cancer treatment with death or pain, resulting in delays in or not pursuing care.

The cross sectional study done in Kenya In total 81 parents (82%) had heard of cancer before their child had been diagnosed with cancer. These parents perceived cancer to be curable (61%), incurable (37%) or unsafe (3%) (41). Similar study done in Bangladesh among 171 children, it was found 92% had parents who heard about the childhood malignancy previously were more timely to bring their children to the doctor cancer and 53.2% had poor knowledge of the cancer to be curable (42).

The other cross sectional study done in Uganda and western Kenya showed that, knowledge of the study participants about cancer was poor and only 5% in Kenya and 19% in Uganda heard about cancer. These parents perceived cancer to be curable (Kenya 65%, Uganda 53%)(43).

2.3.2.2. Belief in Alternative treatment

The study done in Kenya After noticing symptoms of the child, 58 parents (59%) sought alternative treatment for their children: prayer ceremonies (41%), herbalist visit (36%), and attending traditional healer (3%). Use of alternative medicine resulted in significantly longer patient delay and delay in diagnosis and treatment (41). Similarly study done in Indonesia cross-sectional study with sample size 145 children, from this child's symptoms, 115 parents (79%) used alternative treatments. Use of alternative treatment was associated with significantly longer patient delay and total delay(44).

2.4. Factors affecting delay to diagnosis and treatment related to disease

The timely diagnosis of cancer in children is made difficult because of the rarity of the disease and the nonspecific presentation of symptoms. Some studies found that cancer type was an important factor related to diagnosis delay(15). Total times to diagnosis were each significantly associated with histological tumors type of cancer in all studies. For example study done in Nigeria a Cross-sectional study with sample size 90 children acute lymphoblastic leukemia (ALL) had the shortest median at diagnosis 30 days while Hodgkin's disease had delayed as compared to the children among the tumors diagnosed(36). In a study done in Canada a prospective cohort study Patients with ALL had a higher risk of patient delay than non-lymphoblastic leukemia patients. Conversely, in lymphoma, types of cancer was related to Health care system delay, but not patient delay(35).

In the study conducted in Indonesian cross-sectional study with sample size 145 children. The cancer type significantly affected the doctor, diagnosis, treatment, HCS and general delay. Hematological malignancies attend were the most recurrent diagnosis, including 76% of cases. Type of malignancy had a statistically significant association with patient delay, Health care system delay and total delay. Neurological tumors had the longest median Health care system delay and total delay Neurological tumors had the longest delays, while hematological tumors had the shortest(44).

The other study done in turkey a retrospective analysis was performed on 380 children Parent/patient time was significantly longer for children with testicular tumors. Children

with renal tumors, neuroblastoma, and Soft tissue sarcoma had significantly shorter parent/patient time and Time to diagnosis. In children with germ cell and bone tumors, both the patient delay and delay to diagnosis were longer delay ($P = 0.006$ and 0.023 , respectively). The longest median Time to diagnosis was recorded for children with germ cell tumors (125 days) and retinoblastoma (121 days) while the shortest was in children with renal tumors (25 days)(45).

Studies have observed that the initial presentation of symptoms is related to diagnosis delay. The rarity and nonspecific clinical presentation of symptoms influenced parent delay in seeking medical advice and physician delay in reaching diagnosis. For example study done in Switzerland Patients with symptoms of increased intracranial pressure had a shorter diagnosis delay and physician delay than other patients(46).

Disease stage at diagnosis is an important factor to consider because it is a possible indicator of chronology of disease progression and a determinant of the collection of signs and symptoms. A study conducted in Brazil A retrospective cohort study Patients with localized disease had a significantly shorter diagnosis delay than patients with advanced or metastatic disease(47).

2.5. Factors affecting delay to diagnosis and treatment Related to HealthCare System

A study of National reporting and Learning System analysis showed System delay refers to the interval between referral and definite diagnosis or treatment. This includes waiting times for tests in secondary care, further investigations of symptoms in secondary or specialist care, and administration. Waiting times for diagnoses and administrative delays for initiation of treatment and follow up leading to increased patient delays(48).

The study done in Ibadan, Nigeria a retrospective study with 64 children, found a median days of stay from symptom onset to diagnosis of 91 days, patient related delay was 14 median days of stay at home with their symptom and median health system related delay was 61 days(49).

The study conducted in turkey retrospective with sample size 380 children the first medical center contacted was the most significant determinant for physician time. Most of the

patients (77.5%) who first contacted a primary health care center had longer health care system delay. The long health care system delay was detected at a rate of 95.5% for patients living in urban area, with first health professional contact in a primary health care center(45).

A cross-sectional study in Egypt of the 138 children with cancer showed that, from these 116 patients were initially misdiagnosed. Had more than 37 days delay in the diagnosis of childhood cancer. Among the respondents 38 % reported misdiagnosis by the inadequate knowledge of health professional (health care system delay)as the main reason(50).

The other study conducted in Cape Town, South Africa combined prospective and retrospective study of 194 children with cancer from this, 112(58%) patients were misdiagnosed at first. which only 38 patients (34%) were correctly diagnosed and of the remaining 22 patients (8%) there was no information available about how the eventual diagnosis was made(51).

Conceptual framework

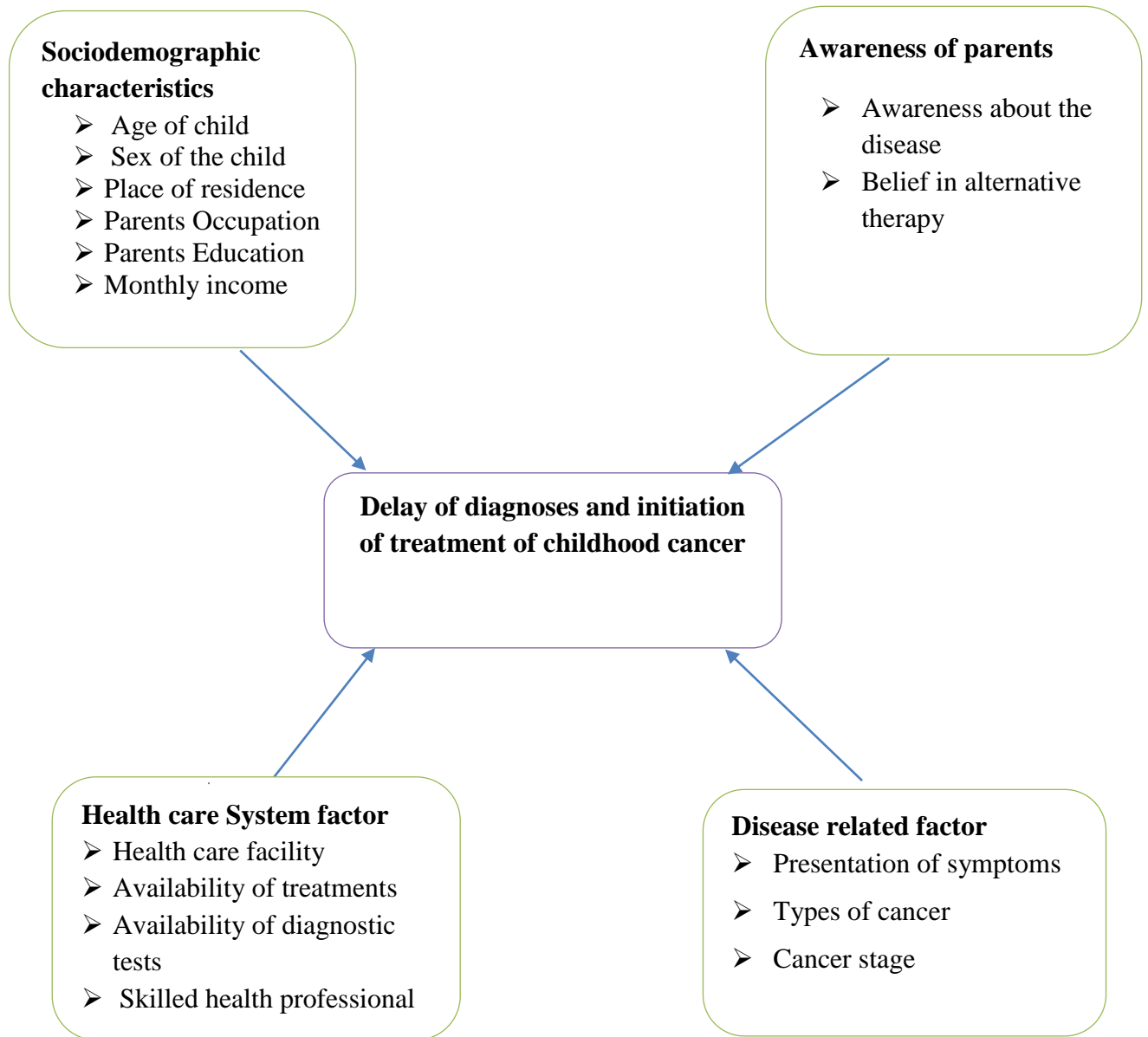


Figure 1: conceptual framework was created based on literature and clinical experience (41, 44, 52).

3. OBJECTIVE

3.1.General objective

- To assess factors influencing delay to diagnosis and initiation of treatment among pediatric oncology patients at black lion specialized hospital Addis Ababa, Ethiopia, 2019.

3.2. Specific objectives

- To identify patient related factors influencing delay to diagnosis and treatment among pediatric oncology patients at black lion specialized hospital.
- To identify health care system related factors influencing delay to diagnosis and treatment among pediatric oncology patients at black lion specialized hospital.
- To identify disease related factors influencing delay to diagnosis and treatment among pediatric oncology patients at black lion specialized hospital.

4. METHODOLOGY

4.1. Study Area and Period

This study was conducted at black lion specialized hospital (BLSH) oncology unit from February – April / 2019.

The hospital has been inaugurated by the title “Prince Mokonnen the Duke of Harar” Memorial Hospital on 3/11/1973 and merged with the princess Tsehay memorial Hospital on 24/5/1975 by the name of black lion hospital. Black lion specialized hospital is government owned large referral teaching hospital, located in Lideta Sub City. Under the administration of Addis Ababa University, College of Health sciences. Black Lion Hospital is a very large referral hospital and sees approximately 370,000- 400,000 patients a year but the exact number is not known. The oncology center at the Hospital is the only referral center in the country. The hospital currently had 800 beds, of which only 60 are allocated for oncology patient’s form these 30 beds for pediatric cancer patient. According to the registry in the unit, more than 3500 pediatric cancer patient were seen in this hospital per year. This hospital worked as the nation’s only cancer referral center and has been given chemotherapy, radiotherapy and palliative care for patients. In BLSH oncology unit there were six senior oncologists, one palliative care specialist, two are hematologists, two pediatric oncologist, five radiotherapist, four medical physicist and sixteen Bsc nurses and ten oncology nurses specialist working in pediatric unit. Treatments offered at black lion specialized hospital cancer center include anticancer drugs, surgery, and radiotherapy. This study were take place at the pediatric oncology unit which is one of the specialty units of the hospital.

4.2. Study Design

Institutional based cross-sectional study design was conducted.

4.3. Population and sampling

4.3.1. Source Population

All children cancer patients attending at black lion specialized hospital.

4.3.2. Study Population

These children diagnosis with cancer patients visiting the hospital and being evaluated or treated at the unit from February – April 2019.

4.3.3. Sample size determination

Sample size was calculated using single proportion formula. the standardized normal distribution curve value for 95% confidence level (1.96) , taking 50% of proportion because no previous similar study in factors influencing delay to diagnosis and treatment among pediatric oncology patients and taking the margin of error to be 5%.

n= required sample size

z= critical value at 95% CI

p= prevalence rate, p is taken as 50%

d=Margin of error to be 5%

Z = 1.96 P = 0.5 d = 0.05

$$N = \frac{(Z a / 2)^2 p (1-p)}{d^2} = \frac{(1.96)^2 0.5(1-0.5)}{(0.05)^2} = 384$$

Since flow of patients during data collection period is less than 10,000 then correction

formulas was applied. $NF = \frac{n}{1 + \frac{n}{N}} = \frac{384}{1 + \frac{384}{525}} = 222$ NF= desired sample size

n= the calculated sample size N= total population

After adding 10% non-response rate the final sample size was **244**.

4.3.4. Study Subjects

Those children diagnosis with cancer patients visiting the hospital and being evaluated or treated at the unit from February – April / 2019 and who fulfill the eligibility criteria.

4.4. Eligibility criteria

4.4.1. Inclusion criteria

- Pediatric oncology patients under 12 years at diagnosis who had a confirmed histological diagnosis of cancer and were on definitive treatment.
- Those who consented to participate in the study.

4.4.2. Exclusion criteria

- New Pediatric oncology patient's not yet started treatment.
- Unable to fill the questionnaire was excluded from the study.
- Those who did not give consent.

4.6. Sampling Procedures

Tikur Anbessa Specialized Hospital was selected because it is currently the only referral hospital which provides different types of therapy including radiation therapy for cancer patients in Ethiopia.

According to the one-year record of pediatric cancer, 3500 cases were seen in the oncology unit at Tikur Anbessa Specialized Hospital. Since the duration of the study was six weeks, the calculated flow within the study period was 522 and the required sample size was 244 study cases that were come for initiation of treatment and on follow-up during data collection period. Based on systematic random sampling technique every 2 study participants were enrolled in the study during data collection period.

4.7. Study variables

4.7.1. Dependent variable

- Delay in diagnosis and treatment of childhood cancer

4.7.2. Independent variables

- **Socio-demographic characteristics:** age of child, sex of the child, Age of the parents, Income, parent's education level, family size and place of resident.
- **Awareness of parents:** Awareness about the disease and Use of alternative therapy.

- **Health care system factor:** health care facility, Availability of treatments and diagnostic materials and Skilled Health professional.
- **Disease factor:** Types of cancer, symptom and cancer stage.

4.8. Operational definitions

- **Parents or children’s care givers-** is an individual nominated by the patient, and who providing consistent giving care. In this study, Parents or children’s care givers is who are responsible to give information and fill the study questioner about the child during the study period.
- **Patient delay-**is the period from the onset of symptom to the first presentation to a health care provider. Patient delay is when it takes for a patient greater than 01months between his first notices of symptoms to his first clinic visit.
- **Health-care system delay-**is the time taken from the first health care visit to the initiation of cancer treatment. A patient is said to have secondary delay if it takes more than 30 days until he gets the first treatment.
- **Diagnosis delay-**is the period between the first patient health care visits and confirming the diagnosis.
- **Treatment delay-**is the time interval between confirmation of diagnosis and initiation of cancer treatment.
- **Misdiagnosis-** is used when the malignant disease is not the first diagnosis and another benign disease will suspected or an incorrect diagnosis of an illness or other problem.

4.9. Data collection tools

Structured questionnaire adapted from literatures with modification. Data was collected through face to face interview with the parents or caretakers, and was supplemented by the patient’s medical review. The questionnaires were developed in English and translated into Amharic version by language expertise for better understanding of enumerators and the study participants. The Amharic version was translated back to English to ensure consistency. The interview was conducted among outpatient and inpatient departments of pediatric oncology units at black lion specialized hospital. Data was collected by four Bsc

nurses and the data collection process was supervised by two MSc (oncology) nurses. The selection of data collectors and supervisors was based on their previous experience of data collection and training was trained for one day on the objective and methodology of the research and data collection technique. On top of that there were continuous follow up and supervision by the principal investigator throughout the data collection period.

4.10. Data Quality control

Training was given to data collectors and supervisors for about a day on the objective and methodology of the research and data collection technique. During the data collection time close supervision and monitoring was made by the supervisor and principal investigator to ensure the quality of the data. At the end of each day, the collected data was checked for its completeness and logical consistency by supervisor and principal investigator and corrective discussion were under taken for data collection the next day with all the data collectors and the supervisor.

4.11. Pre Test

Pre-test was done on 5 % of the samples in study area and important modification was made on the basis of the findings and pretested subjects were excluded from the actual data collection. The reliability of the instrument was identified by calculating cronbach's alpha using SPSS version 20.

4.12. Data Processing and Analysis

The collected data was coded and checked and entered into Microsoft Excel and cleaned and edited accordingly and transferred to STATA 14 statistical software for analysis and was checked for missing values before analysis. The data was also transformed or consolidated into forms that are appropriate for analysis (continues variables were changed to categorical variables) Descriptive statistics was employed to summarize the data and expressed in terms of frequency and percentage and presented using tables, figure and graphs. Bivariate and multivariate logistic regression was used to determine the association between the determinant factors and delay in diagnose and treatment of children cancer

patients. For all analysis a P-value <0.05 was used as cutoff points for significance association.

4.13. Ethical Consideration

Ethical clearance and paper of approval was obtained from Addis Ababa University, College of Health Science, School of Nursing and Midwifery, Department of Nursing Institutional Review Board (IRB). All participants were get information about the purpose of the study, confidentiality of the information, and the right not to be participated or withdraw at any time. Participants were informed that participating in the study was not harm anyone rather the evidence obtained from their participation was bring an improvement on the implementation for the health of general population.

4.14. Dissemination of the Results

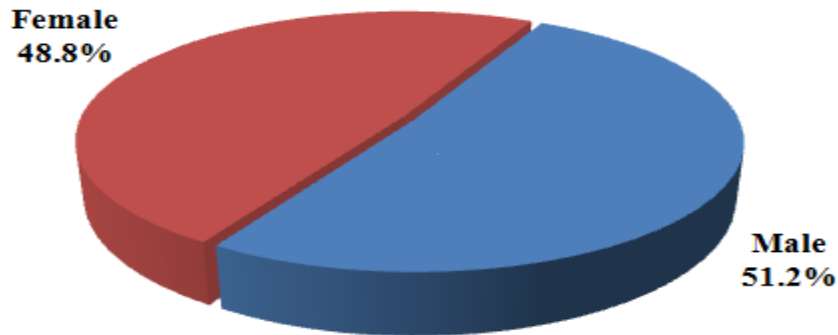
The result of this study will be submitted to Addis Ababa University College of Health science, School of nursing and midwifery, Department of Nursing and it will be disseminate to other concerned bodies like Federal Minster of Health (FMOH), Policy makers, to black lion specialized hospital (BLSH). Furthermore, the paper will be present on workshops, seminars and annual nursing association meeting. Finally, manuscript will be submitted to scientific journals for possible publication.

5. RESULTS

The results of this research were based on 244 participants of the study who successfully completed the interview.

5.1. Socio Demographic Characteristics of Pediatric Oncology Patients

Out of the 244 children, patients recruited 125(51.2%) were males and 119 (48.8%)



females.

Figure 2: Sex Distribution of Pediatric Oncology Patients Attending At black lion specialized hospital, Addis Ababa, Ethiopia June 2019

Patients' age at diagnosis was a mean of 6.4 years (SD = 3.2 years) and Majority 110(45.1%) and 88 (35.7%) of the respondents were in the ages group of 5-9 and 0-4 years respectively. According to the Residence of the children 117 (48.0%) respondents were from urban and the remaining 127(52.0%) were from rural areas. Regarding to region of the respondents 108 (44.3 %) and followed 60 (24.6 %) were from Oromia and Amhara, respectively. most of the parents of children were married 216 (88.5%) followed by divorced 10 (6.6 %).Regarding to parents of the children education, mother level of education (unable to read and write) were the most frequently reported (34.4 %) and father of the children level education Secondary education were the most frequently reported (24.6 %). Regarding to monthly income of the parents of children, 86 (35.2%) had >2000 monthly income. Most families (64.3%) did not have health-insurance when they first came to health facilities and 77.9% lived more than 100 km away from TASH. The socio-demographic characteristics of pediatric oncology patients are presented in the table 1.

Table 1: Socio Demographic Characteristics of pediatric oncology patients at black lion specialized hospital, Addis Ababa Ethiopia, June 2019

Variables	Frequency	Percentage (%)
Sex		
Male	125	51.2
Female	119	48.8
Place of residence(n=244)		
urban	117	48
rural	127	52
Region (n=244)		
Amhara	60	24.6
Oromia	108	44.3
South	32	13.1
Tigray	12	4.9
Addis Ababa	21	8.6
Others*	11	4.5
Age of mother (n=244)		
< 20 in year	2	0.8
21-30 in year	74	30.3
31-40 in year	135	55.3
>40 in year	33	13.5
Age of father (n=216)		
< 20 in year	0	0
21-30 in year	44	18.0
31-40 in year	134	54.9
>40 in year	38	15.6
Marital status (n=244)		
Single	5	2.0
Married	216	88.5
Divorced	16	6.6
Widowed	7	2.9
Mother's education (n=244)		
No education	84	34.4
Primary education	78	32.0
Secondary education	55	22.5
Higher education	27	11.1

Variables	Frequency	Percentage (%)
Father's education (n=216)		
No education	55	22.5
Primary education	55	22.5
Secondary education	60	24.6
Higher education	46	18.9
Mother's occupation (n=244)		
House wife	85	34.8
Government employee	38	15.6
farmer	54	22.1
student	3	1.2
Merchant	15	6.1
Private employee	28	11.5
Daily laborer	21	8.6
father's occupation (n=216)		
Government employee	54	21.2
farmer	91	37.3
Merchant	14	5.7
Private employee	43	17.6
Daily laborer	14	5.7
Monthly income (n=244)		
< 500	7	2.9
501-1500	77	31.6
1501-2000	74	30.3
>2000	86	35.2
Number of children in household (n=244)		
1-2children	84	34.4
3-4 children	136	55.7
>5 children	24	9.8
Do u have Medical insurance (n= 244)		
Yes	87	35.7
No	157	64.3
Distance home to TASH		
<50	21	8.6
50-100	33	13.5
>100	190	77.9

Others*= afar, Harar, Somali, diradawa

5.2. Parent's Level of Awareness

An analysis of the parents of the children level of awareness about cancer and curability of cancer showed that from the total of 244 parents of the children 177(72.5%) of them had never heard about cancer and 67(27.5) had heard about cancer before their child had been diagnosed with cancer. These parents of the children perceived cancer to be curable (59%), incurable (6.1%) or were uncertain (34.8%). The commonest reasons for patient delay were 115(47.1%) of be assumption of healing by itself and 70(28.7) visiting traditional healers and Based on this study after noticing symptoms of the child, about more than half 135 (55.3%) sought traditional healers for their children. Level of awareness parents of the child about cancer are presented in (table 2)

Table 2: parent's level of awareness about cancer among pediatric oncology patients attending at black lion specialized hospital, Addis Ababa, Ethiopia June 2019

Variables	Frequency	Percentage (%)
Previously Heard about cancer		
Yes	67	27.5
No	177	72.5
Cause of cancer		
Bewitchment	17	7.0
Evil eye	14	5.7
Genetic	37	15.2
Infectious	2	0.8
Unknown	55	22.5
I don't know	119	48.8
Cancer is curable		
Curable	144	59.0
Not curable	15	6.1
Am not sure(uncertain)	85	34.8
Visited Traditional Healer		
Yes	135	55.3
No	109	44.7
Reason for delay		
Wasted time using alternative healers	70	28.7
Economical problem	17	7.0
The distance to the hospital was too far	33	13.5
I thought it will relief by it self	115	47.1
Other	9	3.7

Other*: Give priority for others,

5.3. Disease related factor

Regarding to the types of pediatric cancer diagnoses in children at TASH, acute lymphoblastic leukemia was the most common diagnosis with 93 (38.1%) cases, rhabdomyosarcoma accounted for 42 (7.2%) and acute myeloid leukemia accounted for 34 (17.2%) cases respectively. The proportion of respondents diagnosed with cancer at stage I were 15(6.1%) and stage II were 89(36.5%); stage III 99 (40.6%) and stage IV41(16.8%).Disease related factor among pediatric oncology patients are presented in the table 3.

Table 3: Disease Related Factors among pediatric cancer patients attending at black lion specialized hospital, Addis Ababa, Ethiopia June 2019.

Variables	Frequency	Percentage (%)
Types of disease (n=244)		
Acute lymphoblastic leukemia	93	38.1
Acute myeloid leukemia	34	13.9
Rhabdomyosarcoma	42	17.2
Non-Hodgkin lymphoma	15	6.1
Hodgkin Lymphoma	9	3.7
Retinoblastoma	22	9.0
Ewing sarcoma	6	2.5
Wilms tumor	7	2.9
Neuroblastoma	11	4.5
Others*	5	2.0
Stage(n=244)		
Stage 1	15	6.1
Stage 2	89	36.5
Stage 3	99	40.6
Stage 4	41	16.8

Others*= osteosarcoma, testicular Ca, hebatoblastoma

Children suffered from following major symptoms before seeking medical care: neck swelling (29.5%), fever (15.6), fatigue (17.6%), abdominal swelling (9.4), loss of appetite (5.7) and tumor (10.2). (Show in figure 3).

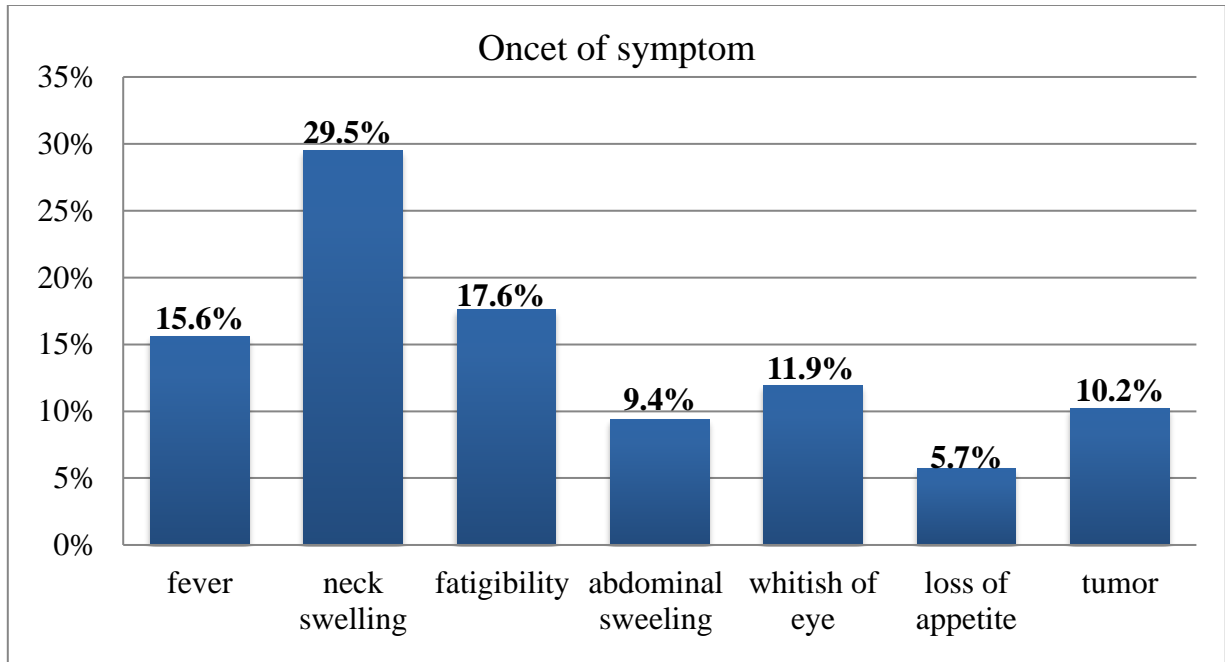


Figure 3: Onset of symptom among pediatric cancer patients attending at black lion specialized hospital Addis Ababa, Ethiopia, June 2019.

In general, in this study, among the children 127(52.0%) were classified as having patient delay with 120 median days of stay at home with their symptom.

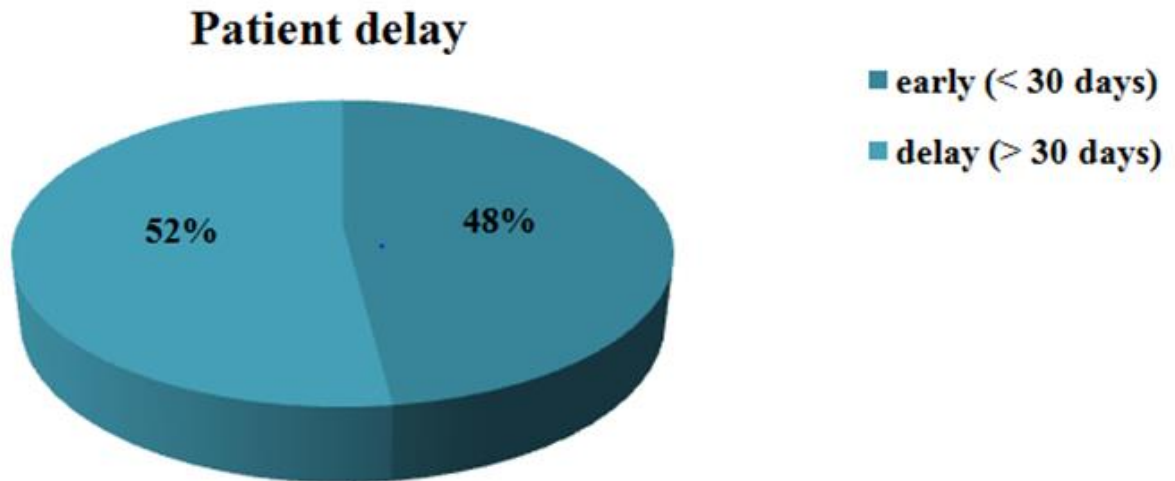


Figure 4: Patient delay at home among pediatric cancer patients attending at black lion specialized hospital, Addis Ababa, Ethiopia, June 2019.

5.4. Health system delay related factors

In this study among participants 179(73.4%) were classified as having health system delay with 210 median days of stay on diagnoses and treatment of pediatric cancer (fig 5). Patients' first contact with a health care facility initially visited when symptoms were first observed, was health center in 60.2 % of the cases, traditional healers in 16.4% of the cases, district hospital in 9.6% of the cases, general hospital in 8.6 %of the cases and private hospital in 4.9% of the cases. Only 6% presented directly to the tertiary health center (show in figure 5)

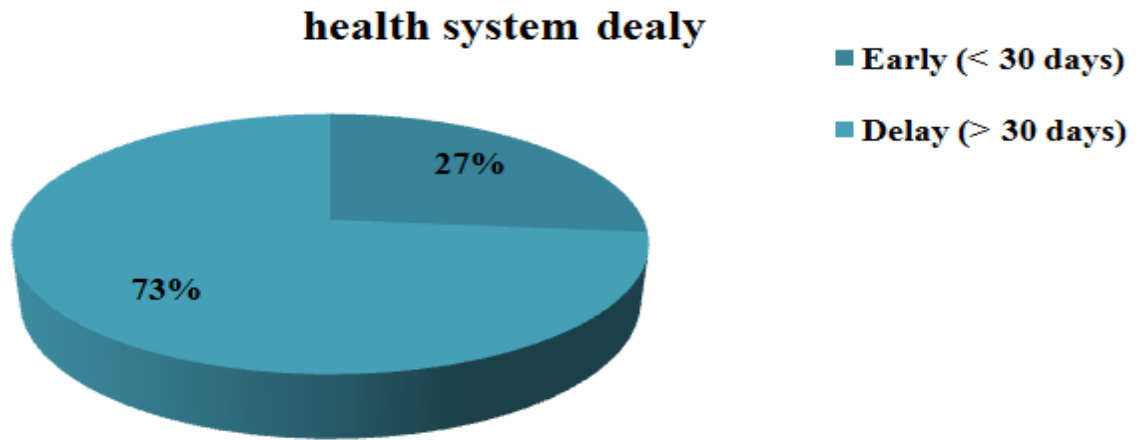


Figure 5: health system delay for Diagnoses and Treatment among Pediatric oncology Patients attending at black lion specialized hospital, Addis Ababa, Ethiopia June 2019.

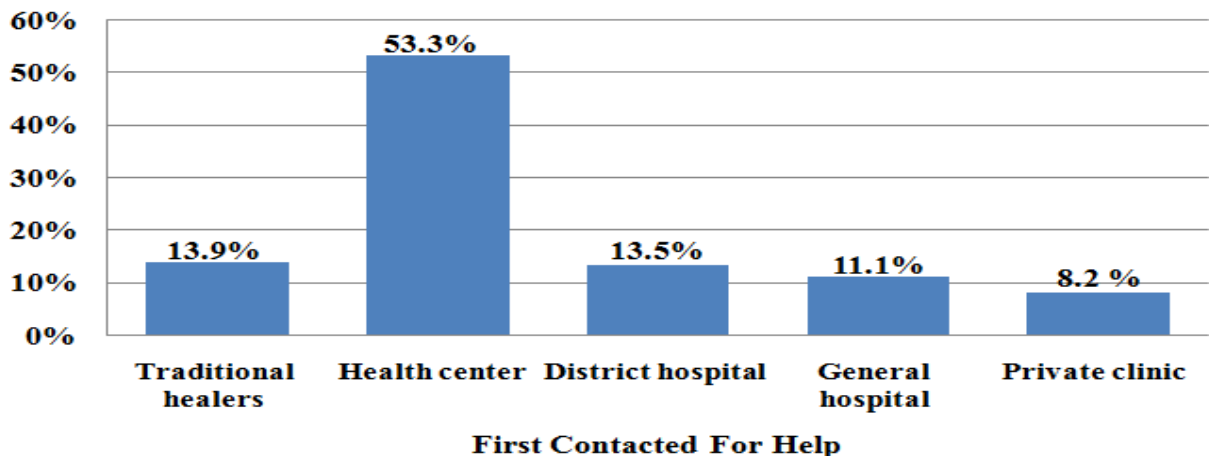


Figure 6: First contacted for help among pediatric oncology patients attending at black lion specialized hospital, Addis Ababa, Ethiopia June 2019

Majority of the participants 111(45.5%), reply the reason for health system delay was reputation of long delays in hospital and also waiting time in the reception indicated by 91(37.3) of the respondents as the reason for late diagnosis and treatment related with hospitals (Table 4).

Table 4: Health system delay related factors among pediatric oncology patients attending at black lion specialized hospital, Addis Ababa, Ethiopia June 2019

Variables	Frequency	Percentage (%)
Initially misdiagnosis		
Yes	144	59.0
No	100	41.0
Total number of visits to health care facilities		
< 2	25	10.2
3-4	183	75
5-6	27	11
>7	9	3.7
The source of referral to TASH		
Health center	13	5.3
District hospital	5	2.0
General hospital	194	79.5
Private clinic	32	13.1
Reason of health system delay		
Lack of cash money at that time	19	7.8
Waiting time	91	37.3
Availability of investigations	23	9.4
Reputation of long delays in hospital	111	45.5

5.5. Associated factors related with patient delay

Bivariate and multivariate analysis was performed between patient delay (dependent variable) and socio demographic factor, parent's awareness and disease related factor (independent variables). Factors like age, place of Residency, diagnosis of the child, father education, parent's awareness about cancer and visiting traditional healers were significant associated to patient delay in binary logistic regression. However age, place of Residency, diagnosis of the child and visiting traditional healers significantly associated with patient related factor delay in multi logistic regression.

In binary logistic regression it was found that had heard of cancer before their child had been diagnosed with cancer are about 2.09times more likely to be delayed as compared had never heard about cancer before their child had been diagnosed with cancer, **COR=2.09(1.17,3.72)**. However, in the multivariate logistic regression analysis there was no significant association.

In multi-logistic regression analysis, it was found that children at the age group of 5-9are about 2.98 times more likely to be delayed as compared to the children under the age group of 0-4, **AOR=2.98, 95% CI (1.35, 6.57)** and those children who came from rural area are about 2.28 more likely to be delayed as compared to the children came from urban, **AOR=2.28, 95% CI (1.07, 4.88)**.

In multi-logistic regression analysis, it was found parents of child Visited traditional healers of 7.85 times more likely to be delayed as compared to the children did not visited traditional healers for their children, **AOR=7.85, 95% CI(3.88,15.89)**.

In multi-logistic regression analysis, Regarding place of residence of patients, living in rural area is 2.28 times more likely to be delayed as compared to the children living in urban area, after adjusting for age, diagnosis of the child, fathers education ,visit traditional healers and heard about cancer **AOR= 2.71, 95% CI (1.61,4.56)**(Table 5).

Table5: Logistic regression analysis of patient delay and related factors among pediatric oncology patients attending at black lion specialized hospital, Addis Ababa, Ethiopia 2019

Variables	Patient delay		Binary and multivariate logistic regression	
	NO	YES	COR (95% CI)	AOR (95% CI)
Age				
0-4	61(70.1)	26(29.9)	1	1
5-9	37(33.6)	73(66.4)	4.62(2.52,8.48)*	2.98(1.35,6.57)*
10-14	19(40.4)	28(59.6)	3.45(1.64,7.26)*	2.54(0.98,6.55)
Dx of the child				
Acute lymphoblastic leukemia	56(60.2)	37(39.8)	1	1
Acute myeloid leukemia	20(58.8)	14(41.2)	1.059(0.47,2.35)	1.33(0.48,3.67)
Rhabdomyosarcoma	11(26.2)	31(73.8)	4.26(1.90,9.52)*	3.80(1.42,10.17)*
Non-Hodgkin lymphoma	5(33.3)	10(66.7)	3.02(0.95,9.56)	4.08(0.99,16.72)
Hodgkin Lymphoma	6(66.67)	3(33.3)	0.75(0.17,3.21)	0.85(0.17,4.33)
Retinoblastoma	6(27.2)	16(72.73)	4.03(1.44,11.26)*	1.79(0.52,6.15)
Ewing sarcoma	1(16.67)	5(83.3)	7.56(0.84,67.40)	4.31(0.36,50.69)
Wilms tumor	5(71.4)	2(28.5)	0.60(0.11,3.28)	0.83(0.13,5.32)
Neuroblastoma	6(54.5)	5(45.4)	1.26(0.35,4.43)	1.84(0.35,9.60)
Others***	1(20)	4(80)	6.05(0.65,56.31)	13.73(0.70,269.16)
Father education				
No education	18(32.7)	37(67.3)	1	1
Primary education	30(54.5)	25(45.4)	0.40(0.19,0.88)*	0.50(0.18,1.35)
Secondary education	33(55.0)	27(45.0)	0.39(0.19,0.85)*	0.61(0.23,1.65)
Higher education	24(52.2)	22(47.8)	0.44(0.19,0.99)*	1.06(0.34,3.22)
Place of residence				
Urban	71(60.6)	46(39.3)	1	1
Rural	46(36.2)	81(63.8)	2.71(1.61,4.56)*	2.28(1.07,4.88)*
Visited traditional healers				
Yes	34(25.19)	101(74.81)	9.48(5.27,17.06)*	7.85(3.88,15.89)**
No	83(76.15)	26(23.85)	1	1
Heard about cancer				
yes	41(61.2)	26(38.8)	1	1
No	76(42.9)	101(57.1)	2.09(1.17,3.72)*	1.88(0.84,4.20)

Significantly association at P* value<0.05 and p** value<0.001

*** Osteosarcoma, testicular Ca, hebatoblastoma

5.6. Associated Factors Related With Health System Delay

Bivariate and multivariate analysis was performed between patient delay (dependent variable) and socio demographic factor, parent's awareness and disease related factor (independent variables). Factors like age, medical insurance, visiting traditional healers, misdiagnosis during first visit and first contacted for help were significant associated to health system delay in binary logistic regression. However medical insurance and first contacted for help were significant associated to health system delay in multi logistic regression.

In binary logistic regression children who visited to traditional healers were 0.45 less likely to delay as compared with children did not visit the traditional healers, **COR=0.45(0.25, 0.82)**. While in multivariate logistic regression analysis there was no significant association.

In binary logistic regression it was found that children's the age group 5-9 are about 2.87 times more likely to be delayed as compared children's of the age group of 0-4, **COR=4.17(2.29,7.59)**. However, in the multivariate logistic regression analysis there was no significant association.

In multivariate analysis first contacted health center for help 16 times more likely delay as compared with first contacted private clinic, after adjusting for age, medical insurance, visit traditional healers and initially misdiagnosis **AOR= 16.13(4.00,65.03)**.

In multivariate logistic regression analysis it was found that children's did not have health insurance at the time of diagnosis about 5.52 times more likely delay compared with have health insurance at the time of diagnosis, after adjusting for age, first contacted for help, visit traditional healers and initially misdiagnosis **AOR= 5.52(2.61,11.69)**.

According to this study, sex, place of resident, diagnosis of the child, stage, parent's educational status, parent's occupational status, marital status, distance and family size had no significant association with Health System Delay by binary and multiple regression analysis (table 6 below).

Table 6: Logistic regression analysis of health system delay and related factors among pediatric oncology patients attending at black lion specialized hospital, Addis Ababa, Ethiopia June 2019

Categorical Variables	health system delay		Binary and multivariate logistic regression	
	NO (%)	YES (%)	COR (95% CI)	AOR (95% CI)
Age				
0-4	15(17.24)	72(82.76)	1	1
5-9	38(34.55)	72(65.45)*	0.39(0.19,0.78)*	0.34(0.14,0.85)
10-14	12(25.53)	35(74.47)	0.60(0.25,1.143)	0.62(0.21,1.79)
Medical insurance				
yes	41(47.13)	46(52.87)	1	1
No	24(15.29)	133(84.71)	4.93(2.69,9.04)*	5.52(2.61,11.69)*
Visit traditional medicine				
Yes	45(33.33)	90(66.67)	1	1
No	20(18.35)	89(81.65)	2.22(1.21,4.06)*	2.11(0.95,4.67)
Child first seen				
Traditional	13(38.24)	21(61.76)	1.97(0.64,6.05)	2.84(0.79,10.22)
Health center	9(6.92)	121(93.08)	16.43(5.40,6.05)*	16.13(4.00,65.03)
				**
District	16(48.48)	17(51.52)	1.29(0.42,3.95)	1.09(0.31,3.75)
General hospital	16(59.26)	11(40.74)	0.84(0.26,2.70)	0.63(0.17,2.32)
Private clinic	11(55.0)	9(45.0)	1	1
Initially Misdiagnosis				
Yes	24(15.89)	127(84.11)	4.17(2.29,7.58)	0.86(0.34,2.16)
No	41(44.09)	52(55.91)	1	1

Significantly association at P* value<0.05 and p** value<0.001

6. DISCUSSION

Make longer duration of pediatric cancer diagnosis and treatment may increase the proportion of advanced stages. Thus, delay in diagnosis and treatment of pediatric cancer patients may impact on poor prognosis and quality of life (17). In this study, delay was classified as patient and health system delay.

Regarding to patient delay of the 244 children, 127(52.0 %) were classified as having patient delay with 120 median days of stay at home with their symptom, these median days of delay was found slightly similar study conducted at Kenya with median patient delay of 104 days(52). This finding contrasts with a study from Uganda and Kenya, the median patient delays which reported significantly shorter patient delays of 30 and 63 median days respectively(43). The difference in the result of this study with other studies might be due to the influence of patient's characteristics such due to parent's perceptions of illness, poor access to health care facilities, the possibly limited availability of transport and dependency on traditional practices may have contributed to a longer patient delay.

Among the socio-demographic characteristics of patients the mean (SD±) age of study participant at the disease onset was 6.4 years (SD ±3.2).This results is consistence with research conducted in Egypt, Peru and Canada with the mean age of 6.5 years (SD±3.8), 6.7 (SD±4.6) and 7.7 years (SD±5.5) respectively.

The age of the patient was an important risk factor for increased patient delays. In our study, age of the patient 5-9 years, was found as a risk factor for longer patient delay when compared with the 0-4 age group. This result is similar with a research done from Egypt, Peru and Canada showed that age of the patient was found as a risk factor for patient delay (33, 34, 53).The risk of longer patient delay increased for children in the older age groups. This may be due to, among young children, it is expected that close up parental observation of the child might help in recognition of symptoms while among older children the detection of signs and symptoms may be more frequently initiated by the patients themselves and may be more unwilling to disclose symptoms to their parents.

Regarding place of residence of patients, living in rural area is associated problem that can affect access to diagnosis and treatment of cancer was found as a risk factor for patient delay. In contrast to these findings, studies done in Canada residence was not significant association patient factors associated with patient delayed(35).This discrepancy might be due to socio demographic characteristics difference, sample size and in urban may have more access to health service than residents of rural area. These differences may contribute to a longer patient delay.

In our study more than half of parents reported use of alternative treatment before coming to TASH. Use of alternative treatment resulted in significantly longer patient. Similar study revealed from Kenya showed that many parents use of alternative medicine for their children(41).This may be due to more developing countries in Africa including Ethiopia are alternative treatment easily accessibility in the setup and difficult to afford easily for modern medical care service given by health center and hospital and cultural acceptability of traditional medicine in the community for some disease.

In terms of level of awareness, parents only 27.3 % had heard of cancer before their child had been diagnosed with cancer. The findings of this study were lower compared to studies conducted in Bangladesh and Kenya with 92% and 82%had parents who heard about the childhood malignancy previously were more timely to bring their children to the cancer center, respectively(41, 42). The difference in the result of this study with other studies might be due education of participants, lack of health information distribution in this study condition, socioeconomic deference, most of our participants are coming from rural so there are lack of awareness about disease. The reason might be social media not available in that area.

Results of the current finding showed that, types of cancer have shown a statistically significant association with the onset of symptom to the first presentation to a health care provider (patient delay). Rhabdomyosarcoma was found as a risk factor for longer patient delay when compared with other types of cancer. Conversely, study conducted in Kenya the cancer type did not show a statistically significant association with patient delay(52).This could imply that signs and symptoms of Rhabdomyosarcoma are not easily

recognized of early symptoms of childhood cancer by parents and health care providers and the appropriate diagnosis of cancer in children is made complex because of the rarity of the disease and the nonspecific presentation of symptoms.

In this present study, out of the 244 patients, the health system delay was observed in 73.4%, which classified as having health system delay with 210 median days, these median days of delay was found higher than study conducted in Kenya median health system delay 91 days(52). The longer health system delay in this study might be due to the health professional workers are not able to suspect and make the right diagnosis. It could also reflect complex referral systems and shortage of diagnostic and treatment centers in this country.

Our study illustrated that was found that children's did not have health insurance at the time of diagnosis was significantly associated with patient delay as compared with did not have health insurance at the time of diagnosis. Similar study revealed from Kenya showed that having insurance at the time of diagnosis resulted in significantly shorter patient delay as compared with did not have health insurance (41). This may be due to more developing countries in Africa including Ethiopia are inadequate medical insurance coverage and financial burden between the two population.

Our finding showed that Patients' first contacted health center initially visited when symptoms were first observed was significantly associated with health system delay. Conversely, study conducted in Nigeria There was no significant impact in health system delay among patients whose first attended health facility visit was tertiary and lower health facilities(health center)(36). This might be due to Lack of knowledge of health care provider working in lower health facilities (health center) inhibits recognition of early symptoms of childhood disease.

According this study finding, more than half of the malignancies were initially misdiagnosed were frequent (59%) of the patient, This study is inline by a study conducted in South Africa showed that initial misdiagnoses were reported (58%)(51). This is higher than a study done in Egypt showed that in 39.5% of the patients incorrect nononcological diagnosis was initially made (34). The difference in the result of this study with other

studies might be due to type of cancer may also influence a health professional ability to make a correct diagnose and the initial contact of patient with a primary care physician has a considerable impact on early childhood cancer diagnosis and Lacks of knowledge by health care provide recognition of early symptoms of childhood cancer.

7. Strength of the Study

- There is high response rate in this study
- This information was confirmed using medical records and referral notes therefore reducing the impact of recall bias.
- The study done in the only oncology center in Ethiopia and patient are coming from all over Ethiopia and hence they can represent the whole population.

8. Limitation of the Study

- Shortage of literatures in delay diagnosis and treatment of pediatric cancer patient in developed countries and in Ethiopia.
- It is possible that some caregivers could not remember the date of onset of symptoms (recall bias) the details information.

9. CONCLUSION

The median patient delay in this study was 120 days while the median health system delay was found to be 210 days. The median Health care system related delay in our study was longer than patient-related delay. Factors associated with long patient delay include age of the patient, diagnosis of the patient, place of resident, used traditional healers and low awareness of the disease. Similarly, factors that were predictor of health system delay were health insurance at onset of diagnosis and first contacted health facility center.

10. RECOMMENDATION

- Design health education strategies to increase the level of awareness of the early signs of cancer among parents and the importance of early presentation at health facilities is recommended to decrease patient delay.
- The education of health professionals on the symptoms suspicious of childhood cancer and timely investigation of suspicious clinical features for early referral for early diagnosis and initiation of definitive treatment is strongly indicated to reduce health system delay.
- Hence, there is a need for a multi-sectored approach in addressing childhood cancer conditions in Ethiopia, that need the involvement of Ministry of Health (MOH), training institutions, hospitals, communities, families and individuals to prevent delay in Improving outcomes for children with cancer.
- Governments support to expanding cancer center to provide early and accurate diagnosis and initiation of definitive treatment and to decrease delay diagnosis of childhood cancer by offering early detection service
- Used for researchers as a base line for further investigation to explore detail reasons of delay in diagnosis and treatment by using qualitative study design which is not included in this study to identify and develop interventions.

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APPENDIX

A. English Version Information Sheet:

Greeting: Good morning/afternoon! Hello.

My name is _____ am member of research team involved a master of oncology nursing student project in Addis Ababa University. I am conducting a study to find out factors influencing delay to diagnosis and treatment in Tikur Anbessa hospital. The results of this study will be used to improve services offered to children with cancer especially in terms of early diagnosis and treatment which will improve the outcome of the disease in the long run.

Risks and discomfort: There are no risks involved except the time you will take in answering the questions. It will take about 15- 20 minutes of your time.

Benefit of the study: There are no direct benefits to you as an individual participant. I would like to include you and your child as a participant. But accordingly the result will provide important information on addressing the problem about the delays and late diagnosis and treatment by creating a convenient programmatic approach to give appropriate service to the respective population.

Incentive: There is no financial or material incentive in participating in this study.

Confidentiality: Study data was coded so that it will not be linked to your name. All information obtained in the course of this study will be held in confidence.

Rights of Participants: You have full right either to participate or refuse as well as to quit at the middle or at any time you want after you start the participation in this study. You may respond to all the questions or you may not answer to questions you don't want to answer. You can ask any question which is not clear for you.

Persons to contact: If you have any question, you can ask at any time. If you have additional questions about the study, you can contact the: Principal investigator: **Aron Kiros** cell phone- 0914046843, E-mail **aronkb7@gmail.com**

C. Questioner form English version

Questions related to factors influencing delay to diagnosis and treatment among pediatric oncology patients in TASH

Part I: Socio-Demographic Characteristics /clinical characteristic			
Regarding the child			
No.	Questions	Alternative answer	Skip
101	Age of the child at Diagnosis	_____ years	
102	Sex of the child	1. Male 2. Female	
103	Place of residence	1. Urban 2. Rural	
To be filled from patient card			
104	Dx of the child	_____	
105	Stage of diseases at diagnosis	1. Stage I 2. Stag II 3. Stage III 4. Stage IV	
Regarding care giver/Guardian			
106	Age of mother	_____ years	
107	Age of father	_____ years	
108	How many children do you have	_____	
109	What is your region?	1. Amhara 2. Oromia 3. SNNPR 4. Tigray 5. Addis Ababa 6. Others (specify) _____	

110	What is your Marital status?	1. Single 2. Married 3. Divorced 4. Widowed	
111	What is the highest level of schooling mother attended?	1. No education 2. Primary education 3. Secondary education 4. Higher education	
112	What is the highest level of schooling father attended?	1. No education 2. Primary education 3. Secondary education 4. Higher education	
113	What is the mother's current occupation?	1. House wife 2. Government employee 3. Farmer 4. Student 5. Merchant 6. Private employee 7. Others (specify)_____	
114	What is the father current occupation?	1. Government employee 2. Farmer 3. Student 4. Merchant 5. Private employee 6. Others (specify)_____	
115	What is your monthly income in Ethiopian Birr?	_____ In birr	
116	Do you have medical insurance cover?	1. Yes 2. No	
117	What is distance from ur home to TASH in Km Distance from specialized care (km):	_____ in km	
II. clinical profile and health seeking behavior			
No.	Questions	Coding category	Skip
201	What was the child onset of primary main symptoms?	1. Fever 2. Neck swelling 3. Fatigability	

		4. Abdominal swelling 5. Whitish of eye 6. Pain 7. Tumor 8. Other specify_____	
202	Who/Where was the child first seen when the symptoms first started	1. Traditional healers 2. Health center tonsil 3. District hospital 4. General hospital 5. Private clinic 6. other specify_____	
203	Initially misdiagnosis	1. yes 2. No	
204	Total number of visits in Health care facilities visited before coming to TASH for this disease?	_____	
205	The source of referral to TASH	1. Health center 2. District hospital 3. General hospital 4. Private clinic 5. Self- referred	
206	Time from onset of symptoms to first contacting health-care provider in days/weeks/months.	_____ (days/weeks/months)	
207	First contacting health-care provider to confirmed diagnoses.	_____ (days/weeks/months)	
208	Days from confirmed diagnosis to initiation of treatment.	_____ (days/weeks/months)	
209	From onset of symptoms to initiation of treatment?	_____ (days/weeks/months)	
210	Did the child visit traditional healer?	1. Yes 2. No	
III: parents/caregiver Level of Awareness.			
301	Have you heard about cancer before?	1. Yes 2. No	

302	What do you think is the cause of cancer?	<ol style="list-style-type: none"> 1. Bewitchment 2. Evil eye 3. Genetic 4. Infectious 5. Unknown 6. I don't know 7. Other specify_____ 	
303	Do you think cancer is curable?	<ol style="list-style-type: none"> 1. Yes 2. No 3. Am not sure 	
IV: Information on reasons for delay(supported by medical record)			
401	Reasons for delay to attending TASH	<ol style="list-style-type: none"> 1. Wasted time using alternative medicine 2. Economical problem 3. Distance from primary health care 4. I thought it will relief by it self 5. Other (specify) _____ 	
402	What are the reasons for late diagnosis and treatment?	<ol style="list-style-type: none"> 1. Lack of cash money at that time(took time to manage money) 2. Waiting time 3. Availability of investigations 4. Reputation of long delays in hospital 5. Others (specify)_____ 	

Thank you very much for your participation!!!

D. Subject information sheet (Amharic Version)

አዲስ አበባ ዩንቨርሲቲ የድህረ-ምረቃ ት/ቤት ጤናና ህክምና ሳይንስ ኮልጅ የነርቲንግ ት/ክፍል

ሀ. የጥናቱ መረጃ፡- ጤና ይስጥልኝ፤ እንደምንአደሩ? እንደምንዋሉ? እንደምንአመሹ?

ጤና ይስጥልኝ፡፡ ስሜ _____ ይባላል፡፡

ሕጻናት ካንሰር ህመምን ታካሚዎች ሳይዘገዩ ወይም ህክምና ያልሂዱ በትን እና ህክምና ያላገኙ በትን ምክና ያቶችን እና ተዛማጅነት ያላቸውን መንስኤዎች የሚያጠነው የጥናቱ አባል ነኝ፡፡ በአሁን እዚህ የተገኘሁት ስለ

ሕጻናት ካንሰር ህመምን ታካሚዎች ሳይዘገዩ ወይም ህክምና ያልሂዱ በትን እና ህክምና ያላገኙ በትን ምክና ያቶችን እና ተዛማጅነት ያላቸውን መንስኤዎች ለማጥናት የተዘጋጀ ቃለ መጠይቅ መረጃ ለመሰብሰብ ነው፡፡ ይህ ጥያቄ የተዘጋጀው ለምርመራ ስራ ሲሆን በአዲስ አበባ ዩንቨርሲቲ በጥናትና ምርመራ ኮሚቴ ተገምግሞ እንደ አስፈላጊ ጊነቱ ግድፈት ካለበት እርማት ይደረግበታል፡፡ በዚህ ጥናት መሳተፍ ወይም የሚያገኙት ቀጥተኛ የሆነ ጥቅም የለም ቢሆንም ከዚህ ጥናት የሚገኘው ውጤት በቀጥታ ለህዝብ ማህበረሰቡ ላይ የሚጠቅም ሲሆን ለእርስዎ ደ ግምጃ ለሕይወት እንደሚሰጥ ዎት ተስፋ አደርጋለሁ፡፡ ለዚህ ቃለ መጠይቅ የተመረጡት ጥናቱ በሚካሄድበት ወቅት በመገኘት ዎነው፡፡ ከጥናቱ የሚገኘው መረጃ ከላይ ከተጠቀሰው ዓላማ ውጭ አላማ ተግባር የማይወጠው ሆኖ መረጃው በሙሉ በሚስጥር የሚጠበቅ መሆኑን ቃል እየገባሁ ለወደፊት ለሚፈጸሙት የጤና አገልግሎት በአርስዎ ምሆን በቤተሰብዎ ላይ ምንም ዓይነት ተጽእኖ እንደሌለው ልገልጸልዎት እወዳለሁ፡፡

አላማ፡-

በጥቁር አንበሳ ሆስፒታል የሚገኙትን ሕጻናት ካንሰር ህመምን ታካሚዎች ሳይዘገዩ ወይም ህክምና ያልሂዱ በትን እና ህክምና ያላገኙ በትን ምክና ያቶችን እና ተዛማጅነት ያላቸውን መንስኤዎች ለማጥናት.

አደገኛዎች እና ምቹት፡ ለጥያቄዎች መልስ ከሚሰጡበት ጊዜ በስተቀር ምንም ዓይነት አደጋዎች አይኖሩም. የእርስዎን ጊዜ ከ15-20 ደቂቃዎች ይወስዳል፡፡

ለተጠያቂው የሚሰጠው ጥቅም፡ እንደ እያንዳንዱ ግለሰብ ምንም ቀጥተኛ ጥቅም ላይ የማይውልም. እርስዎን እና ልጅዎን እንደ ተሳታፊ ማካተት እፈልጋለሁ. ይሁን እንጂ ውጤቱ ለተጠያቂው ተገቢ አገልግሎት ለመስጠት

አመቺስርዓተምህዳርበመፍጠርስለመዘግየትናየዘገምተምርመራእናህክምናችግርንአስመልክቶችግሩ
ንለመመለስጠቃሚመረጃይሰጣል.

የሚያስከትለው ጉዳት፡-

በዚህጥናት ላይ መሳተፍ የሚያስከትለው ምንም አይነት ጉዳት የለም የተጠያቂው መብቶች፡-

ለመሳተፍ ምሆነ ላለመሳተፍ ሙሉ መብት አሉት፤ መጠየቅን ጀምረው ከመሀል የማቆም ምሆነ ያልፈለጉት
ንጥያቄ ያለመመለስ ሙሉ መብት አሉት ለሁሉም ጥያቄዎች ማሻሻያ ለሌሎች ላይም ለመመለስ የማይፈልጉትን
ንጥያቄዎች መልስ ላያገኙ ይችላሉ ለእርስዎ ያልተገለጸ ማንኛውም ጥያቄ መጠየቅ ይችላሉ።)

ማበረታቻ፡- በዚህ ጥናት ውስጥ ለመሳተፍ ምንም ዓይነት የገንዘብ ወይም የቁሳዊ ማበረታቻ
የለም

ሚስጥራዊነት፡ ሁሉም መረጃ ሚስጥራዊነቱ የተጠበቀ ሲሆን የዕርሰ ስም በመጠየቅ ላይ አይሰፍርም የምን
ንጠቀመው የሚስጥረቁጥር ነው።

Consent sheet (Amharic Version)

የፈቃደኝነት ማረጋገጫ ቅጽ

ከላይ የጥናቱ አላማ፣ ጥቅሙ፣ ጉዳቱ፣ እንዲሁም ሚስጥራዊነቱ በሚገባኝ እና በምረዳው ቋንቋ ተገለጿል
። በጥናቱ ላይ ያለ መሳተፍ ምሆነ ከጀመርኩ በኋላ በፈለኩት ጊዜ አቋርጬ የመሄድ ሙሉ መብት አለኝ።

በዚህ ጥናት ላይ ተሳትፎዬ ፈፀሞ በፍላጎት ላይ የተመሰረተ ነው

በዚህ ጥናት ላይ ለመሳተፍ ፍቃደኛ ንዎት?

- 1. አይደለሁም (አመሰግናለሁ) 2. አዎ (እንቀጥል)

ፊርማ ----- ቀን -----

የጥናቱ አድራጊው ስም፡- አሮን ኪሮስ ብፁእ

ስልክ ቁጥር፡- +251914046843

ኢ-ሜይል:- aronkb7@gmail.com

የጠያቂው ስም ፊርማ

የተጠየቀበት ቀን/...../.....

የጥናቱ ውጤት: 1. ተጠናቋል 2. መጠየቅ አልፏል

3. በክፍል ተጠናቀቀ 4. ተጠያቂው አልተገኘም

በተቆጣጣሪ ተረጋግጧል ስም ፊርማ ቀን

E. Amharic version structured questionnaires

መለያ ቁጥር - _____

መረጃ ሰብሳቢው ስም ፊርማ _____

መረጃው የተሰበሰበበት ቀን የተጀመረበት ሰዓት _____ የተጠናቀቀበት ሰዓት _____

የክትትል አድራጊው ስም ፊርማ _____

ክፍል አንድ - ማህበራዊና ግላዊ መረጃ ልጁን በተመለከተ			
ተ. ቁ	ጥያቄ	መልስ	ማሳለፊያ
101	የሕፃኑ ዕድሜ	_____ ዓመት	
102	የሕፃኑ ጾታ	1. ወንድ 2. ሴት	
103	በቋሚነት የሚኖሩበት ከተማ ወይስ ገጠር ነው?	1. ከተማ 2. ገጠር	
ከታካሚ ካርድ ለመሞላት			
104	የልጁ በሽታ		

105	በምርመራው ወቅት የበሽታ ደረጃዎች	<ol style="list-style-type: none"> 1. ደረጃ አንድ 2. ደረጃ ሁለት 3. ደረጃ ሶስት 4. ደረጃ አራት 	
ተንከባካቢ / አሳዳጊን በተመለከተ			
106	የእናትየው ዕድሜ	_____ ዓመት	
107	የአባትየው ዕድሜ	_____ ዓመት	
108	ምን ያህል ልጆች አላችሁ?	_____	
109	የሚኖሩበት ክልል የት ነው?	ሀ/አማራ ለ/አሮሚያ ሐ/ደቡብ መ/ትግራይ ሠ/ አዲስ አበባ ረ/ሌላ ካላይ ጥቀሱ----- --	
110	የጋብቻ ሁኔታ?	<ol style="list-style-type: none"> 1. ያላገባች 2. ያገባች 3. በሞት የተለያዩች 4. በፍች የተለያዩች 	
111	የእናትየው ትምህርት ከፍተኛው ደረጃ ስንት ነው?	<ol style="list-style-type: none"> 1. መጻፍና ማንበብ የማትችል 2. የመጀመሪያ ደረጃ ትምህርት 3. ሁለተኛ ደረጃ ትምህርት 4. የሁለተኛ ደረጃ ከዘበላይ 	
112	የአባትየው ከፍተኛው የትምህርት ከፍተኛው ደረጃ ስንት ነው?	<ol style="list-style-type: none"> 1. መጻፍና ማንበብ የማትችል 2. የመጀመሪያ ደረጃ ትምህርት 3. ሁለተኛ ደረጃ ትምህርት 	

		4. የሁለተኛ ደረጃ ከዘበላይ	
113	የእናትየው የሥራ ሁኔታ	ሀ/ የቤት እመቤት ለ/ የመንግሥት ሠራተኛ ሐ/ ገበሪ መ/ ተማሪ ሠ/ ነጋዴ ረ/ የግል ሰራተኛ	
114	የአባትየው ሥራ ምንድን ነው?	ሀ/ የመንግሥት ሠራተኛ ለ/ ገበሪ ሐ/ ተማሪ መ/ ነጋዴ ሠ/ የግል ሰራተኛ ረ/ ሌላ ካላይ ጥቀሱ----- ---	
115	የቤተሰብዎ የወር ገቢ ምን ያህል ነው?	----- ብር	
116	የጤና መድሀን	1. አለኝ 2. የለኝም	
117	ከሚኖሩበት እስከ ጥቁር አንበሳ ሆስፒታል ርቀቱ ምን ያህል በግምት ይሆናል? በኪሎሜትር?	-----በኪሎሜትር	
ክፍል ሁለት - ክሊኒካዊ መግለጫ እና የጤና ፍላጎት ጠባይ ናቸው			
ተ/ ቁ	ጥያቄዎች	መልስ	ማሳለፊያ
201	ልጁ ዋና ዋናዎቹ የሕመም ምልክቶች ምን ነበር?	_____	

202	ልጁ ለመጀመሪያ ጊዜ የተገናኘበት የት ነበር?	<ol style="list-style-type: none"> 1. ባህላዊ ህክምና 1. የጤና ማዕከል 2. የወረዳ ሆስፒታል 3. አጠቃላይ ሆስፒታል 4. የግል ክሊኒክ 5. ሌላ ካለ ይጥቀሱ 	
203	መጀመሪያ ላይ ህጻኑ ምን ታኩሞ ነበር?	_____	
204	ለዚህ በሽታ ወደ TASH ከመምጣትዎ በፊት በጤና ጥበቃ ተቋማት ውስጥ የተገኘ ጠቅላላ ጉብኝት?	_____	
205	ወደ ጥቁር አንበሳ የመጡት ከየት የጤና ተቋማት ነው?	<ol style="list-style-type: none"> 6. የጤና ማዕከል 7. የወረዳ ሆስፒታል 8. አጠቃላይ ሆስፒታል 9. የግል ክሊኒክ 10. በራሳችን 	
206	የበሽታ ምልክቶችን ከመጀመሪያው አንስቶ የጤና ጥበቃ አገልግሎት ሰጪዎችን	_____ (በቀናት / ሳምንታት / በወር)	
207	መጀመሪያ ጤና ተቋም ሄደው በሽታው እስከተረጋገጠበት ጊዜ ድረስ ስንት ቀናት ወሰደብዎት?	_____ (በቀናት / ሳምንታት / በወር)	
208	ከተረጋገጠ ምርመራ ጀምሮ እስከ ሕክምና ጊዜ	_____ (በቀናት / ሳምንታት / በወር)	
209	በቀናት ውስጥ ያለው የጤንነት ቆይታ	_____ (በቀናት / ሳምንታት / በወር)	
210	ልጆችን ወደ ባህላዊ ሐኪምን ስንት ወስደች ነበር?	<ol style="list-style-type: none"> 1. አወ 2. አልወሰድኩም 	
ክፍል ሶስት - የአሳዳጊ እውቀትና የካንሰር ግንዛቤ			
301	ስለ ካንሰር ሰምተው ያውቃሉ?	1. አዎ	

		2. የለም	
302	የካንሰር መንስኤ ምን ይመስሎታል?	<ol style="list-style-type: none"> 1. እርግማን 2. ወቀሳ 3. መጥፎው ዓይን 4. ከዘር የተወረሰ 5. ተላላፊ 6. የማይታወቅ 7. ሌሎች ይግለጹ 	
303	ካንሰር ሊታከም(ይድናል)ብለው ያስባሉ?	<ol style="list-style-type: none"> 1. አዎ 2. የለም 	
ክፍል አራት - ለመዘግየት ምክንያቶች መረጃ			
401	የቆዩበት ዋናው ምክንያት ምንድን ነው?	<ol style="list-style-type: none"> 1. የባህል ህክምና መሄድ 2. የገንዘብ ማጣት 3. የህክምና መስጫ በቅርብ አለመኖር 4. ልሎች ካለ ባጭር ይግለጹ..... 	
402	በሕክምና ተቋማት ውስጥ ምርመራ ውጤት ቶል ሕክምና ሳይጀምሩ የቆዩበት ምክንያት ምንድን?	<ol style="list-style-type: none"> 1. ህክምና ለማግኘት ወረፋ/ተራ መጠበቅ 2. የገንዘብ ማጣት 3. በህዝብ ሆስፒታል ውስጥ ረጅም ጊዜ መቆየት 4. ምርመራዎች አለመገኘታቸው 5. ልሎች ካለ ባጭር ይግለጹ... 	

ስለተሳትፎዎ እናመሰግናለን !!!!

F: Training Guide Manual for Data Collectors and Supervisors

Topic: factors influencing delay to diagnosis and treatment among pediatric oncology patients at black lion specialized hospital, Addis Ababa, Ethiopia.

Introductions: this training manual helps the research team to be familiar with words and sentences used in the checklist, in adopting with data collection techniques and help to get experience for correctly recording of the data of study subjects. It also helps on how to perform supervision and how to control data quality.

Objectives of the research; factors influencing delay to diagnosis and treatment among pediatric oncology patients at black lion specialized hospital, Ethiopia.

Purpose of the training:

- To familiarize the data collectors & supervisors with unfamiliar words and sentences used in the checklist.
- To adopt data collectors & supervisors with techniques to be followed in data collection and supervision procedures
- To enable data collectors& supervisors in resolving problems in case of inconveniences

Methods of training: Discussion of data collection tool, Filed practice/pre-testing

Responsibility of research team members:

Principal investigators – control the overall activities of the study

Supervisors – monitor for the correctness of data collations at the spot in the filed

- Monitor for constancy and completeness of data at the spot of data collection
- Monitor for availability of necessary supplies for the Data collection
- Ensure data quality at the spot of data collection

Data collectors

- handle necessary supplies to perform the study
- perform the Data collection and enumerate correctly
- handle and manage any inconveniences properly
- communicate with supervisors and principal investigator for solving problems which are beyond their capacity, and for information which needs more clarifications
- check for completeness of checklists at the site

How to fill the checklists: each data collector should be checked whether he/she has pencils and checklist to be filled before starting.

Table 8: schedule of data collectors and supervisors training date and time.

DAY1	ACTIVITIES
Time breakdown (all in local time)	
2:30–4:00 AM	Welcome, survey objectives and training overview
4:00-4:15 AM	TEA BREAK
4:15-6:00AM	Overview of survey methodology <ul style="list-style-type: none">• Key aspects of survey design• Roles and responsibilities of personnel
6:00–7:00 PM	LUNCH
7:00–8:30 PM	Data collection procedures <ul style="list-style-type: none">• Preparation for data collection• Procedures before, during and after observing data extraction forms at oncology department

	<ul style="list-style-type: none"> • What to do at the end of data collection
8:30-8:45 PM	TEA BREAK
8:45-11:00 PM	Logistics for data collection <ul style="list-style-type: none"> • Instructions for completing the form • Key rules to remember Final comments, evaluation of workshop Closing of the workshop

G: PROBLEMS PRIORITIZING CRITERIA TABLE

Problem/ Topic	CRITREA							
	R	A	F	P	APPL	U	E	T
1*	5	5	5	5	4	5	5	34
2	5	4	3	5	4	3	5	29
3	5	4	3	4	4	3	4	24

Key

R-relevance

A-Avoid duplication

F-feasibility

P-political acceptance

APPL-applicable

U-urgency

E-ethical acceptance

T-total

Topics Which Was Proposed:

1. factors influencing delay to diagnosis and treatment among pediatric oncology patients at black lion specialized hospital, Addis Ababa Ethiopia
2. knowledge, attitude about breast cancer and practice of breast cancer screening among female health care professional in ayder comprehensive specialized hospital, mekelle university ,Ethiopia
3. pattern of adverse drug reaction due to cancer chemotherapy in ayder comprehensive specialized hospital, mekelle university ,Ethiopia