PHARMA COLLEGE SCHOOL OF GRADUATE

STUDIES, HAWASSA CAMPUS

DEPARTMENT OF EPIDEMOLOGY

DETERMINANT OF TREATMENT ABANDONMENT IN CHILDREN WITH ACUTE LYMPHOBLASTIC LEUKEMIA: A CASE CONTROL STUDY AT TIKUR ANBESSA SPECIALIZED HOSPITAL.

BY; SHIMELS BONSA

JANUARY 2025

ADDIS ABABA ETHIOPIA

DETERMINANT OF TREATMENT ABANDONMENT IN CHILDREN WITH ACUTE LYMPHOBLASTIC LEUKEMIA. A CASE CONTROL STUDY AT TIKUR ANBESSA SPECIALIZED HOSPITAL

BY SHIMELS BONSA

ADVISOR: DEJENE HAILU (PhD)

A THESIS SUBMITTED TO THE DEPARTMENT OF EPIDEMOLOGY PHARMA COLLEGE HAWASSA CAMPUS FOR PARTIAL FULFILLMENT OF THE REQUIREMENTS FOR MPH DEGREE IN EPIDEMOLOGY

JANUARY, 2025

ADDIS ABABA, ETHIOPIA

AUTHOR'S STATEMENT/DECLARATION

I hereby declare that this MSc/MA/MPH/MBA/ thesis is my original work and has not been presented for a degree in any other College or University, and all sources of material used for this thesis have been duly acknowledged.

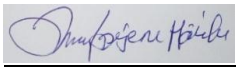
Name: SHIMELS BONSA TESSEMA

Signature: ____  **_____**

Place and date of submission: PHARMA COLLEGE, HAWASSA JANUARY 24.

Advisors' Approval Sheet

This is to certify that the thesis entitled "**DETERMINANTS OF TREATMENT ABANDONMENT IN CHILDREN WITH ACUTE LYMPHOBLASTIC LEUKEMIA. A CASE CONTROL STUDY AT TIKUR ANBESSA SPECIALIZED HOSPITAL.**" submitted in partial fulfillment of the requirements for the degree of **Masters** in **Epidemiology,** Graduate Program of the **Department/School of public health,** and has been carried out by **SHIMELS BONSA TESSEMA** Id. No **PHE MPHE 268359-15**, under my/our supervision. Therefore I recommend that the student has fulfilled the requirements and hence hereby can submit the proposal to the department.

DEJENE HAILU (PhD)  January,24,2025

Name of major advisor Signature Date

ACKNOWLEDGEMENTS

Special thanks and appreciations go to my advisor Dr Dejene Hailu, in giving me valuable lesson in preparation of this research thesis. I would like also to thank Pharma Health Science College for giving this opportunity and appreciate the AAU, Tikur Anbessa hospital for letting the study with availing records and others valuable helps.

ABBREVIATIONS AND ACRONYMS

ALL:	Acute Lymphoblastic Leukemia
AAU:	Addis Ababa University
B-cell:	B Lymphocyte (a type of white blood cell)
BLSH:	Black Lion Specialized Hospital
CAR T-cell:	Chimeric Antigen Receptor T-cell
CNS:	Central Nervous System
HICs:	High-Income Countries
HSCT:	Hematopoietic Stem Cell Transplantation
LMICs:	Low- and Middle-Income Countries
MRD:	Minimal Residual Disease
ORs:	Odds Ratios
Ph+ ALL:	Philadelphia Chromosome-Positive Acute Lymphoblastic Leukemia
TASH:	Tikur Anbessa Specialized Hospital
T-cell:	T Lymphocyte (a type of white blood cell)
TKIs:	Tyrosine Kinase Inhibitors
TP53:	Tumor Protein 53 (a gene involved in cancer suppression)
TxA	Treatment abandonment
WBC:	White Blood Cell

TABLE OF CONTENTS

T

LIST OF TABLES

LIST OF FIGURES

ABSTRACT

Background: Acute lymphoblastic leukemia (ALL) is the most prevalent childhood cancer, accounting for nearly 20-25% of all pediatric malignancies globally. Contemporary childhood ALL studies have shown improved 5-year overall survival (OS) rates exceeding 90%. However, this remarkable progress has not been mirrored in low- and middle-income countries (LMICs). Evidence show that high treatment abandonment in these LMICs contributes to decreased child survival rates.

Objective: To identify determinants of treatment abandonment/refusal among children with lymphoblastic leukemia attended Addis Ababa University , Tikur Anbessa Specialized Hospital, Pediatrics hemato-oncology treatment Unit, 2025.

Methods: A facility based unmatched case control study was conducted among 414 (142 cases and 272 controls). The cases were those patients who refused or abandoned treatment and the controls are those who completed treatment. All Acute lymphoblastic leukemia patients who fulfil inclusion criteria for both the cases and controls were included consecutively to the study till the sample size fulfilled. The data was collected using structured questionnaires, via a phone call and medical record review. Data were analyzed by SPSS version 30. Bivariate and multivariable logistic regression analysis was done to identify independent determinants of treatment abandonment.

Result: In the multivariate analysis, malnutrition (AOR=3.13, 95%:1.44, 6.83), parental/guardian occupation (AOR= 0.3, 95% CI:0.07, 0.92), belief in Curability (AOR=2.92, 95% CI: 1.28, 6.66), day 29 bone marrow status (AOR= 5.80, 95% CI: 1.29, 25.95), Counseling (AOR=0.31, 95% CI :0.11, 0.86) and role in treatment decisions (AOR=2.26, 95% CI: 1.04, 4.94) were determinants of treatment abandonment among ALL children.

Conclusion and recommendation: Due to significant effect on overall survival of children on ALL treatment; proper counseling, good nutritional support, parental support economically and availing treatment centers so that both parents can care will significant impact in reducing treatment abandonment.

Key words: Pediatrics, Acute lymphoblastic leukemia, Determinants, Treatment, Abandonment.

1. INTRODUCTION

1.1. Background

Childhood cancers are a substantial contributor to the global disease burden, affecting children and their families all around the world. Acute lymphoblastic leukemia (ALL) is the most prevalent childhood cancer, accounting for nearly 20-25% of all pediatric malignancies globally(1). The cure rates and survival outcomes for pediatric patients with ALL have improved dramatically over the past several decades. Contemporary childhood ALL studies have shown improved 5-year overall Survival (OS) rates exceeding 90%(2). However, this remarkable progress has not been mirrored in low- and middle-income countries (LMICs), where survival rates remain low, largely due to a range of challenges that compromise treatment adherence and completion. The main contributing factors to these reduced survival rates are late presentation, malnutrition, and suboptimal supportive and intensive care facilities, resulting in high treatment-related mortality (TRM). A high abandonment rate also contributes to decreased survival rates in LMICs(3)

Due to the complexity and cost of ALL therapy and uncertainties about survival, as well as acute and long-term sequelae, the refusal or abandonment of treatment was a culturally embraced alternative in many areas. Understanding and addressing treatment abandonment is crucial for bridging the pediatric cancer survival gap between high-income (HIC) and low-and middle-income countries (LMC).

In childhood cancer, The International Society of Pediatric Oncology defines treatment abandonment as failure to start (refusal) or continue treatment for four or more consecutive weeks(4). This issue has a profound impact on the prognosis of children with ALL, contributing significantly to morbidity and mortality. Families' low socioeconomic status, low education, and long travel time, are influential in increasing risk of treatment abandonment. Treatment-related considerations such as preference for complementary and alternative medicine and concerns about treatment adverse effects and toxicity, were perceived to play an important role in both LMC and HIC (5)

Ethiopia, as one of the LMICs, faces these challenges in its healthcare system, particularly in the field of pediatric oncology. In past few years Ethiopian Ministry of health, has given much focus in prevention and treatment of non-communicable diseases like cancer. With limited resources starting treatment and follow up of patients need international collaborative effort. The ASLAN

project is one of the exemplary USA based initiative that is strengthening Ethiopia's first comprehensive pediatric cancer programs by sharing knowledge and expertise and teaching health professionals to treat pediatric cancer cases in different corners of the country(6).

Tikur Anbessa Specialized Hospital (TASH) in Addis Ababa, Ethiopia, serves as the primary referral center for pediatric cancer care in the country, treating a significant number of children diagnosed with ALL who come from all corner of the country. Despite the recent focus from MOH and collaborators helping increase availability of chemotherapy and supportive care, treatment abandonment remains a major hurdle to improving survival rates among Ethiopian children specifically with ALL.

Even if there is a study that estimate childhood cancer treatment abandonment rate in Ethiopia as 34%(7). This study was done in questioning the care provider doctors and nurses and didn't fully assess the reasons for abandonment from parents/patients perspective. Also there is no data on the prevalence of treatment abandonment and its associated factors on patients with ALL, as these patients have high cure rate if we target the most in alleviating problems that lead to abandonment, to increase the overall ALL treatment outcome.

This case control study aims to fill this gap by examining the factors of treatment abandonment among children receiving treatment for ALL at the Tikur Anbessa Specialized Hospital oncologic center and follow-up clinic. By identifying the socio-demographic, economic, clinical, treatment and other factors associated with treatment discontinuation, this study seeks to provide valuable insights that can inform future strategies to reduce treatment abandonment and improve outcomes for pediatric cancer patients in Ethiopia.

1.2 Statement of the problem

Treatment for Acute lymphoblastic leukemia (ALL) requires a prolonged and intensive regimen, spanning 3 years mostly, and any interruption can significantly reduce the chances of remission and long-term survival. If treated with proper chemotherapy, adequate supportive care and good patient adherence and compliance to treatment and follow-up, survival outcomes for children with ALL in low LMICs will reach the treatment outcome achieved in HICs.

A major contributing factor to the current disparity is treatment refusal and /or abandonment, where children/parents fail to initiation of treatment, or discontinuation of one or multiple treatment modalities for 4 or more weeks. This premature discontinuation of treatment has been

identified as one of the primary causes of failed treatment in pediatric oncology patients in LMICs, including Ethiopia.

Estimated survival in many countries in sub-Saharan Africa is below 20% and treatment abandonment is common. In a systematic review on 'Treatment abandonment in children with cancer in Sub-Saharan Africa', mothers only having primary education, being HIV negative, parents not being employed, travel and no insurance are significantly associated with treatment abandonment(8). And when parents who had abandoned treatment were asked, the most common reason was finance, followed by insurance, transport, lack of social support, their child appearing well, fear and waiting.

At Tikur Anbessa Specialized Hospital (TASH) in Addis Ababa, Ethiopia's largest referral center for pediatric oncology, a proportion of children the risk of abandonment varies according to cancer type, phase of treatment or treatment outcome.With overall perceived abandonment rate of 23%(7). In the case of ALL, the highest risk is in the maintenance phase, or if the patient didn't respond to treatment or relapse. Treatment abandonment in Ethiopia is influenced by multiple factors, such as socioeconomic constraints, cultural beliefs, geographical inaccessibility, and lack of sufficient healthcare resources. These barriers prevent children from receiving uninterrupted care and contribute to the high rates of mortality from a disease that is otherwise treatable.

Effect of treatment abandonment is variable. Delaying start of treatment or avoiding one form treatment increases the risk of death significantly. One study finds out that a treatment delay of four weeks is associated with an increase in the risk of death. For surgery, this is a 6-8% increase in the risk of death for every four week delay (9). Treatment discontinuations may also result in lower cure rates as a consequence, including the relapse of highly curable malignancies(10). Of the 35% patients refused or abandoned treatment in ALL patient in Indonesia, 23% experienced treatment-related death, 22% had progressive or relapsed leukemia, and 20% had an overall event-free survival (11). In Ethiopia, patients with an overall delay between 30 and 90 days were more likely to experience induction mortality(12).

Reported effective interventions to prevent treatment abandonment include providing assistance with costs for the families, adequate counselling of the disease and the need to complete treatment and active encouragement of families to return for treatment appointments (13).

Despite the importance of this issue, there is limited research on the magnitude of Acute lymphoblastic leukemia treatment abandonment and the factors that contribute to it in Ethiopia. Without clear data, efforts to reduce abandonment and improve treatment adherence remain hindered. Understanding the underlying causes of treatment abandonment is crucial for designing targeted interventions aimed at ensuring that more children complete their therapy and achieve better outcomes.

In addition, there was no follow-up system to detect and contact dropouts in most cancer centers(11) and health care providers were not fully aware that their own attitude and communication skills were important for ensuring compliance of patients and parents.

This study seeks to address this gap by examining determinant factors of treatment abandonment among children with ALL at TASH. The findings from this case control will provide crucial insights for healthcare providers and policymakers to develop strategies that reduce abandonment rates and ultimately improve survival for children with ALL in Ethiopia.

1.3 Significance of the study

This research is important for a number of reasons, especially in light of the fact that pediatric cancer care is concentrated at Tikur Anbessa Specialized Hospital (TASH), understanding the problem of treatment abandonment among children receiving therapy for Acute Lymphoblastic Leukemia (ALL) is imperative for enhancing survival rates and care quality in low- and middle-income nations (LMICs), such as Ethiopia.

For health authorities, this study will provide a much-needed foundation for additional research and interventions. For the hospital, the investigation will yield critical data on the prevalence of treatment desertion among children with ALL at TASH. In addition the professionals working at this and similar site will get information on the determinant factors and act up on to take their part in subsequent patient management.

To address the obstacles families encounter in completing the entire course of treatment, it is imperative to understand these variables. Determining these factors can help with the establishment of focused interventions that are suited to the particular requirements of the Ethiopian healthcare system and its patients. The study's findings will bring light on any settings where children with ALL and their families are not receiving enough care and support. The impact of this research could be strengthened by using the TASH findings to guide similar programs in

other LMICs dealing with related issues. In conclusion, this study is important because it aims to enhance treatment outcomes and lower treatment abandonment rates for ALL children at Tikur Anbessa Specialized Hospital. Additionally, it can be used as a model to address similar issues in other low-resource settings across the globe.

1.4 Objective of the study

To identify determinants of treatment refusal/abandonment among children with Acute Lymphoblastic Leukemia (ALL) at Tikur Anbessa Specialized Hospital Pediatric Oncology Treatment Center who took treatment between September 2019 to September 2024.

2. LITERATURE REVIEW

2.1 Burden of Acute lymphoblastic leukemia and abandonment of treatment in children.

Acute lymphoblastic leukemia is the most common pediatric malignancy, representing approximately 25% of cancer diagnoses and 75%–80% of acute leukemia among children(14,15). The age-adjusted incidence rate of ALL is 1.38- 4 per 100,000 individuals per year. In one systemic review ALL treatment abandonment rates in high-income, middle-income and low-income regions were 1.9%, 2.1% and 6.1%, respectively. The rate of treatment abandonment was 24.4% (22 patients) in Iran(16)In a physician based survey in Ethiopia for all pediatrics cancer cases, the mean perceived abandonment rate was 34% (standard error (S.E) 2.5). The estimate was the lowest for TASH 28.3% (S.E 3.5%), while it was 40.7% (S.E 4.4%) for Jimma University Hospital (JUH) and 40.6% (S.E 3.7%) for Gonder university hospital (GUH) (9).

2.2 Predictors of Treatment abandonment in children with acute lymphoblastic leukemia

2.2.1 Socioeconomic factors

Low socioeconomic status, low parental education, and long travel time to center (these three are here on referred to as social/economic factors)(17). In Ugandan study, financial difficulty, other obligations, the child falsely appearing cured, preference for alternative treatments, belief that cancer was incurable, fear that the child's death was imminent and chemotherapy side effects were the caregivers' reasons for treatment abandonment(18).

Economic difficulties were considered the main reason for abandonment across the all three income strata ($p<0.0001$) Patients from families in which the parents had only 9 years or less of education, were farmers or blue collar workers or were unemployed and thus earned less than CN¥50 000 per year were significantly more likely to abandon treatment for economic reasons than were patients from the remaining families; whereas families with more educated parents who had better paid occupations, the patients tended to abandon treatment for non-economic reasons, mainly the lack of belief in cure of ALL (exact X2 test, $p<0.05$).(19).

Based on the findings of the telephone survey study, it was evident that economic constraints were the primary driver of treatment abandonment in both ALL and AML patients, accounting for 92.8% and 94.4% of cases, respectively (20)

In a research assessing ‘Influence of socioeconomic status on childhood acute lymphoblastic leukemia treatment in Indonesia’, treatment results differed significantly between patients with different socioeconomic status; 47% of poor and 2% of prosperous patients refused or abandoned treatment. Most poor patients could not afford treatment. Access to donated chemotherapy also was inadequate (11). Nonmedical expenditure , the maximum expenditure being on food, risk of loss of job while in care are also reasons associated with treatment interruption and lost to follow-up(21)

However a study from Pakistan showed monthly income, age, and number of siblings had no impact on the decision to abandon treatment (22) .

Many studies indicate that abandonment rates markedly decrease when economic and educational support are provided to families with a child with cancer. In addition, interventions to enable treatment completion included full funding of costs to the family (treatment, transport, accommodation and food in the hospital) and tracking of patients if they did not attend treatment appointments, has decreased treatment abandonment from 19% (49/264) to 7% (10/150) ($p < .001$), in Malawi(23).

2.2.2 Clinical /patient factors

Treatment abandonment was significantly associated with age <1year or ≥10 years (p=0.0151), standard or high-risk treatment group (p=0.0004), failure to achieve complete remission (p<0.0001), positive MRD at day 19 (p=0.0127) or day 46 (p<0.0001) of remission induction, unfavourable leukaemia genotype (BCR-ABL1 fusion, MLL or PDGFRB rearrangement; p=0.0001)(19).

Some studies found Sex independently predicted TA on multivariable analysis. TA was higher in females than males (16·4% vs. 13·3%; p = 0·022) with adjusted MFR of 0·81 (0·66–0·98)(24). However recent systematic review found no difference in the proportion of treatment abandonment in girls relative to estimates observed in boys (rate ratio [RR] 0.95, 95% CI: 0.79-1.15; P = .61)(25)

2.2.3 Chemo toxicity related factors

According to a Chinese study, Of the 83 /out of 2641 cases of treatment abandonment, 28 (33.7%) occurred during the window/ induction phase, 18 (21.7%) during consolidation treatment, 19 (22.9%) during continuation treatment and 18 (21.7%) during the maintenance

phase(19).However result from global study showed risk of treatment abandonment was otherwise similar between pre-treatment, induction, and maintenance therapy phases(17). In Jordanian study, the most common reasons to abandon or refuse therapy were treatment intensity in view of poor tumor outcome or bad quality of life (26).Reactions to the severe side effects of intensive therapy (11/83, 13.3%) and concern over long-term complications (6/83, 7.2%)(19)

2.2.4 Knowledge and attitude related factors

The belief that leukaemia is incurable, reported by 27.7% of the respondents, was the second most common reason for abandonment, in Chinese multi center study (23/83, 27.7%)(19). The caregivers and medical team's discordant EM about the child's cancer and treatment must be acknowledged and shared decision making considered, together with consistency in the strategies that currently demonstrate to be effective decreasing abandonment(27). Global survey showed also preference for complementary and alternative medicine (CAM) and strongly held faith or religious beliefs, specially in LMIC plays significant reason for treatment abandonment.(17).

In a recent study from Kenya, interviews with parents who abandoned treatment showed a large proportion of parents to be ill-advised by their community (74% of parents had been advised to seek alternative treatment and 54% to stop medical treatment)(28). Without the balancing act of good communication strategies by providers and social/economic supports to complete therapy (through governmental or non-governmental program assistance), it should be no surprise if families opt to follow the guidance provided by their established social networks

2.2.5 Health system related factors

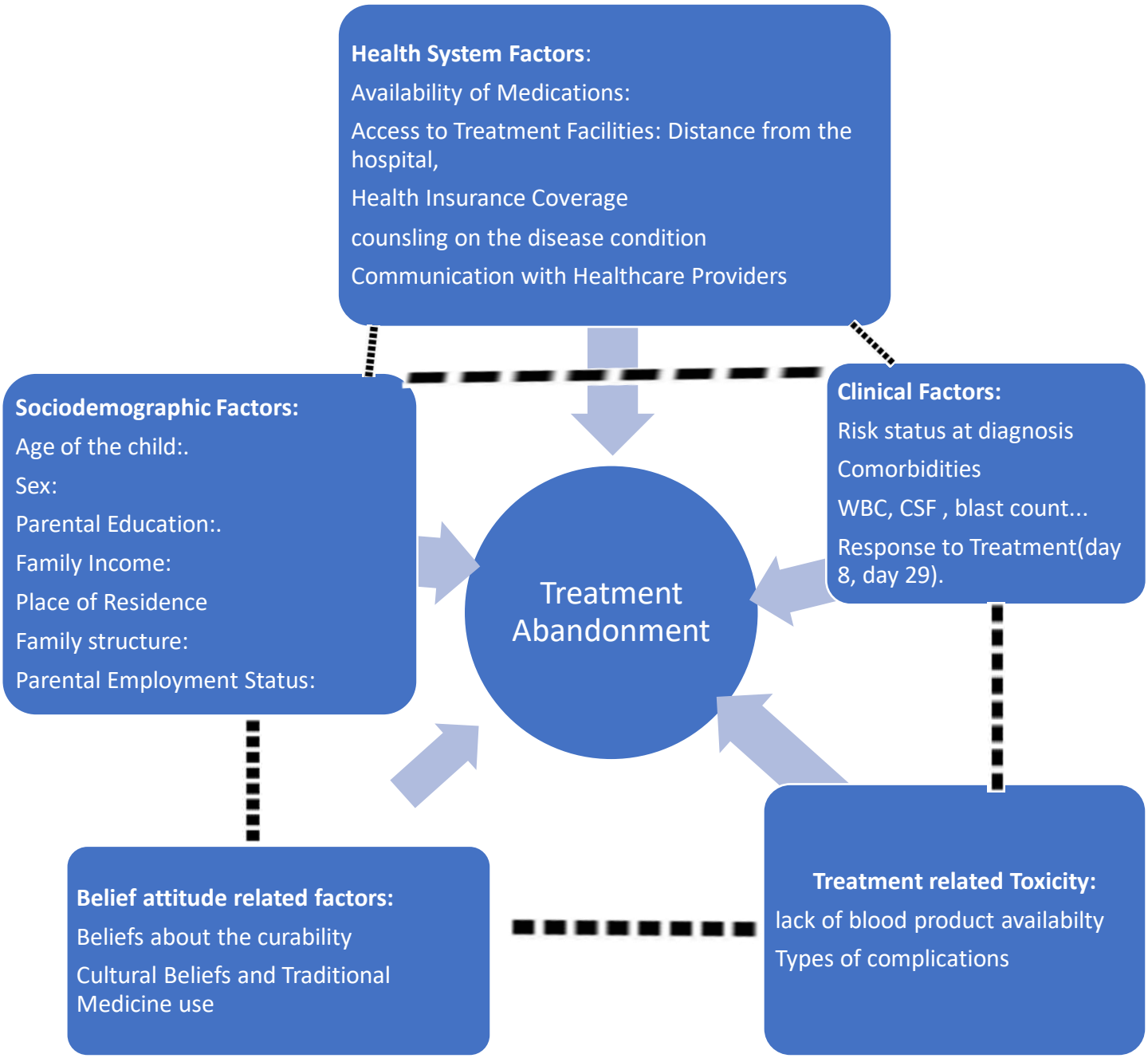
Most studies looking at determinants of TxA focus on the family. However, the role providers and centers play in swaying this phenomenon are emerging and the benefits of an integral and multidisciplinary approach have been documented. A shift in focus from static determinants of TxA (age, gender, diagnosis, prognosis, etc.) to more actionable factors such as perceived prognosis, communication, center’s capacities, and public awareness, allows shifting from traits we can’t necessarily control, to areas we can improve. Diagnostic delay, lack of specialized care provider and institutions are some of the reasons patients may be reluctant to start treatment. Insufficient communication, and painful diagnostic or therapeutic procedures were found to be associated with TxA(17).

Counseling should be given as per standard guidance of the institution by most senior cancer treating professional as conflicting recommendations from other health care providers has resulted being reason for discontinuing treatment(26).

2.2.6 Conceptual frame work

This framework is synthesized from different literatures which give a tabulated date and discussed the independent factors in the result sections(11,17,19,20,22,26–28). The frame work reflects how various factors interact to influence the likelihood of treatment abandonment, which is the study's central focus. Sociodemographic factors influence how a family might perceive and deal with treatment challenges. Clinical factors directly affect the medical aspects of treatment adherence and could contribute to abandonment if the disease is advanced or complications arise. Health system factors are crucial, especially in resource-limited settings, where lack of medications, long distances, and high costs can discourage families from continuing treatment. Social and psychological factors add another dimension, where stigma, cultural beliefs, or family dynamics can sway decisions to abandon treatment.

Figure 1. Figure 1 Conceptual frame work of determinant factors for treatment abandonment/refusal in management of children with Acute lymphoblastic leukemia at Tikur Anbessa Specialized hospital pediatrics oncologic treatment center, case control study, (11,17,19,20,22,26–28)



3. METHODS

3.1 Study area

The study was conducted at Tikur Anbessa Specialized Hospital, Addis Ababa Ethiopia, pediatrics hematology oncology unit. Tikur Anbessa Specialized Hospital is the largest tertiary hospital in the country and was the only pediatric hemato-oncology treatment center in the country until recently(29). The TASH pediatric cancer program, Supported by Aslan project is established in 2013G.C as independent unit and remains the most advanced and robust pediatrics hematology and oncology service unit in Ethiopia, handling more than 7000 in- and out-patient visits annually (both malignant and nonmalignant diseases) and an estimated 700 new cancer cases each year, coming from all over the country(12,30). Approximately 25-30 % of this cases are ALL (rough estimate of ALL will be 180-210, yearly). The unit is staffed with 4 consultant pediatrics- hemato-oncologists and seven (7) fellows who are to graduate in the field. The Unit treats oncologic patients at emergency, inpatient with 39 beds, and at separate follow-up and daycare clinic (a.k.a 'Amstegna'), where patients are being treated as outpatient or inpatient bases(12).

3.2 Study design and period

Unmatched case control study design was conducted from November 2024, to January 11, 2025.

3.3 Population

3.3.1 Source population

All Acute lymphoblastic leukemia patient managed at TASH pediatrics Hemato-oncology unit from September 2019 to August 2024

3.3.2 Study population

All children with acute lymphoblastic leukemia, who have full medical records and managed at TASH pediatrics Hemato-oncology unit from September 11, 2019 to August 31, 2024.

3.4 Eligibility criteria

3.4.1 Inclusion criteria

- **Cases**
    - Acute lymphoblastic leukemic Children (0-18) who didn't start treatment after decision to start or who lost from treatment schedule for four (4) or more weeks.

- **Controls**
    - Acute lymphoblastic leukemic Children (0-18), who received and completed treatment at Tikur Anbessa Specialized Hospital's Pediatric Oncology Treatment Center.

3.4.2 Exclusion criteria

For Both Cases and Controls

- Patients who were referred to other facilities/abroad
- Those ALL children on treatment currently, before 3years, unless abandoned Rx.

3.5 Study variables

3.5.1 Dependent variable/s

Treatment Abandonment (yes or No)

3.5.2 **Independent variables**:

Sociodemographic factors: Parental age, education level, religion, permanent residence and income, community health insurance availability

Clinical factors: age, sex, NCI risk status, response for induction (remission status)

Treatment related: phase of therapy at interruption time, drug related toxicity as reason for TxA,

Health service issues: Availability of drugs, communication problems with health care providers

Behavior, belief and attitude towards chemotherapy: seek alternative therapy, believe incurability

3.6 Operational definition

Treatment Abandonment = in this paper treatment abandonment refers to refusal to start treatment with diagnosed case of ALL or discontinuation of treatment for 4 or more consecutive weeks of the proposed treatment protocol.

Induction Remission= achievement of bone marrow status M1 (blast <5%) at the end of induction (day 29).

ALL diagnosis; presence of >25%lymphoblasts in the peripheral blood or bone marrow.

LMIC (low and middle income countries): Low and middle-income countries (LMICs) are economies with less than $12,615 GNI(gross national income) per capita(31)

3.7 Sample size determination

The sample size is determined by EPI info online sample size calculating application and cross checking with two population proportion formula for case control study (depicted here).

$$n \text{ (each group)} = \frac{(p_0q_0 + p_1q_1)\,(z_{1-\alpha/2} + z_{1-\beta})^2}{(p_1-p_0)^2}$$

By assuming:

- 95% of confidence interval ,
- 80% of power, 10% non-response rate ,
- proportion of exposed case 4%
- proportion of exposed control 13 % with
- AOR of 23.8 for race type as determinant for RxA(31)
- The sample size will be 376, and with 10% of nonresponse rate the final sample size becomes 414(controls= 272and cases=142).The case to control ratio is almost 1:2.

3.8 Sampling technique and procedure

Consecutive convenient sampling technique was employed to include the sample patients to the study. All Acute lymphoblastic leukemia patients who fulfil inclusion criteria for both the cases and controls were included consecutively to the study till the sample size fulfilled. We used consecutive sampling technique since our study population (pediatric leukemia/hematologic cancer) were rare, we used the average numbers of pediatrics ALL cases which is usually seen at our center per year times the number of years, the study is focusing.

3.9 Data collection procedure and instruments

3.9.1 Data collection procedure

The data was collected using structured questionnaires by phone calling the parents or guardians and medical record review was conducted. Data collectors were professionals who are pediatrics residents and psychologist working at the cancer center. During the data collection period the target study populations were included based on the sample size of the study which is a total of 414 patients (142 treatment refused or abandoned cases and 272 treatment completed cases). Data was collected by consecutive sampling techniques from the oncologic unit record data base.

3.9.2 Data collection measurements

Height and weight was measured according to WHO guidelines. For weight measurment: by using beam balance Height is measured by stadiometer by making knees strait, head in Frankfurt plane, heels, buttocks and shoulder blades touching vertical line of the stadiometer. For those age less than 2 years height is also measured in supine position with stadiometre. Calibration was made in between every patient and after moving instruments by measuring a known standardized material. BMI was calculated by dividing weight by height in meter squares. Mid upper circumference (MUAC) was measured by standard meter for MUAC at the mid point of upper arm.

3.10 Data Quality Control

First English version questionnaires were developed. Then it was translated to Amharic and then translated back to the English version to ensure its consistency. Three days intensive training to data collectors and supervisors were given about the purpose, study tools and the overall data collection procedures. In addition, pre-testing of the study tools was carried out in 5% of the total sample size at Saint. Powel Hospital Millennium Medical College, to identify potential problems in data collection tools so modification of the questionnaire will be done.

A total of 3 second year residents and 1 psychologist were employed as data collectors, and 1 third year resident was assigned as supervisor. The residents are selected with Good Amharic and Afaan Oromo language considering majority of parent's catchment area. Regular supervision and support was given for data collectors by supervisor and principal investigator. The collected data was reviewed and checked for completeness by the supervisor and principal investigator.

3.11 Data processing and analysis

Data was entered into kobotool box then exported to Statistical Package for Social Sciences (SPSS) version 30 for cleaning and analysis. Descriptive statistics was done to describe data. Bivariable logistic regression analysis was done. Those variables with p value less than 0.25 were entered for multivariable analysis. Adjusted odds ratio (AOR) with 95% Confidence interval was used to determine the strength of association. Variables with P<.05 were considered to indicate statistical significance. Variables that has association with treatment abandonment on bivariate analysis were checked for multicolinierity before the final model, and all the candidate for final models had variance inflation factor less than 1.2 and tolerance of greater than 0.87. Therefore there is no

problem with multicolinierity;- Hosmer and lemeshow test with Chi-squere of 5.631 with p value of 0.688

3.12 Ethical consideration

Ethical clearance letter was obtained from Pharma Health science and business college IRB committee and also from TASH pediatrics department ethical review committee. The data collectors clearly explained the aims of the study for study participants. Information was collected after obtaining verbal consent from each participant. The right was given to the study participants to refuse or discontinue participation at any time they want and the chance to ask anything about the study. For the purpose of anonymity the participant's name was not used at the time of data collection and all other personnel information kept entirely anonymously and confidentiality was assured throughout the study period. Data collector put their signature so they could obtain verbal consent for the interview from the respondents.

3.13 Data Dissemination

The results of the study will be submitted to Pharma college of Bussiness and Health Science, and after getting approved, hard copies of the findings will be disseminated to Addis Ababa University TASH health science college and other concerned bodies as well. The research paper will be presented in health professional organisations" annual meetings, professional conferences and training. Finally, attempts will be made to publish results in national and international journals to disseminate worldwide.

4. Results

4.1 Sociodemographic characteristics of respondents and children

In this study boys accounted, 69.5 % of the sex and out of the total 142 treatment abandoned (cases) 104(73.0%) were male. The mean (±SD) age was 6.37(±3.24) years for all the patients. Majority of the cases 104(73%) and controls 218(80%) were in the age group between 1 - 9.99 years. Parents from rural area account 44% but 48%(68/142) of the cases. Most of the case's (42%) and most of the control's (44%) parents has tertiary level education. Majority of the cases and controls (70% each) use community health insurance with government support. 58% of Respondents have monthly income less than 7500 ETB(Table 1)

Table 1: Socio economic characteristics of respondents and ALL children in Tikur Anbessa specialized hospital, Ethiopia, 2025

Characteristics		Group		Total (%)
		Cases (%)	Controls (%)	
Parental/Caregiver occupation	Unemployed	5(45.5)	6(54.5)	11(2.7)
	Daily laborer	11(35.5)	20(64.5)	31(25.1)
	Farmer	39(37.5)	65(62.5)	104(25)
	Merchant	24(27)	65(73)	89(21.5)
	Government employee	63(35.2)	116(64.8)	179**(43.2)**
Parental marital status	Divorced /Single	12(30)	28(70)	40(9.7)
	Widowed	2(25)	6(75)	8(1.9)
	Married	128(35)	238(65)	**366(88.4)**
Religion	Others (catholic, wakefena..)	5(31.3)	11(68.8)	16(3.9)
	Protestant	43(36.8)	74(63.2)	117(28.2)
	Orthodox Christians	45(32.8)	92(67.2)	137(33.1)
	Islam	49(34)	95(66)	**144(34.8)**
Role in treatment decisions	Other family member	5(45.5)	6(54.5)	11(2.7)
	Mainly father	34(34.7)	64(65.3)	98(23.7)
	Mainly mother	37(28.7)	92(71.3)	129(31.2)
	Both parents	66(37.5)	110(62.5)	**176(42.5)**

4.2 Clinical characteristics laboratory investigation findings of ALL patients enrolled in the treatment center.

The data shows that, 40.8% of cases and only 25% (83) of controls had known comorbidity. 50% cases and 43% of controls had either moderate or severe acute malnutrition. Most of, both controls and cases have complete blood count (CBC) in the range of less than 10, 000. Only 3% of controls but 43% cases found to have M2/M3 or uknown day 29 bone marrow status. Also in this study 65% of cases, while only 37% of controls in the high risk ALL group (Table2)

Table 2: Clinical characteristics and laboratory results of ALL children in Tikur Anbessa specialized hospital, Ethiopia, 2025.

Characteristics		Group		Total (%)
		Cases (%)	Controls (%)	
Day 8 response	Poor	20(64.5)	11(35.5)	31(7.5)
	Unknown	32(100)	0	32(7.7)
	Good	90(25.6)	261(74.4)	**351(84.8)**
CNS status at presentation	Positive	19(59.4)	13(40.6)	32(7.7)
	Negative	123(32.2)	259(67.8)	**382(92.3)**
Day 29 Bone marrow status (morphology)	M3 and M2	10(58.8)	7(41.4)	17(2)
	UKNOWN	48(98)	1(2)	49(6)
	M1	84(24.1)	264(75.9)	348(92%)
Risk group class	High	93(47.4)	103(52.6)	196(47.3)
	Standard	49(**22.5**)	169(77.5)	**218(52.6)**

4.3 Health service and clinical care providers related factors

The study data shows 57% of controls and 62% of cases come from a distance of 100-500km from the treatment center (Figure 2). The proportion of cases and controls not properly counselled, were 17% and 5% respectively (Table 3).

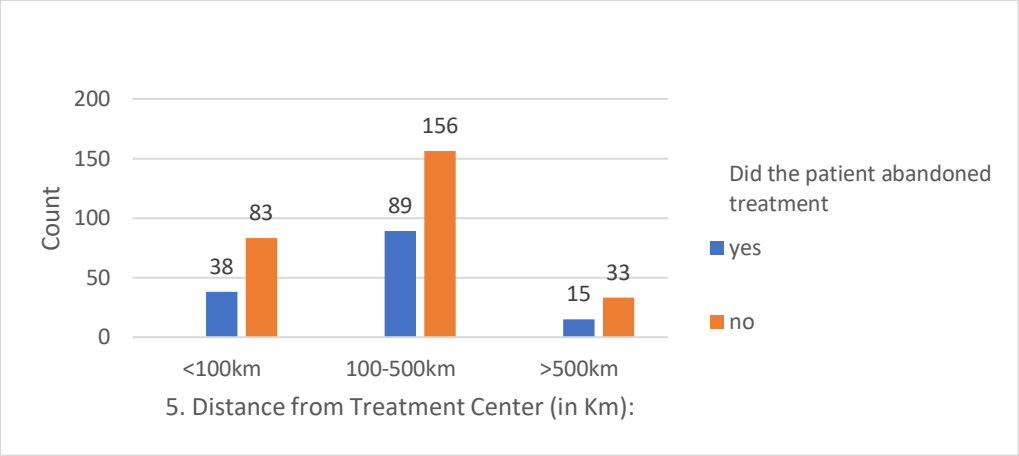


Figure 2: Respondent's residence distance from treatment center of pediatrics patients treated for acute lymphoblastic leukemia at Addis Ababa University , Tikur Anbessa Hospital, Jan, 2025 (N=414)

Table 3 Health service related characteristics of respondents and ALL children in Tikur Anbessa specialized hospital, Ethiopia, 2025.

Characteristics		Group		Total N(%)
		Cases (%)	Controls (%)	
Counseling about the disease and prognosis given by HP during start of treatment	No	24	14	38(9.2)
	Yes	118	258	**376(90.8)**
Blood product availability	Rarely available	9(64.3)	5(35.7)	14(3.4)
	Sometimes available	48(46.6)	55(53.4)	103(24.8)
	Always available	85(28.6)	212(71.4)	**297(71.8)**

4.4 **Belief and attitude of respondents and treatment related characteristics**

Fifty three percent of respondents believe curability to be less than 50 %, while 67% of the controls believe ALL is more curable than 50%. Almost equal percentage (50% each) of both cases and controls believe it is possible ALL is cured in non-medical intervention way.

Table 4 Belief, attitudes and treatment related characteristics of respondents and ALL children in Tikur Anbessa specialized hospital, Ethiopia, 2025

Characteristics		Group		Total
		Cases (%)	Controls (%)	
Involvement in religious or other support group	No	52	92	144(34.8)
	Yes	90	180	**270(65.2)**
Belief in non-medical alternative treatment for curative purpose	No	68	147	**215(52)**
	Yes	74	125	199(48)
Believe in curability of the diseases	incurable	8(80)	2(20)	10(2.4)
	<25% curable	10(62.5)	6(37.5)	16(3.9)
	25-50%	58(40.8)	84(59.2)	**142(34.3)**
	50-75%	39(35)	73(65)	112(27)
	>75%	27(20.2)	107(79.8)	134(32.3)
Complication During treatment	Neutropenic fever	69(27.9)	178(72.1)	**247(59.7)**
	Thrombocytopenia	8(72.7)	3(27.3)	11(2.6)
	Organ dysfunction	14(50)	14(50)	28(6.7)
	Significant nausea and vomiting	6(54.5)	5(45.5)	11(2.6)
	No complications	45(38.5)	72(61.5)	117(28.2)

4.5 Determinants of treatment abandonment in pediatrics ALL patients

The finding from this study shows that parental/guardian occupation of being a merchant has a 70% reduced risk (AOR=0.30, 95% CI, 0.07, 0.92)) in treatment abandonment than not employed counterparts. This study also reveals that those parents who believed curability of the disease is 25-50% is 3 times more likely to abandon treatment than those who believed curability is above 75% (AOR=2.92, 95% CI: 1.28, 6.66). Additionally, children who were severely malnourished had 3.1 times more risk of treatment abandonment (AOR=3.13, 95% CI: 1.44, 6.83) and those whose day 29 bone marrow result is either M2 or M3 had 5.8 times higher risk than those who

achieved remission (M1 marrow) (AOR= 5.77, 95% CI: 1.29. 25.95). Children when cared by both parents, has lesser risk for abandonment than those cared single parent or by other family member (AOR=2.26, 95% CI: 1.036, 4.94).

Table 5:- Bivariate and Multivariate analysis for independent predictors of treatment abandonment in children treated for ALL, at Tikur Anbessa Specialized Hospital, Ethiopia, 2025.

Characteristics		Group		COR(95%CI)	AOR (95%)	P value
		Cases (%)	Controls (%)			
Belief in curability of the disease	Incurable	8(80)	2(20)	4(.849-18.8)	.3(0-446)	.762
	<25%	10(62.5)	6(37.5)	1.667(.606-4.58)	3.4(.518-21.957)	.203
	25-50%	58(40.8)	84(59.2)	.690(.494-0.951)	2.9(1.283-6.659)	.011*
	50-75%	39(34.8)	73(65.2)	.543(.362-.788)	2.3(1.036-4.939)	0.041*
	>75%	27(20.1)	107(79.9)	1	1	
Nutritional status at diagnosis (W/H or BMI)	SAM	31(43.1)	41(56.9)	.756(.474-1.206)	3.1(1.437-6.833)	0.004
	MAM	40(34.2)	77(65.8)	.519(.355-.761)		.669
	No malnutrition	71(31.6)	154(68.4)	1	1	
Day 29 Bone marrow status (morphology)	M3 and M2	10(58.8)	7(41.4)	1.43(0.54, 3.75)	5.8(1.29, 25.95)	0.022*
	UKNOWN	48(98)	1(2)	48(6.63, 347.75)	144(12-1653)	0.001
	M1	84(24.1)	264(75.9)	1	1	
Provision of counseling during treatment start	No	24(72)	14(28)	1	1	
	Yes	118(24)	258(76)	0.58(0.30, 1.13)	0.3(0.11, 0.86)	0.024
Parental/Caregiver occupation	Unemployed	5(45.5)	6(54.5)			
	Daily laborers	11(35.5)	20(64.5)	0.55(.26, 1.15)		.552
	Farmer	39(37.5)	65(62.5)	0.60(0.40, 0.89)		.928
	Merchant	24(27)	65(63)	0.37(0.23, 0.59)	0.3(0.07, 0.92)	0.037*
	Government employee	63(35)	116(75)	.833(.254-2.731)	0.960(0.118-7.842)	.970

*Factors that have association at P- value <0.05, 1= reference value.

5. Discussion

There are various reasons for treatment abandonment in different studies. However, our study showed that factors independently associated with treatment abandonment of acute lymphoblastic leukemia were; severe malnutrition at admission, poor day 29 morphologic response, caregiver occupation, belief in curability of the disease, and provision of counseling at the start of treatment and care giver type.

In this study the Parents belief in curability had made significant difference in treatment abandonment rate. A study done in Ethiopia showed poor public awareness about the curability of childhood cancer was perceived barriers for treatment abandonment (7). In similar study in Indonesia, belief about incurability of ALL was the reason for abandonment, reported by 22 (60%) respondents. *(32)* . Similarly in large cohort study in china, the belief that leukaemia is incurable, reported by 27.7% of the respondents, was the second most common reason for abandonment(19). This finding is also in line with that done in southeast Iran (16). Parents of patients who refused treatment due to their beliefs about incurability thought that chemotherapy would not result in a better quality-of-life and would only cause side-effects. Their beliefs were based on stories from sources such as magazines, newspapers, and internet. Proper education on curability will change the perception, hence continuation of treatment (32)

This study reveals that severe wasting was 3 times independently associated with treatment refusal and abandonment in children with ALL. Similarly a study done in Mexico also found children with good nutritional status at presentation was able to complete their treatment(33). Good nutritional status improves tolerance of treatment, diminish toxicity, and improve the quality hence helping parents continuing treatment with hope iof survival(34). However, this result was not strongly supported In a global survey done in 2016, that the overall importance attributed to nutritional status was lower, but may be significant in LMIC(17)

In the present study poor day 29 response of induction treatment was independently associated with treatment abandonment. This finding is consistent with study done in a tertiary hospital in Mexico where a significant association was found with positive minimal residual disease after induction treatment (p=0.001) and treatment abandonment (33). And also, this finding is consistent with study conducted in China (OR 3.57, 95% CI 1.90 to 6.74) (19). The association of day 29

(end of induction) and treatment abandonment is explained by that those having poor response for induction is likely to

In this study counseling was significantly determinant in abandonment. A study in Indonesia also shows lack of communication with doctors, resulting in a lack of parental understanding of the necessity to continue treatment was a strong factor for treatment abandonment(35). Similar study in India showed treatment abandonment is lower in group counselled (20.3%) as compared with those with basic support (30.2%), (P = 0.001)(36) Hence, parental counselling, emphasizing on treatment adherence and the aftermaths of treatment abandonment, is indispensable for preventing abandonment in semi-literate populations.

In the current study, type of occupation was found to be treatment abandonment factor. This was also supported in the Chinese multi-center study (19)were farmers or blue collar workers or unemployed were significantly more likely to abandon treatment patients from who had better paid occupations. This could be indirectly due to economic reasons that those in the above jobs earned less per year, hence likely to withdraw from treatment for the obvious reason. This finding was also supported by a study in Pakistan, Karachi, were guardians occupation correlated with increased abandonment (37)

5.1 Limitation of the study

The study has several limitations, but the major shortcoming is that we conducted a phone interview to parents who most has already lost their child and to ask the parent why they abandoned or refuted treatment in such condition may give biased answer in some aspect. As a result, we may have missed some key influencing factors on demand side barriers. Another limitation is that this is a retrospective data collection from medical records in which recall and not getting full data has made us to remove some of our independent factors which may have association with our dependent variable. However, our findings are still relevant in terms of informing national childhood cancer control programs and augmenting global knowledge about the incidence and risk factors of abandonment of childhood cancer treatment, given that the findings are consistent with those of other studies conducted in a similar setting.

6. CONCLUSION AND RECOMMENDATION

6.1 Conclusion

The present finding suggest that treatment refusal and abandonment are still a really significant problem. Based on our results Distance from treatment center, beliefs about ALL curability, fear and experience of severe side-effects, improper counsling and dissatisfaction with HCP should all be addressed to prevent abandonment. Education programs for parents and communities as well as psychosocial support for parents and patients are recommended. Other important interventions are improvement of supportive care, improvement of knowledge and skills of HCP, better coaching of young residents and prevention and adequate management of severe side-effects.

6.2 Recommendations

To Ministry of health, Ethiopia

The MOH through the national childhood cancer programs, should prioritize and address the supply- and demand-side barriers for treatment and supportive care of children with acute lymphoblastic leukemia.

Give emphasis in stablishing satellite clinics for continuing the treatment of this prolonged treatment course for ALL, at the parents vicinity as much as possible.

Create media advocacy to advice the public about curability of child hood Acute lymphoblastic leukemia.

To Addis Ababa University, Tikur Anbessa Specialized Hospital

Search and establish twining projects with international support agents in improving care, both medical and social for cancer treatment.

Avail supporting staff like nutritionist and psychologists for the nutritional support and proper counseling on the disease at the start and course of treatment.

For future researchers

It is highly recommended if future researches target projects that will trace parents who abandoned treatment and any supportive ways provided with help of government of Ethiopia and international organizations.

7. REFERENCES

1. CureAll Framework: WHO Global Initiative for Childhood Cancer Increasing access, advancing quality, saving lives.
2. Inaba H, Mullighan CG. Pediatric acute lymphoblastic leukemia. Vol. 105, Haematologica. Ferrata Storti Foundation; 2020. p. 2524–39.
3. 22204242.
4. Mostert S, Singh Arora R, Arreola M, Bagai P, Friedrich P, Gupta S, et al. Comment Abandonment of treatment for childhood cancer: position statement of a SIOP PODC Working Group. 2011; Available from: www.thelancet.com/oncology
5. Benedetti DJ, Hammack-Aviran CM, Diehl C, Beskow LM. Landscape of pediatric cancer treatment refusal and abandonment in the US: A qualitative study. Front Pediatr. 2023 Jan 9;10.
6. cc2013_108-112-Ethiopia-PEDIATRIC-ONCOLOGY-NEW_2012.
7. Mirutse MK, Tolla MT, Memirie ST, Palm MT, Hailu D, Abdi KA, et al. The magnitude and perceived reasons for childhood cancer treatment abandonment in Ethiopia: from health care providers' perspective. BMC Health Serv Res. 2022 Dec 1;22(1).
8. Mansell R, Purssell E. Treatment abandonment in children with cancer in Sub-Saharan Africa: Systematic literature review and meta-analysis. J Adv Nurs [Internet]. 2018;74(4):800–8. Available from: https://onlinelibrary.wiley.com/doi/abs/10.1111/jan.13476
9. Hanna TP, King WD, Thibodeau S, Jalink M, Paulin GA, Harvey-Jones E, et al. Mortality due to cancer treatment delay: systematic review and meta-analysis. BMJ. 2020 Nov 4;371:m4087.
10. Salaverria C, Rossell N, Hernandez A, Fuentes Alabi S, Vasquez R, Bonilla M, et al. Interventions targeting absences increase adherence and reduce abandonment of childhood cancer treatment in El Salvador. Pediatr Blood Cancer. 2015 Sep 1;62(9):1609–15.
11. 17074838.
12. Hailu A, Mekasha A, Hailu D, Fentie AM, Korones DN, Gidey AM. Impact of Delay Prior to Treatment in Ethiopian Children with Acute Lymphoblastic Leukemia. Pediatric Health Med Ther. 2023 May;Volume 14:147–57.
13. Chagaluka G, Afungchwi GM, Landman L, Njuguna F, Hesseling P, Tchintseme F, et al. Treatment abandonment: A report from the collaborative African network for childhood cancer care and research—CANCaRe Africa. Pediatr Blood Cancer. 2021 Dec 1;68(12).
14. Brown P, Inaba H, Annesley C, Beck J, Colace S, Dallas M, et al. Pediatric acute lymphoblastic leukemia, version 2.2020. Vol. 18, JNCCN Journal of the National Comprehensive Cancer Network. Harborside Press; 2020. p. 81–112.
15. Inaba H, Pui CH. Advances in the diagnosis and treatment of pediatric acute lymphoblastic leukemia. J Clin Med. 2021 May 1;10(9).
16. Naderi M, Esmaeili Reykande S, Tabibian S, Alizadeh S, Dorgalaleh A, Shamsizadeh M. Childhood acute lymphoblastic leukemia: Refusal and abandonment of treatment in the southeast of Iran. Turk J Med Sci. 2016;46(3):706–11.

17. Friedrich P, Lam CG, Kaur G, Itriago E, Ribeiro RC, Arora RS. Determinants of treatment abandonment in childhood cancer: Results from a global survey. PLoS One. 2016 Oct 1;11(10).
18. Atwiine B, Busingye I, Kyarisiima R, Baluku E, Mbabazi R, Bamwine B, et al. "Money was the problem": Caregivers' self-reported reasons for abandoning their children's cancer treatment in southwest Uganda. Pediatr Blood Cancer [Internet]. 2021;68(11):e29311. Available from: https://onlinelibrary.wiley.com/doi/abs/10.1002/pbc.29311
19. Cai J, Yu J, Zhu X, Hu S, Zhu Y, Jiang H, et al. Treatment abandonment in childhood acute lymphoblastic leukaemia in China: A retrospective cohort study of the Chinese Children's Cancer Group. Arch Dis Child. 2019 Jun 1;104(6):522–9.
20. Tejada Vasquez AC, Gomez E, De La Garza F, Coronado Alejandro EU, De La Cruz-De La Cruz C, García-Zárate V, et al. Lost and Found: A Mixed Methods Study on Treatment Abandonment in Acute Leukemia. Blood. 2023 Nov 2;142(Supplement 1):2439–2439.
21. 25940031.
22. 28960700.
23. Chakumatha E, Khofi H, Landman L, Weijers J, Bailey S, Chagaluka G, et al. Towards zero percent treatment abandonment of patients with common and curable childhood cancer types in Blantyre, Malawi. Pediatr Blood Cancer [Internet]. 2022;69(12):e29899. Available from: https://onlinelibrary.wiley.com/doi/abs/10.1002/pbc.29899
24. Bhatia KP, Ganguly S, Sasi A, Kumar V, Agarwala S, Meel R, et al. Sex Bias in Treatment Abandonment of Childhood Cancer in India. Indian J Pediatr [Internet]. 2024; Available from: https://doi.org/10.1007/s12098-023-05010-z
25. Palagyi A, Balane C, Shanthosh J, Jun M, Bhoo-Pathy N, Gadsden T, et al. Treatment abandonment in children with cancer: Does a sex difference exist? A systematic review and meta-analysis of evidence from low- and middle-income countries. Int J Cancer [Internet]. 2021;148(4):895–904. Available from: https://onlinelibrary.wiley.com/doi/abs/10.1002/ijc.33279
26. Amayiri N, Bouffet E. Treatment abandonment and refusal among children with central nervous system tumors in Jordan. Pediatr Blood Cancer [Internet]. 2021;68(8):e29054. Available from: https://onlinelibrary.wiley.com/doi/abs/10.1002/pbc.29054
27. 27862585.
28. 24789661 (1).
29. Mamo W, Moges A, Yesuf SA, Mohamedsaid A, Arega G. Treatment outcomes of pediatrics acute myeloid leukemia (AML) and associated factors in the country's tertiary referral hospital, Ethiopia. BMC Cancer. 2024 Dec 1;24(1).
30. cc2013_108-112-Ethiopia-PEDIATRIC-ONCOLOGY-NEW_2012.
31. Alvarez M, Grillo E, Bolivar S, Piedrahita V, Guerrero J, Ardila J, et al. Cali's Cancer Registry (2009-2024); Sanofi-Espoir-Foundation. Colombian Oncology and Hematology Association-ACHOP. 2009.
32. Sitaresmi MN, Mostert S, Schook RM, Sutaryo, Veerman AJP. Treatment refusal and abandonment in childhood acute lymphoblastic leukemia in Indonesia: an analysis of causes and consequences. Psychooncology [Internet]. 2010;19(4):361–7. Available from: https://onlinelibrary.wiley.com/doi/abs/10.1002/pon.1578

33. Luis J, Melo R, Gonzalez-Ramella O, Friedrich P, Ramirez J, Gallegos S, et al. RISK FACTORS FOR TREATMENT ABANDONMENT IN CHILDREN WITH ACUTE LYMPHOBLASTIC LEUKEMIA. A STUDY FROM A TERTIARY CARE HOSPITAL IN MEXICO RISK FACTORS FOR TREATMENT ABANDONMENT IN CHILDREN WITH ACUTE LYMPHOBLASTIC LEUKEMIA. A STUDY FROM A TERTIARY CARE HOSPITAL IN MEXICO Background and Aims. Available from: https://www.researchgate.net/publication/365319318
34. Khatib S El, Omar M. Nutritional Considerations in Childhood Acute Lymphoblastic Leukemia. Cancer and Oncology Research. 2020 Jan;6(1):11–25.
35. Mostert S. Influence of socioeconomic status on childhood acute lymphoblastic leukemia treatment in Indonesia , 2006
36. Alam A, Kumar A. Impact of financial support and focussed group counselling on treatment abandonment in children with acute lymphoblastic leukaemia. Experience over 22 years from North India. Psychooncology. 2019 Feb 1;28(2):372–8.
37. Siddiqui DE, Predictors of treatment abandonment for patients with pediatric cancer at Indus Children Cancer Hospital, Karachi, Pakistan. 2018

8. APPENDICES

QUESTIONNER

Research title: DETERMINANT FACTORS OF TREATMENT REFUSAL AND ABANDONMENT IN CHILDREN WITH ACUTE LYMPHOBLASTIC LEUKEMIA AT TIKUR ANBESSA SPECIALIZED HOSPITAL PEDIATRICS ONCOLOGIC UNIT, A CASE CONTROL STUDY.

Data Collection Questionnaire

This questionnaire is designed to collect data on treatment abandonment and determinant factors in children with acute lymphoblastic leukemia at Tikur Anbessa specialized hospital pediatrics oncologic unit, retrospective case control study. The privacy of patients and hospitals is rigorously maintained. Please complete the following sections carefully to ensure the study's success

I. Socio - Demographic Information

1. Patient ID/Record Number (to maintain anonymity): _____
2. Age at Diagnosis _____
3. Gender:
    a. Male
    b. Female
4. Place of Residence:
    a. Rural
    b. Urban
5. Distance from Treatment Center (in Km):
    a. <100km
    b. 100- 300km
    c. 300- 500km
    d. >500km
6. Parental Education Level:
    a. No formal education
    b. Primary education

c. Secondary education

d. Tertiary education

7. Parental Occupation:

    a. Unemployed

    b. Laborer

    c. Professional

    d. Other (specify): _____

8. Marital status of the caregiver parent

    a. Married

    b. Divorced /Single

    c. Widow

9. Religion

    a. Orthodox Christian

    b. Muslim

    c. Protestant

    d. Catholics

    e. Others (specify)

10. Family Income Level:

    a. Low

    b. Middle

    c. High

11. Financial Support for Treatment

    a. community health insurance

    b. own pocket money

    c. From institution, parent is working

12. Access to Medication during course of treatment:

    a. Always available

b. Sometimes available

c. Usually unavailable

13. Access to Health Services:

a. Easy

b. Moderate

c. Difficult

14. Adherence to Follow-up Appointments:

a. Regular

b. Occasional

c. Rare

II. Knowledge and Psychosocial

1. Family Involvement and Support:

a. High

b. Moderate

c. Low

2. Role in Treatment Decisions:

a. Mother

b. Father

c. Both

d. Other (specify): _____

3. Belief of curability of the disease

a. Incurable

b. <25% curable

c. 25-50% curable

d. 50-90% curable

e. Highly curable(>90%)

4. Involvement in religious and or other support group

a. Yes (specify) _____

b. No

5. Belief in alternative medicine for treatment/ curation of the disease

a. None

b. Religious / praying

c. Going to holy water

d. Traditional medicine use

e. Others(specifiy_____

III. Baseline Medical History and Clinical Information

1. Family History of Cancer:

a. Yes

b. No

2. Weight and Height at Diagnosis:

a. Weight: _____

b. Height: _____

3. Nutritional Status at Diagnosis

a. Well-nourished

b. Moderate malnutrition

c. Severe malnutrition

4. White Blood Cell Count at Diagnosis:

a. <10,000/µL

b. 10,000-50,000/µL

c. >50,000/µL

5. CNS Involvement at Diagnosis:

a. Yes

b. No

6. Risk Group Classification:

a. Standard-risk

b. Intermediate-risk

c. High-risk

7. Comorbidities at Diagnosis:

a. Yes

b. No

c. If yes, specify: _____

8. Blast Cell Percentage in Bone Marrow at Diagnosis: _____%

9. Day 8 response

a. Good

b. Poor

10. Day 29 bone marrow status

a. Remission achieved

b. Remission not achieved

IV. Treatment and Health service related factors

1. Chemotherapy Compliance:

a. Yes

b. No

c. If no, specify reason: _____

2. Complications During Treatment:

a. Infections (specify type and frequency): _____

b. Organ toxicity (specify): _____

c. Significant nausea and vomiting

d. Other (specify): _____

3. Requirement of expensive antibiotics

a. Yes

b. No

4. Adherence to Treatment:

a. High (≥95%)

b. Moderate (75-94%)

c. Low (<75%)

d. Reasons for non-adherence (specify): _____

5. Treatment Interruptions:

a. Yes

b. No

If yes, specify reason: _____

6. Blood product availability,

a. Available the whole treatment course

b. Available sometimes

c. In available most of the time

7. Counseling given on the disease, treatment and expected outcome by health profesionals

a. Yes

b. No

8. How do you assess communication of health care workers during treatment

a. Good

b. Bad

c. Fair

V. Treatment completion status

1. Did the patient abandoned treatment

a. Yes

b. No

2. When was treatment abandoned: during _____

a. Before the start of induction

b. induction

c. Consolidation

d. Interim maintenance
e. Delayed intensification
f. Maintenance 1
g. Maintenance 2

3. Reason for treatment abandonment given by the care giver (can circle many)_____

a. Family issues
b. Financial inability to continue treatment
c. Treatment center distant from home
d. Toxicity during therapy
e. Belief in incurability
f. Seeking alternative treatment
g. Others (specifiy)