**ADDIS ABEBA UNIVERSITY**

**COLLEGE OF HEALTH SCIENCE**

**SCHOOL OF NURSING AND MIDWIFERY**

**DEPARTMENT OF CLINICAL ONCOLOGY**

# HEALTH RELATED QUALITY LIFE (HRQoL) AMONG PATIENTS WITH CHILDHOOD LEUKEMIA IN TIKUR ANBESSA SPECIALIZED HOSPITAL, ADDIS ABABA, ETHIOPIA. 2023

**BY: MEGERTU KALBESSA (BSc.)**

**ADVISORS: MR. YOHANNES AYALEW (ASSISTANT PROFESSOR)**

**MR. BOKA DUGASSA (MSC)**

**A THESIS SUBMITTED TO ADDIS ABABA UNIVERSITY, COLLEGE OF HEALTH SCIENCES, SCHOOL OF NURSING AND MIDWIFERY, DEPARTMENT OF NURSING IN PARTIAL FULFILLMENT OF THE REQUIREMENTS FOR MASTER OF SCIENCE IN CLINICAL ONCOLOGY NURSING**

**MAY, 2023**

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## APPROVAL SHEET
## ADDS ABABA UNIVERSITY

## COLLEGE HEALTH SCIENCE SCHOOL OF ALLIED SCIENCES

## DEPARTMENT OF NURSING AND MIDWIFERY

I, the undersigned MSc student, declare that I have submitted my original work on a title Health Related Quality Life (HRQoL) Among Patients with Childhood Leukemia for the examination.

**Submitted by:**

_____ _____ _____

Name of student Signature Date

Approved by:

1. _____ _____ _____

   Name of Major Advisor Signature Date

2. _____ _____ _____

   Name of Co-Advisor Signature Date

**3.** Dr.Girum Sebsibe ( PhD, Asst. professor) _____ _____

Department Head Signature Date

## Statement of Declaration

By my signature below, I declare and affirm that this thesis is my own work. I have followed all ethical principles of scholarship in the preparation, data collection, data analysis and completion of this thesis. All scholarly matter that is included in the thesis has been given recognition through citation. I affirm that I have cited and referenced all sources used in this document. Every effort has been made to avoid plagiarism in the preparation of this thesis.

This thesis is submitted in partial fulfillment of the requirement for a graduate degree from the Addis Ababa University at College of Health Sciences, School of Allied Health Sciences department of Nursing and Midwifery. The thesis is deposited in the Addis Ababa University Digital Library and is made available to local, national and international scientific community. I solemnly declare that this thesis has not been submitted to any other institution anywhere for the award of any academic degree, diploma or certificate.

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## Acronym

ALL: Acute lymphoblastic leukemia

AML: Acute myeloid leukemia

HRQoL: Health related quality of life

IRB: Institutional Review Board

Peds- Pediatrics

PI: Primary Investigator

TASH: Tikur Anbesa Specialized Hospital

WHO: World Health Organization

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# Abstract

**Background**

There has been a paradigm shift in health service delivery to a more holistic approach, which considers Health Related Quality of Life (HRQoL) and overall functioning. HRQoL is a multidimensional construct that encompasses physical functioning as well as psychosocial aspects of emotional and social functioning. Childhood Leukemia is among threats to HRQoL to the patients and parents of the children, which trigger extensive studies on the subject.

**Objective**

The study objectives were twofold. Primarily, the statuses of HRQoL of childhood leukemia patients in TASH were assessed. Secondly, factors affecting HRQoL among childhood leukemia patients in TASH were examined.

**Method**

The study employed mixed research approach where descriptive design and explanatory research design concurrently utilized. Questionnaire distributed to sample of 422 respondents with 100% response rate. Data were analyzed through descriptive analysis, regression analysis and correlation analysis.

**Result**

The study revealed that, f 422 patients (57% males) with leukemia; their ages ranged from 5 to 14 years (Mean = 8.58, Standard Deviation = 2.56). Age and gender had a significant and positive relationship with HRQoL of childhood leukemia in TASH. Male children were found to be more exposed to the disease, while an increase image improves physical functioning aspect HRQoL. Addiction free habit of parents had a positive relationship with HRQoL and school functioning at $p < 0.05$. Chemotherapy morbidity however worsens physical wellbeing of the patients. All other correlations were statistically non-significant. The current findings added to HRQoL research, and provided an impetus for more research in the area of HRQoL for children with leukemia in Ethiopia.



Key words

Health Related Quality of Life, Childhood Leukemia

# 1. INTRODUCTION

## 1.1. Background of the Study

Leukemia is the cancer of the white blood cells. It is a cancer that exerts negative effects on blood-producing tissues including bone marrow and related with asymmetrical progression of white blood cells. The malignant disease causes abnormal hematopoietic tissue that can seriously threaten the life and health of any age but particularly children ([1], [2]).

According to WHO Leukemia is the most common type of cancer in children aged less than 15 years, worldwide [1]. The incidence rate of leukemia may have varied from region to region, ranging from 17.94 per 100,000 in Asia and Oceania to 37.74 per 100,000 in America, Canada, and Europe [2]. In the same trend, leukemia is found to be leading type of cancer among developing countries' children for decades particularly surging in children less than 14 years of age . Childhood leukemia is mostly acute lymphocytic or acute myeloid leukemia; chronic types are rare, but characterized by high malignancy. Despite its prevalence the survival rates have increased over the last 50 years [1], but relapse is frequent. Chemotherapy is found to be the main treatment that boosted survival rates of childhood leukemia. Under this treatment only few high-risk patients need radiotherapy or hematopoietic stem cell transplantation. Chemotherapy generally involves combinations of multiple drugs and courses of treatment. Without timely intervention, the leukemia patient's condition may deteriorate, with anemia, infection, disseminated intravascular coagulation, septicemia, intracranial hemorrhage, and other serious complications affecting prognosis.

Despite excellent survival outcomes from chemotherapy complains from patients, parents and researchers raise questions about how to balance treatment-related morbidity and HRQOL among children [3]. The adverse effect of the cancer and its treatment process is that it significantly impact the life quality the patients and their care-givers. Quality of life in children is defined as a multidimensional construct, comprised of the children's perception of the impact of disease and treatment on their functioning in the various domains of life; including physical, emotional, social and school [4].

Regarding the level of quality of life in children with cancer, the results of the previous studies can be different, while some studies reveal that cancer children reported the cancer-threatening quality of life ([5], [6]), few researchers reported high quality of life [7].

However, majority concluded that children with leukemia and their parents face unusual challenges that affect their quality of life (HRQOL) and psychological health. Even though assessment of pediatric patients' HRQOL is quite difficult this research sought to assess quality of life among children attended to TASH oncology unit based on KINDIL's standards of HRQOL for children.

## 1.2. Statement of the problem

According to empirical evidences, chemotherapy treatment significantly improved the survival rate of children with leukemia to over 87% in UK, US, Canada and developing countries with no increase in relapse risk associated [8]. However**,** these excellent survival outcomes raise questions about how to balance treatment-related morbidity and health-related quality of life. In this regard, many studies indicate that the number of leukemic children is increasing and the quality of life of the patients and their parents were affected due to the disease related factors and other various factors. Some of the factors included Physical side effects of chemotherapy, repeated hospitalizations and associated limitations for social and physical opportunities ([9], [3]). Other factors included social, economic and demographic characteristic of both patients and parents [4]. Some investigations affirmed that psychological impact of the cancer adversely influences life quality of leukemic children ([4], [10]). Empirical evidences explained impact of leukemia on various HRQOL indicators of pediatric patients. The most common impact of leukemia on HRQoL discussed in literature is the physical wellbeing of patients ([2], [10], [11], [4]). Despite variations on socio-demographic factors, treatment related factors, and clinical stage factors, the studies indicated that more than 80% of patients suffer in their quality of life from physical impact of the cancer ([4], [10], [11]). Some of these studies also analyzed impact of the cancer on children on HRQoL like social wellbeing and self-esteem also known as psychological wellbeing (2, 8). In this regard the studies also found out quite impact of leukemia on self-esteem and their relationship with friends, family and school mates ([4], [11], [7, 12]). Studies also investigated the economic impact of leukemia on caregivers and the patients (4, 46). The outcomes of the studies may have slight variations considering contributing factors of

HRQoL. However, it is indicated that leukemia impact HRQoL in Pysical health related perspective, psychological perspective, and social, family and school relationship perspectives. In addition majority of the studies explained the relationship between HRQoL and socio-demographic factors, treatment related factors, clinical stage factors and risk group factors ([1], [10], [11], [4, 13], [14], [15]). On the other hand child leukemia is a concern in all economic settings, developed and developing economies [16]. In developing countries, the influence of leukemia is massive attributable to premature death of children, loss of parents, failure of productivity due to disability, and high medical costs affecting the social, economic , health well-being of the population and over all patients HRQOL ([14], [15]).

Despite empirical evidences across the world, there is scanty HRQOL related empirical evidence of pediatric patients suffering from leukemia in Ethiopia. This study motivated by the adversity of the cancer on HRQOL on children and the fact that there is knowledge gap in Ethiopian context.

## 1.3. Significance of the study

Understanding the magnitude and impact of leukemia is essential to guide establishing evidence-based decision making and what action would be required. Also, it provides up to date information that helps in formulating policies, strengthening existing prevention program and maintaining the public health. Besides, the study would serve as important reference by adding the value of existing literature on hematological abnormalities and assist the teaching-learning process in a development-related discipline like oncology-related specialties.

## 1.4. Research question

The following research questions direct the research problem discussed in this study:

•RESEARCH QUESTION 1: How is the health related quality of life (HRQOL) of pediatric patients with leukemia in Tikur Anbessa Specialized Hospital, Oncology department, Addis Ababa, Ethiopia?

RESEARCH QUESTION 2: What are the factors affecting the health related quality of life (HRQOL)pediatric patients with leukemia in Tikur Anbessa Specialized Hospital, Oncology department, Addis Ababa, Ethiopia?

# 2. LITERATURE REVIEW

## 2.1. Overview of Leukemia

Leukemia is defined as the cancer of the white blood cells. It is a cancer that exerts negative effects on blood-producing tissues including bone marrow and related with asymmetrical progression of white blood cells [1]. It is the most common childhood cancer, and despite cure rates exceeding 90% in children, it remains an important cause of morbidity and mortality in children and adults [17]. The past decade has been marked by extraordinary advances into the genetic basis of leukemo-genesis and treatment responsiveness in leukemia ([1], [4]). Both B-cell and T-cell leukemia comprise multiple subtypes harboring distinct constellations of somatic structural DNA rearrangements and sequence mutations that commonly perturb lymphoid development, cytokine receptors, kinase and Ras signaling, tumor suppression, and chromatin modification. Recent studies have helped to understand the genetic basis of clonal evolution and relapse and the role of inherited genetic variants in leukemo-genesis.

Many of these findings are of clinical importance, and ongoing studies implementing clinical sequencing in the management of leukemia are expected to improve diagnosis, monitoring of residual disease, and early detection of relapse and to guide precise therapies, overall survival rate. One the greatest success story in the field of oncology is the dramatic increase in survival rate of children with leukemia [4]. However, the challenges of morbidity and alleviated life quality of patients' during course of treatment or post treatment emerged as spotlight of investigation. The literature review section present the theories, empirical evidences of quality of life among Pediatric leukemia patients.

## 2.2. Overview of Quality of Life among Leukemia Patients

The review of the literature identified classical sources as early as 1989 in which the focus was an attempt to define and develop a measurement tool for HRQOL from the perspective of patients with leukemia [18]. There have been numerous research studies that have tried to define HRQOL from the parent's perspective, the nurse's perspective, and the child's perspective ([8, 19, 20] ).

However, earlier literatures did not reveal any specific research measuring the HRQOL of childhood cancer survivors, more specifically, children treated for leukemia.

Studies as recent as 2021, were focused on; physical, emotional, family and social wellbeing dimensions of HRQOL.

The chronological review of the studies may show different dimensions of HRQOL in different countries and cultural settings. However, despite emphasis on one among physical, emotional, social and other dimensions, the perspectives of HRQOL are commonly considered in western, Asian and other developing economies and concluded that children undergoing cancer treatment may experience reduced HRQoL [12,41]. Therefore the following empirical reviews discuss dimensions and impact of leukemia cancer on Peds HRQOL in various countries.

## 2.3. Empirical Reviews

Leukemia is very much prevalent among children. It affected about 876,000 peoples in 2015 and resulted in about 111,000 deaths globally [1]. Occurrence of the cancer is in between the age group of 2-5. An increase in survival rates among children has been reported from 10% in the 1960s to 90% in 2015, it is 25% among childhood cancers and approximately 75% of childhood leukemia. The survival rate has improved from virtually zero to the current overall approximately 80% with the initiation of modern chemotherapy and radiotherapy [4].

However, assessment of long-term effect of the cancer on quality of life became a subject of empirical studies. The following paragraphs discuss assessment methods of quality of life for children with leukemia.

In china assessment scales are typically used to evaluate patients' HRQOL, which is used both in China and abroad. Experts outside of China have developed HRQOL assessment scales for children. The most commonly used is the Children's Quality of Life Assessment Scale System (PedsQLTM), developed by Dr. James W. Varni of the United States[21,36] . The Peds QLTM includes generic core scales and modules. Although the Peds QLTM [21,38] has been widely used for evaluating the HRQOL of children with malignant tumor, the items of the scale reflect the economic, cultural, and other features of the country of origin, and in a different culture direct translation of the original scale compromise the measurement results[22,40].

In western economy more comprehensive HRQOL assessment methods is used. For example the classical KINDL questionnaire developed in Germany by was revised as recent as 2016 and adopted in almost all regions of the world[22]. The KINDL questionnaire consists of 24 items that assess six subscales: physical well-being, emotional well-being, self-esteem, family, friends, and everyday functioning (school). Similar proxies were adopted to assess impact of leukemia on children HRQOL in Asia and Africa by different researchers ([4], [10], [11], [2]). Deniz et al investigated the health-related quality of life (HRQOL) in survivors of pediatric acute lymphoblastic leukemia (ALL) and evaluated the perceptions of the children, their siblings, and their parents [4]. The study considered 70 leukemia survivors, who were between 7 and 17 years of age and had completed therapy over two years. While control group consisted of their healthy siblings, the study assessed HRQOL by the age-specific KINDLR questionnaire.

The result of the study showed that there is no significant difference among HRQOL scores of leukemia survivors with respect to variables such as sex, risk group, and having chronic illness. HRQOL scores for physical well-being, emotional well-being, family, and social functioning of the patient and sibling self-reports and parent proxy reports were lower than the expected values for healthy and chronically ill children. The study emphasized on psychological dimensions to improve HRQOL among leukemic children. Bawazir et al with intent of studying the extent of the disease in demographic and geographic disparities assessed leukemia in Saudi Arabia [10]. This study surveyed population-based cancer registry in the country over a period of 15 years. Cancer registry retrieved from the Saudi Council of Health of the country were analyzed using factors such as age, sex, years of incidence, residency, and histo-pathological type of leukemia. Result of this study showed that considering all dimensions of HRQOL male pediatric patients are exposed to the disease and the extent of the cancer also varied from regions to regions and based on the type of cancer. Most importantly they concluded that, regardless of the factors the disease has surged and adversely impacted physical and psychological wellbeing of the patients.

Other study investigated physical activity as physical wellbeing and social interaction impact of 47 leukemic children aged 7–18 years old who were off-treatment and attended school on a regular basis [11].

Using modified structured questionnaire from the Youth Risk Behavior, the study found that majority (more than 77%) of the children with leukemia had low levels of daily physical activity and wellbeing after intensive chemotherapy.

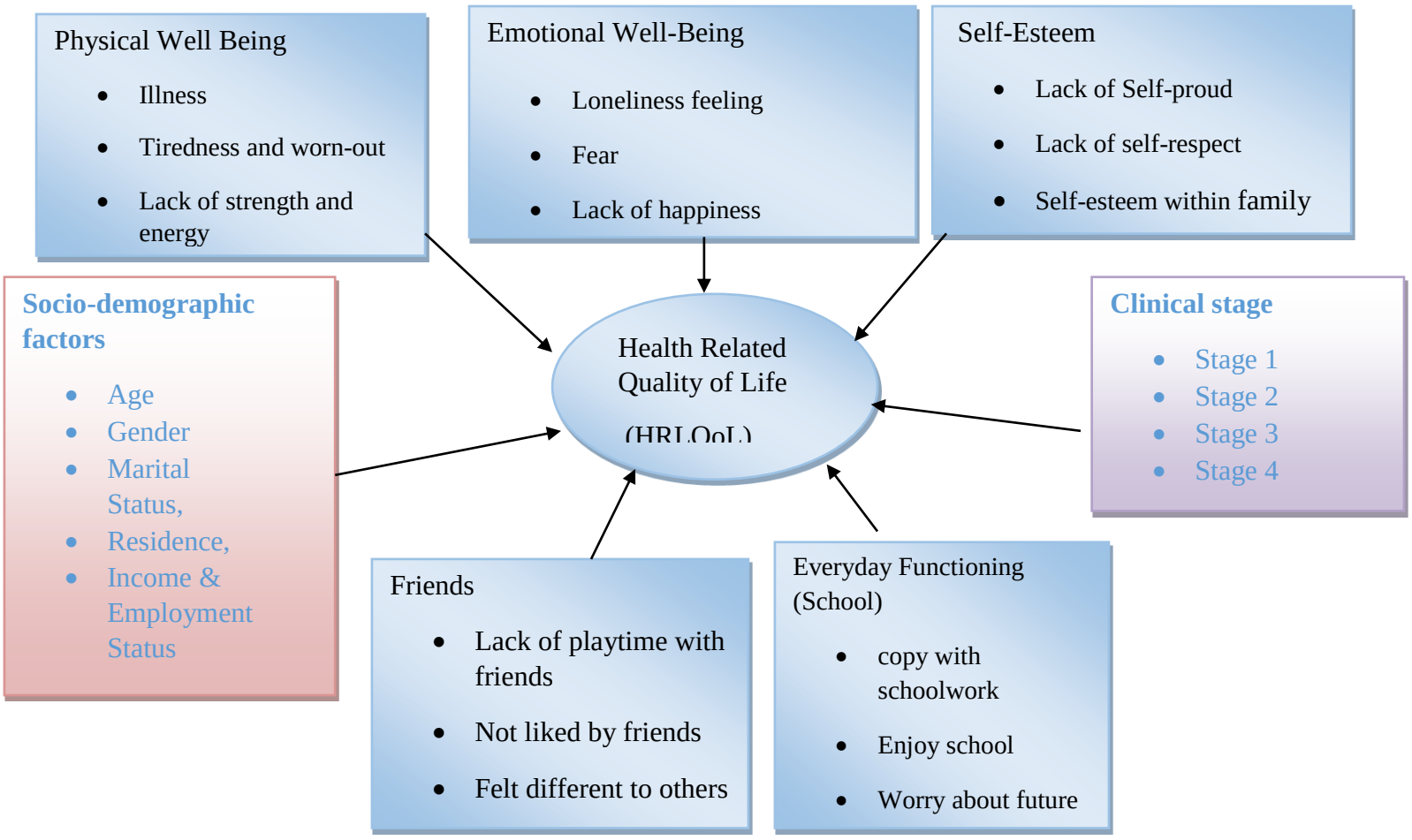
The study also indicated that the patients struggle to interact in social physical activities and also feel depressed which is related to emotional wellbeing. The study can imply that treatment related factors like (intensity of chemotherapy) may have adverse effect on HRQOL among children with leukemia [11].

The authors encouraged other researchers to do comprehensive investigations of relevant factors and predictors are needed with more modern diagnostic methods and investigate correlation factors with the treatment protocols used and impact of Leukemia on HRQOL. Study by Carol et al [23] and also Berihun [24] explored factors related to HRQOL in Asian Pediatric patients with leukemia in Singapore. They considered variables such as: age, treatment duration, household income, gender, ethnicity, religion, diagnosis, and phase of treatment. It is found in this study that the relationships between the variables and HRQOL would be significant. The study concludes that health service delivery should be based on more holistic approach, which considers Quality of Life (HRQOL) and overall functioning. The study asserts that HRQOL should be a multidimensional construct that encompasses physical functioning as well as psycho-social aspects of emotional and social functioning [9].

On slightly related subject, Yismaw et al studied drug-related problems among childhood cancer patients in Ethiopia [24, 25]. The observational study was conducted to assess drug related problems on patients admitted at the pediatric hematology/oncology ward of Tikur Anbessa Specialized Hospital. The result showed that from the total 156 participants, drug related problems were identified in 68.6% of the study subjects. These problems included dosing problems which include dosage too low and high were the top ranking (39.3%) of all drug related problems followed by needs additional therapy (27.2%) and non-adherence (14.0%). Systemic anti-infectives were the most common class of drugs involved in drug related problems [24]. These problems can be traced as treatment related factors affecting HRQoL similar to problems related to chemotherapy administration[26].

In conclusion, the reviewed literatures address physical, psychosocial, emotional and social functioning dimensions of HRQOL and associated factors like socio demographic characteristics; treatment related factors and clinical stage factors were studied. The following conceptual frame work depicts considered factors that have an impact on HRQOL of leukemic children.

## 2.4. **Conceptual frame work**




Source: Deniz *et al* (2019)

Figure 1: Conceptual framework -Health-Related Quality of Life (HRQoL) of pediatrics patients with leukemia

# 3. OBJECTIVES

## 3.1. General objective

- To assess the health-related quality of life (HRQoL) of childhood patients with leukemia in TASH in Addis Ababa, Ethiopia.

## 3.2. Specific objectives

- To determine the magnitude of Quality of life among Childhood patients with Leukemia in Tikur Anbessa Specialized Hospital in Addis Ababa, Ethiopia.
- To identify factors associated with health related Quality of life among childhood patients with Leukemia in Tikur Anbessa Specialized Hospital in Addis Ababa, Ethiopia.

# 4 .MATERIAL AND METHOD

## 4.1. Study area and period

Thestudy was conducted at TASH leukaemia chemotherapy centre. Tikur Abbess Specialized hospital (TASH) is one of governmental referral hospitals which is found in Addis Ababa City, Lideta Sub City with more than 1000 beds in medical, gynaecological, obstetrics, surgical, paediatrics, emergency and Out-patient oncology. In general, the study was conducted at the oncology unit of TASH, College of Health Sciences, between January 2023 and June, 2023.

## 4.2. Study Design

An institution based cross sectional study was conducted.

## 4. 3. Study Population

This study includes parents of all positive pediatrics age less than 14 years and whoever started chemotherapy in Black lion specialized teaching hospital, Addis Ababa, Ethiopia.

Although ratings of child -HRQOL should be made by both child and parent [8], it is often necessary to rely on parents' proxy ratings, especially where children are too young or ill to respond by themselves. In addition, family care-giving burden enables them to well understand status of their children quality of life and capable in evaluation of the topic.

## 4.4 Source Population

All pediatric diagnosed with leukemia in TASH was considered as source of population.

## 4.5 Study Unit

The study units were all leukemia patients treat (radiotherapy, surgery and chemotherapy) in TASH those are selected by random sampling technique and who fulfilled the inclusion criteria.

## 4.6. Study Variables

### 4.6.1 Dependent Variable

Quality of Life among Childhood patient with Leukemia

### 4.6.2 Independent Variables:

Socio-demographic characteristics of parents (sex, age, educational level, address, employment status)

Clinical stage factors (Stage 1, Stage 2, Stage 3, and Stage 4).

Physical Well-being, (feeling ill, tiredness and worn-out, lack of energy and strength)

Self-esteem (lack of self-proud, lack of self-esteem within family)

Emotional well-being (loneliness, fear, lack of happiness)

School (everyday functioning) (copy with school work, enjoy to school, worry about future)

Friends (lack of play time with friends, not liked by friend, feel different to others)

## 4.7. Inclusion and Exclusion Criteria

**Inclusion criteria:**

Leukemia diagnose Ages between 5 and 14

Completion of 6 months of chemotherapy

**Exclusion criteria**:

Under the following conditions patients/parents are excluded from course of the study

- Treatment course complicated by other medical conditions, severe medical and/or psychological consequences from their treatment.
- Parents' perception of the potential psychological distress that may result from study participation.

## 4 .8. Sample Size Determination and Sampling Procedures

### 4.8.1 Sample Size determination

The sample size was determined by using single population proportion formula and taking 50% proportion at 95% confidence level and at 5 % margin of error.

Where: n= sample size

n = (Z@/2)2 * p(1- p)/d 2

n = (1.96)2 *0.5 (1- 0/ (0.05)2=384 and add 10% of non-respondent and the final sample size was 422.

### 4.8.2. Sampling Procedure

The study participants were selected from Pediatric leukemic center using random sampling technique. The sampling method helps to avoid bias and select respondents of children within5-14 years of age group.

## 4.9. Data Collection Instrument

The study adopted standardized HRQoL questionnaire to collect data. The questionnaires were distributed to active patients admitted to TASH oncology center. All necessary ethical clearance was made to get necessary approval to collect data. To evaluate socio-demographic status, quality of life, and clinical variables, Interviewer-based questionnaire was specifically distributed to parents of active patients at TASH oncology unit. The data gathered were using standardized and validated data collection tools and reliability of data was ascertained.

### 4.9.1. Data collection process

Data was collected by distributing the questionnaire to the respondents at the cancer unit of TASH. The procedure was done after the respondents received their respective service. Data collector's team was involving three nurses under supervision of the principal investigator.

Training was given for the data collectors on the contents of the questionnaire and how to approach the respondents for two days prior to the data collection period by the principal investigator.

## 4.10. Operational Definition

**HRQoL** - a multidimensional construction that measures patients' perception of the positive and negative aspects associated with their disease and its treatment, in at least four aspects: physical, emotional, self-esteem, and treatment-related.

**Good quality of life**-Mean score greater than 4 in all aspects of HRQoL

**Poor quality of life**- Mean score less than 3 in all aspects of HRQoL

**Stage 1**-Apatient has high levels of white blood cells and enlarges lymph node

**Stage2**-A patient has high level of white blood cells and is anemic. He or she may also have enlarged lymph node

**Stage 3**-Apatient has high level of white blood cells and is anemic; he or she may also have enlarged lymph nodes and enlarged liver or spleen.

**Stage4**-Apatient has high level of white blood cells and low platelets. He or she may also be anemic, have enlarged lymph nodes and have an enlarged liver or spleen.

## 4.11. Data Management

For each respondent, his/her identity and corresponding patient was kept confidential and would access only by the researcher. Data cleaning, an inspection of distributions and contingency cleaning was made for accuracy. The data backup was kept by storing it in various files on the device.

## 4.12. Data Processing and Analysis

The data was entered in to SPSS version 20.0 for analysis. Descriptive and summary statistics was carried out. The researcher was measure the Quality of Life and each of the outcomes separately. Linear regression model was used to identify determinant factors Quality of life. Variables having p value 0.05 or less was fitted in to the model. The 95% percent confidence interval was computed and variables having p - value less than 0.05 in the multi variable adjusted odd ratio model was considered as significantly associated with treatment failure.

## 4.13. Data Quality Control

Data collection was accomplished using BSc nurses who working in the oncology departments and two assistants serving the patients' records. The PI was give one day training for data collectors and research assistants on the purpose of the study, the contents of the questionnaire, the efficient use of resources, and communication skills and was supervised by the investigators. Pre-test of questionnaires and data collection charts were conducted to check the quality and reliability of the questionnaire[27]. Five percent of the sample size was used to check the pre-test to ensure consistency and precision in gathering the intended data.

The study was done modification of the data collection tools and translation of the questionnaires to the local language (Amharic) by expert. Completeness of records was checked every day by the investigator. It was not include the pre-test outcome in the final analysis.

## 4.14. Ethical Consideration

Ethical approval of the research proposal was obtained from the Institutional Review Board (IRB), Protocol CTA#2/2017 of Addis Ababa University's College of Health Sciences. A formal letter was written to Tikur Anbessa Specialized Hospital in Addis Ababa and the Oncology Special Clinic to permit us to undertake the research. Informed verbal consent was obtained from all study subjects before conducting the data collection. For this purpose, a consent form was attached to each questionnaire that explains the purpose of the study, its confidentiality, and the respondent's full right to take part or not in the study. The respondents were given an honest clarification of the survey's intent, a summary of the benefits, and an invitation to answer all inquiries. The study did not find any physical harm, social discrimination, psychological trauma, or economic loss. This study process has no harmful form of inducement or coercion, and the study does not bring any risks that incur compensation. To protect the confidentiality of the meeting, participants' privacy was identified using a code.

## 4.15. Dissemination of the Findings

This study's primary objective is to fulfill the requirements for a Master of Science degree in oncology clinic nurse. The study result was submitted to the Addis Ababa University College of Health Sciences. A copy would be given to the Ministry of Health and TASH. It also attempts to publish in reputable journals.

# 5. RESULTS

This section presents results of questionnaire distributed to childhood leukemia patients. The section is organized as 5.1. Socio-demographic characteristic of respondents, 5.2 HRQoL assessment of the pediatric patients and 5.3 factors affecting HRQoL in the pediatric patients, 5.4 Regression Analysis, 5.5 Correlation Analysis, 5.6 Discussion, 5.7 Conclusion and Recommendation, and 5.8 Strength and Limitations.

### 5.1. Socio-demographic characteristic of childhood Leukemia patients

In this study, a total of 422 pediatrics patients were included, making a response rate of 100%. Accordingly, Table 5.1 indicates that the gender profile of pediatric patients showed 56.9% male and 43.1% female patients. The mean (±SD) ages of participants were 8.58 ±2.56 years range from 5 to 14 years of the participants. Table 5.1 also summarized demographic profiles of the parents. Accordingly, the marital status of the parents materializes towards married family (69.2%), followed by widowed parents (20.6%), and divorced family 10.2% (Table 5.1). The religion profile of the parents (Table 5.1) indicates that majority are orthodox Christian (39.6%), followed by Muslim (29.4) and Protestants (21.3%). The illiteracy rate of the parents(Table 5.1) indicates only 12%,while 35.5% have basic education, and remaining 52.4% have either college certificate, degree or above. Majority of the patients and their parents resides in urban areas (60.9%), remaining 39.1% were from rural areas. Regarding occupational status of the parents, private business (26.1%) slightly ranges over, government employees (21.3%) and others (23%). Likewise, the patients' median monthly income was Birr 4893.84.257 (60.9%) which may range ±2693.04 (Table 5.1).

**Table 5.1: Socio-demographic characteristics of participants, 2023(N=422)**

| Variables | Category | n=422(%) |
|---|---|---|
| Sex of participants | Male | 240 (56.9) |
| | Female | 182(43.1) |
| Age in years | mean ± standard deviation | 8.58±2.56 |
| Marital status | Married | 292 (69.2) |
| | Divorced | 43 (10.2) |
| | Widowed | 87 (20.6) |

| | | |
|---|---|---|
| | Orthodox | 167 (39.6) |
| Religion | Muslim | 124 (29.4) |
| | Protestant | 90 (21.3) |
| | Others | 41 (9.7) |
| Educational background | | |
| | Illiterate | 51 (12.1) |
| | Read and write | 150 (35.5) |
| | College and certificate | 122 (28.9) |
| | Degree and above | 99 (23.5) |
| Residence | Urban | 257 (60.9) |
| | Rural | 165 (39.1) |
| occupational status | Government | 90 (21.3) |
| | Private | 110(26.1) |
| | Farmer | 42(10) |
| | Merchant | 83(19.7) |
| | Others | 97(23) |
| Monthly income | Mean±std | 4893.84±2693.04 |

### 5.2. HRQoL Assessment of the childhood Leukemia patients

Based on the five dimensions of HRQoL assessments for childhood Leukemia, the results on Physical wellbeing, Emotional Wellbeing, Self-Esteem, Friends and Everyday Functioning (School) assessments were shown as follows.

#### 5.2.1. Physical Well-Being of the respondents

The physical well-being dimension measures health related physical distress of the patients dichotomizing various feelings (illness, worn-out, headache, lack of energy). Table 5.2.1 shows that mean value of the patients feeling illness is 1.737 which depicts majority of the patients strongly agree or agree that they feel illness. The patients also indicates that they agree to feeling worn-out or tiredness (mean=2.24) (Table 5.2.1).

Similarly, majority of the patients felt headache with mean 1.98. However, the patients were indifferent (mean3.08) on whether they feel full of energy. In general mean values of pediatrics Physical Well-Being were nearer to 2(Table 5.21) which indicates, impact of leukemia on HRQoL of children from the physical wellbeing dimensions is high.

**Table 5.2**.1 **Physical Well-Being Assessment**

| | N | Minimum | Maximum | Mean | Std. Deviation |
|---|---|---|---|---|---|
| Feeling Ill | 422 | 1.0 | 5.0 | 1.737 | .9523 |
| Tired and Worn-out | 422 | 1.00 | 5.00 | 2.2464 | .95302 |
| Feeling Headache | 422 | 1.00 | 5.00 | 1.9858 | .76428 |
| Full of Energy | 422 | 1.00 | 5.00 | 3.0829 | 1.21755 |
| Valid N (list wise) | 422 | | | | |

The graphical presentation of Physical illness assessment of respondents indicates that feeling ill is the utmost threat to HRQoL amon childhood leukemia patients in TASH. Majority of the patients strongly agreed (53%) and others agreed (32%) that feeling of physical illness as the most cause for poor HRQoL of the cancer.

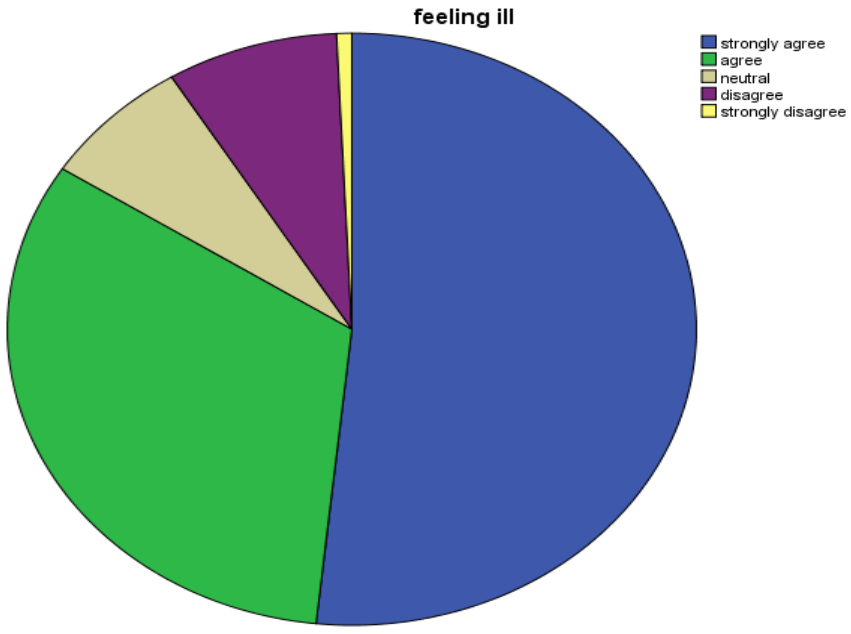



Figure 5.2.1 Physical Illness

### 5.2.2. Emotional wellbeing of the respondents

The parameter for emotional wellbeing is range of agreement whether the patients feel happiness, feel lonely or scared. Based on Table 5.2.2, the mean values of respondents' Emotional well-being were between 3 to 4, feel happy (3.38), lonely (3.6) and Scared (3.6) which indicates Disagree. Therefore, the impacts of leukemia on HRQoL of children were low. This implies that the patients are close to neutral on their happiness, emotion or slightly closer to disagree on feeling lonely or scared. It can be generalized from these results that the association between the emotional wellbeing and HRQoL from this dimension is low.

Table 5.2.2 Emotional Wellbeing Assessment

| | N | Minimum | Maximum | Mean | Std. Deviation |
|---|---|---|---|---|---|
| Feel happy | 422 | 1.00 | 5.00 | 3.3815 | 1.08277 |
| Lonely | 422 | 1.00 | 5.00 | 3.6185 | 1.06284 |
| Scared or unsure | 422 | 1.00 | 5.00 | 3.6493 | 1.06342 |
| Valid N (list wise) | 422 | | | | |

### 5.2.3. Self-Esteem of the Patients

The other aspect of HRQoL is patient's level of self-esteem. This aspect includes patients proud in his/herself, feeling top and feeling accepted at home. Table 5.2.3 indicates that the mean values of respondents' self-esteem of the patients were almost near to 4 (disAgree), particularly feeling proud (3.6), feeling top (3.7), feeling pleased and fine at home 3.6 and 3.54 respectively. This implies that the impacts of leukemia on Self-esteem aspects HRQoL of children were low

Table 5.2.3 **Self-Esteem Assessment**

| | N | Minimum | Maximum | Mean | Std. Deviation |
|---|---|---|---|---|---|
| Proud of himself | 422 | 1.00 | 5.00 | 3.6019 | 1.06456 |
| Feeling the top | 422 | 2.00 | 5.00 | 3.7464 | .94488 |
| Feeling Pleased | 422 | 1.00 | 5.00 | 3.6445 | 1.03005 |
| Good Idea with Family | 422 | 1.00 | 5.00 | 3.5521 | 1.11602 |
| Well with Family | 422 | 1.00 | 5.00 | 3.5758 | 1.02588 |
| Fine at Home | 422 | 1.00 | 5.00 | 3.5379 | 1.10375 |
| Bossing Him Around | 422 | 1.00 | 5.00 | 3.5521 | 1.12661 |
| Valid N (list wise) | 422 | | | | |

Graphical presentation of patients' self-esteem indicates that the leukemic children do not have a good self-esteem particularly not feel proud of themselves. This can be justified that 72% of respondents disagreed that they feel proud of themselves.


Figure 5.2.3 Self-esteem of patients

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### 5.2.4. Friends

The acceptances with friends are other indicator of HRQoL assessment. Table 5.2.4 summarized friendship dimension of HRQoL. This includes playing with friends (3.57), liked by friends (3.37), felt different from others (3.63) and did things with others (3.76). The patients are nearly neutral whether they are liked by their friends or other kids. However, in other aspects of friendship wellbeing the patients mean score is slightly close to 4(disagree). The patients less do things with others but they don't feel different from others. The result in this aspect is mixed.The patients are not sure whether they are liked by others, but they don't feel different either. They less does things with others and got along with them which imply leukaemia's impacts on friendship aspect of HRQoL are substantial.

**Table 5.2.4. Friendship wellbeing assessment**

| | N | Minimum | Maximum | Mean | Std. Deviation |
|---|---|---|---|---|---|
| Play with friends | 422 | 1.00 | 5.00 | 3.5758 | 1.11678 |
| Liked by other kids | 422 | 1.00 | 5.00 | 3.3791 | 1.08470 |
| Felt different from other | 422 | 1.00 | 5.00 | 3.6374 | 1.10659 |
| Did things with friends | 422 | 1.00 | 5.00 | 3.7678 | 1.00266 |
| got along well with other | 422 | 1.00 | 5.00 | 3.5427 | 1.08184 |
| Valid N (list wise) | 422 | | | | |

5.2.5. **Everyday Functioning (School)**

School life is HRQoL assessment criteria for children between ages of 5-14. The parameters include easily cope of homework, enjoying lessons, hopeful about future and optimistic of bad marks. The assessment on the school functioning of the patients is presented below. Table 5.2.5 indicates that the mean value of respondent on every day function (school) of the patientswere nearer to 3 which indicates neutral. Consequently, the impacts of leukemia on school functioning dimension of HRQoL of children were neutral.

**Table 5.2.5 School functioning assessment**

| | N | Minimum | Maximum | Mean | Std. Deviation |
|---|---|---|---|---|---|
| easily cope of homework | 422 | 1.00 | 5.00 | 3.4739 | 1.13800 |
| enjoy the school lesson | 422 | 1.00 | 5.00 | 3.5355 | 1.14191 |
| worry about future | 422 | 1.00 | 5.00 | 3.3318 | 1.20722 |
| made lots of mistake | 422 | 1.00 | 5.00 | 3.2678 | 1.17853 |
| afraid of bad mark | 422 | 1.00 | 5.00 | 3.0545 | 1.18757 |
| Valid N (list wise) | 422 | | | | |

### 5.3. Factors Influencing HRQoL

Various factors were identified to impact HRQoL in childhood leukemia. Empirical evidences discussed the association between age of the children, gender, habit of the parents, pain of chemotherapy, length of treatment and HRQoL in the children with leukemia**.** Simple descriptive survey of 422 parents of leukemic children on the associations between these factors is presented below.

The result in table 5.3 indicates that the mean value of respondents factor influencing HRQoL of the patientswere nearer to 3 for age (2.9), Gender (2.8) and parents habit (2.5), which implies that respondents were neutral that three factors particularly age of children, gender of the patients and habit of the parents impact HRQoL of the children. However, two factors are likely to impact HRQoL which are pain of chemotherapy (2.17), and length of treatment (2.13).

Table 5.3 Factors affecting HRQoL

| | N | Minimum | Maximum | Mean | Std. Deviation |
|---|---|---|---|---|---|
| Age of Children | 422 | 1.00 | 5.00 | 2.8910 | 1.19280 |
| Gender of Your Child | 422 | 1.00 | 5.00 | 2.7536 | 1.21586 |
| Your Habit | 422 | 1.00 | 5.00 | 2.5213 | 1.08248 |
| Pain of Chemotherapy | 422 | 1.00 | 12.00 | 2.1754 | 1.02814 |
| Length of Treatment | 422 | 1.00 | 5.00 | 2.1374 | .88270 |
| Valid N (listwise) | 422 | | | | |

### 5.4. Regression Analysis

The regression analysis explains effects of Gender of the Children, Habit of the parents, Age of Children and Pain of Chemotherapy on HRQOL. The result introduces Model overall summary, ANOVA and regression significance for independent variables.

**5.4.Regression Model Summary**

| Model | R | R Square | Adjusted R Square | Std. Error of the Estimate |
|---|---|---|---|---|
| 1 | .814[a] | .78 | .73 | .87026 |

a. Predictors: (Constant), intensity of treatment, pain of chemotherapy, gender of your child, disease status, length of treatment, your habit, age of children

The model summary which shows the relationship between the independent variable and dependent variable shows that 0.73 (73%) changes in HRQoL in childhood leukaemia could be accounted for intensity of treatment, pain of chemotherapy, gender of your child, disease status, length of treatment, your habit, and age of children.

From the findings in table 5.4 there was a strong positive relationship between the study variables as shown by 0.814(Table 5.4).

**5.4.1. ANOVA Statistics [a]**

| Model | | Sum of Squares | Df | Mean Square | F | Sig. |
|---|---|---|---|---|---|---|
| 1 | Regression | 6.195 | 7 | .885 | 6.455 | .000[b] |
| | Residual | 56.756 | 414 | .137 | | |
| | Total | 62.950 | 421 | | | |

a. Dependent Variable: HRQoL

b. Predictors: (Constant), intensity of treatment, pain of chemotherapy, gender of your child, disease status, length of treatment, your habit, age of children

The ANOVA statics in table above, the processed data which is the population parameters, had a significance level of 0% which shows that the data is ideal for making a conclusion on the population's parameter as the value of significance (p-value) is less than 5%. The calculated value was greater than the critical value (6.455 > 1.984) an indication that intensity of treatment, pain of chemotherapy, gender of your child, disease status, length of treatment, your habit, and age of children significantly influence HRQoL in childhood leukaemia.

**5.4.2. Regression Coefficients[a]**

| Model | | Unstandardized Coefficients | | Standardized Coefficients | t | Sig. |
|---|---|---|---|---|---|---|
| | | B | Std. Error | Beta | | |
| 1 | (Constant) | 3.913 | .098 | | 40.011 | .000 |
| | Age of Children | .067 | .019 | .207 | 3.573 | .000 |
| | Gender of Your Child | .021 | .019 | .067 | 1.152 | .250 |
| | Your Habit | .040 | .019 | .111 | 2.093 | .037 |
| | Pain Of Chemotherapy | -.36 | .018 | -.096 | -1.971 | .049 |
| | Length of Treatment | -.005 | .021 | -.011 | -.227 | .820 |
| | Disease Status | -.004 | .023 | -.009 | -.181 | .856 |
| | Intensity of Treatment | .007 | .026 | .012 | .261 | .794 |

a. Dependent Variable: HRQoL

Based on the regression results three variables were significant in predicting HRQoL in childhood leukaemia at 5% significance level (Age of Children, Habit of the parents and the pain of chemotherapy).

The pain of chemotherapy was indicated to show negative impact on HRQoL at .36 which implies that unit increase in pain of chemotherapy would lead to decrease in HRQoL in childhood leukaemia by a factor of 0.36. Likewise, a unit increase in age of the children would lead to increase in HRQoL in childhood leukaemia by a factor of 0.7. Parents behaving pattern was also found to improve HRQoL in the childhood leukaemia 0.4(Table 5.4.2).

## 5.5. Correlation Analysis

**5.5. Correlations Analysis Table**

| | | age of children | gender of your child | your habit | pain of chemotherapy | Length of treatment | disease status | intensity of treatment | HRQoL |
|---|---|---|---|---|---|---|---|---|---|
| Age of children | Pearson Correlation | 1 | .556** | .373** | .167** | -.044 | .107* | .015 | .270** |
| | Sig. (2-tailed) | | .000 | .000 | .001 | .363 | .028 | .755 | .000 |
| | N | 422 | 422 | 422 | 422 | 422 | 422 | 422 | 422 |
| Gender of your child | Pearson Correlation | .556** | 1 | .410** | .069 | -.075 | .048 | .021 | .222** |
| | Sig. (2-tailed) | .000 | | .000 | .158 | .126 | .330 | .673 | .000 |
| | N | 422 | 422 | 422 | 422 | 422 | 422 | 422 | 422 |
| Your habit | Pearson Correlation | .373** | .410** | 1 | .131** | .002 | .159** | .105* | .203** |
| | Sig. (2-tailed) | .000 | .000 | | .007 | .969 | .001 | .031 | .000 |
| | N | 422 | 422 | 422 | 422 | 422 | 422 | 422 | 422 |
| Pain of chemotherapy | Pearson Correlation | .167** | .069 | .131** | 1 | .191** | .088 | -.005 | -.045 |
| | Sig. (2-tailed) | .001 | .158 | .007 | | .000 | .071 | .919 | .000 |
| | N | 422 | 422 | 422 | 422 | 422 | 422 | 422 | 422 |
| Length of treatment | Pearson Correlation | -.044 | -.075 | .002 | .191** | 1 | .144** | -.106* | -.046 |
| | Sig. (2-tailed) | .363 | .126 | .969 | .000 | | .003 | .030 | .348 |
| | N | 422 | 422 | 422 | 422 | 422 | 422 | 422 | 422 |
| Disease status | Pearson Correlation | .107* | .048 | .159** | .088 | .144** | 1 | -.033 | .024 |
| | Sig. (2-tailed) | .028 | .330 | .001 | .071 | .003 | | .500 | .623 |
| | N | 422 | 422 | 422 | 422 | 422 | 422 | 422 | 422 |
| Intensity of treatment | Pearson Correlation | .015 | .021 | .105* | -.005 | -.106* | -.033 | 1 | .031 |
| | Sig. (2-tailed) | .755 | .673 | .031 | .919 | .030 | .500 | | .532 |
| | N | 422 | 422 | 422 | 422 | 422 | 422 | 422 | 422 |

| | | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|
| HRQoL | Pearson Correlation | .270** | .222** | .203** | -.045 | -.046 | .024 | .031 | 1 |
| | Sig. (2-tailed) | .000 | .000 | .000 | .358 | .348 | .623 | .532 | |
| | N | 422 | 422 | 422 | 422 | 422 | 422 | 422 | 422 |

**. Correlation is significant at the 0.01 level (2-tailed).

*. Correlation is significant at the 0.05 level (2-tailed).

The correlation analysis indicates both direction and strength of relationship between dependent and independent variables. Accordingly, four variables namely; age of the children, gender of the childhood patients, Habit of the parents and pain of chemotherapy had significant relationship with HRQoL in childhood Leukaemia. Except the pain of Chemotherapy which had negative relationship with HRQoL (.045), the rest of three variables (age of the children=.27, gender of the childhood patients=.22, Habit of the parents=.20) have positive correlation with HRQoL in childhood leukaemia

# 6. DISCUSSION

The study focused on childhood Leukemia specifically, as it is the most common cause of pediatric cancer. The aims of the study were two-fold. Primarily, the study made assessment of childhood leukemia on HRQoL among pediatric patients. Secondly, it explained the relationships and impacts of Age of patients, Gender, Habit of parents, pain of chemotherapy and intensity of the disease on HRQoL in the age group of pediatric patients.

The number of male patients slightly exceeded female patients 240 to 182. This result is consistent with study in Saudi Arabia which indicates male patients suffer more from the cancer compared to female (10). The mean age of the patient was 8 years and 5 months, which indicates majority of the childhood patients in this study was less than 10 years of age. This is also consistent to findings by some studies on mean age of childhood leukemia average age between 8-10 years (2, 6,8). The patients were found to be from multiple corners of religious background with less variation between orthodox Christian and Muslim patients. In this regard there is limited study to compare implications religious background of the patients on HRQoL.

Majority of patients were from urban area, employed in private businesses and in government institutions. Vast majority of the leukemic children have married family, followed by widowed parents. In addition, a high percentage of the parents are educated to fill in the questionnaire and enhance credibility of the study. The geographic distribution patients, marriage status and literacy profile of patients caregivers were relatively comparable to studies in some countries ( 1, 2, 10,29)

The study findings demonstrate that the mean HRQoL in physical wellbeing aspect was close to 2 where the patients agreed that they face physical wellbeing problem in HRQoL. The majority of the children had poor HRQoL. The social (friendship), behavioral and mental states of pediatric patients (self-esteem) indicate less relevant indicator of HRQoL in TASH. However, children describe chemotherapy as the most unpleasant part of cancer therapy, which causes distress and increases suffering. This reason aligns chemotherapy pain as one of the causes for poor HRQoL among childhood leukemia in TASH. Age and parents habits were also found to be significant impact on HRQoL in childhood leukemia in TASH.

On the other hand, regression and correlation results showed consistent results on some factors affecting HRQoL among childhood leukemia at TASH. ; Age of the children, gender of the childhood patients, Habit of the parents and pain of chemotherapy had significant relationship with HRQoL in childhood Leukaemia. Likewise, regression results showed that three variables were significant in predicting HRQoL in childhood leukaemia (Age of Children, Habit of the parents and the pain of chemotherapy).

The pain of chemotherapy was indicated to show negative impact on HRQoL at .36 which implies that unit increase in pain of chemotherapy would lead to decrease in HRQoL in childhood leukaemia by a factor of 0.36. Likewise, a unit increase in age of the children would lead to increase in HRQoL in childhood leukaemia by a factor of 0.7. Parents behaving pattern was also found to improve HRQoL in the childhood leukaemia

Study in Singapore, which explored the factors related to HRQoL in Asian podiatric patients with leukaemia, also reported that age had a positive association with physical functioning, physical health, and HRQoL in patients with leukaemia. Furthermore, the treatment duration demonstrated a significant correlation with functioning at school.According to these findings, childhood patient gets better in HRQoL as his/her age increases. This might be that age had a positive association with physical functioning, physical health, and total HRQOL in patients with leukemia. Conversely, parents with ill-mannered behavior are likely to disturb their children's' HRQoL.

Overall, the study result is relatively consistent with some of previous studies in other countries that the childhood leukaemia patients score low HRQoL in physical aspects (4, 8, 10, and 12). However, this study did not recognize length of treatment and disease status as significant impact on HRQoL among childhood leukaemia patients in context of the study.

# 7. CONCLUSIONS AND RECOMMENDATION

## 7.1. Conclusions

The study concludes that most patients had poor physical wellbeing aspect of HRQoL. The exposure also has a significant association between the male sex, urban area, and younger age, poor family habits and difficulty to bear pain of chemotherapy. Male children were exposed to the cancer than their counter female children. HRQoL improve with an increase with the age of patients as the physical wellbeing of patients also improves with an increase in ages. Even though most patients were from urban areas, the religious background of parents (children) was not determining factor to HRQoL among childhood leukemia patients in TASH.

The childhood leukemia patients in TASH recorded low self-esteem. However, the patients were neutral in their school functioning and friendship well-beings. The physical wellbeing comes into light as the most challenging factor to HRQoL among TASH patients. This also goes in line with the result that chemotherapy related morbidity effect, which is found to impact physical wellbeing dimension of HRQoL.

### 7.2. Recommendations

Health practitioners might need to consider factors identified in this study to alleviate problems related to HRQoL among childhood leukemia patients. Accordingly, the study addresses the following points of recommendations.

- Even though gender and ages of childhood leukemia patients are naturally inevitable, health practitioners should consider both factors to assess the intensity of the cancer treatment.
- The physical morbidities of the cancer among the patients were also related to the pain of chemotherapy which poses threat to physical wellbeing aspect of HRQoL. Thus the cancer treatment should explore more tools to alleviate pain of the treatments and be aware of physical morbidity aspect of the cancer.
- The cancer treatments night need synchronize continuous professional counseling service to improve self-esteem (psychological) wellbeing aspect of HRQoL.

For future studies, the researcher recommends a routine assessment of the psychological and social status of pediatric patients and measurement of the HRQoL of children during each visit. In addition studies can be made on factors that cause variation of the cancer in urban and rural areas, between genders and economic settings.

# 8. STRENGTHS AND LIMITATIONS

This study was among the fewest to explore the subject of HRQoL in Ethiopia. Particularly, the study is rare in childhood leukemia. The study also used adequate sample of active patients which makes data valid. These aspects of the study can be taken as strengths of the study. However, the study has a few limitations. First, the study duration was short. Second, the survey was performed only once, and HRQOL may differ during chemotherapy. Third, owing to the younger age group and use of the parent proxy might not be an accurate of patient's answers and feelings.

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# Annexes

## Annex 1: Information Sheet

### Addis Ababa University, College of health Sciences

My name is Megertu Kalbessa Debel. I am working as a Principal Investigator for the study being conducted under Addis Ababa University, College of health Sciences. I kindly request you to give me your attention to explain about the study.

**Title of the study:** Assessment of Quality Life (HRQOL) Among Childhood Patients with Leukemia in Tikur Anbessa Specialized Hospital, Addis Ababa, Ethiopia.

**Objective of the study:** To assess the health-related quality of life (HRQOL) of childhood patients with leukemia in TASH in Addis Ababa, Ethiopia.

**The purpose/Aim of the Study**: The findings of the study provides base line information for hospital manager and health care providers to strengthen the cancer care service.

**Procedure and Duration:** The data collectors distribute questionnaire to the participants in their first language and it takes 25-30 minutes.

**Risk and Benefit:** The participants do not have any risk being participating in this study. There is no direct benefit given being participated in this study, but your participation helps to generate base line information for strengthening the cancer service.

**Confidentiality:** Participant's information is confidential. Your name and other personal identifiers would not be recorded on data collection format and the information that you give us are kept confidential and only used for this study purpose alone.

**Rights:** The participants have the right to refuse the participation or to answer any questions that they feel uncomfortable. And if you have any questions about the conducted study, you can ask the principal investigators with the following address.

Phone -+251920886029

Are you voluntary to participate in this research as a participant?

1. Yes 2. No

## Annex 2: English version questionnaire

**Title of the study:** Assessment of Quality Life (HRQOL) Among Pediatrics Patients with Leukemia in Tikur Anbessa Specialized Hospital, Addis Ababa, Ethiopia.

Dear Sir/Madam,

The purpose of this study is to assess quality life of children with Leukemia attending Tikur Anbessa Specialized Hospital. The study also vows to identify factors that adversely impact the pediatric leukemia patient's quality of life in essence to improve evidence-based decision making in leukemia treatment. This study is for academic purpose and the confidentiality of the data you provide is sincerely maintained.

Date of Survey_____

Time started_____ Time completed_____

Result of Survey - 1.Completed 2.Respondent not available 3. Refused 4. Incomplete.

Checked by Supervisor_____Signature _____Date _____

For any convenience and problem, you can contact Principal investigator

Phone -0920886029

Advisor: Yohannes Ayalew(PhD Fellow)

Address- A/A,

Phone number: _____

## *Health Related Quality of Life (HRQoL) among Childhood L*eukemia Patients at TASH

## I. Demographic characteristics of the Parents

**1. Gender.**

1. Male
2. Female

**2. Age (In Yrs)._____**

**3. Marital Status:**

0. Un Married
1. Married

**4. Education Level**

1. Read and Write
2. Primary (1-8)
3. Secondary (9-12)
4. College Diploma/Certificate
5. Degree And Above

**5. Occupational Status**

1. Government
2. Private
3. House Wife
4. Student
5. Merchant
6. Farmer
7. Others

**6. Residence**

1. Urban
2. Rural

**7. Religion**

1. Orthodox
2. Muslim
3. Protestant
4. Other

## II. Quality of Life Standard Questions

1. ***SA-Strongly Agree, 2.SD- Strongly- Disagree, 3. N-Neutral, 4.A-Agree, 5.D-Disagree***

| ***Fill*** in Space provided Number given in option spaces | 1 | 2 | 3 | 4 | 5 |
|---|---|---|---|---|---|
| **1. Physical Well-Being** | | | | | |
| 1. my child felt ill | | | | | |
| 2. my child had a headache or tummy- | | | | | |
| 3. my child was tired and worn-out | | | | | |

| | | | | | |
|---|---|---|---|---|---|
| 4. my child felt strong and full of energy | | | | | |
| **2. Emotional Well-Being** | | | | | |
| 5. My child had fun and laughed a lot | | | | | |
| 6. my child felt alone | | | | | |
| 7. my child felt scared or unsure of itself | | | | | |
| **3. Self-Esteem** | | | | | |
| 8. my child was proud of himself | | | | | |
| 9. my child felt on top of the world | | | | | |
| 10.my child felt pleased with himself | | | | | |
| 11.my child had lots of good ideas Family | | | | | |
| 12.my child got on well with us as parents | | | | | |
| 13. my child felt fine at home | | | | | |
| 14.we quarreled at home | | | | | |
| 15. my child felt that I was bossing him around | | | | | |
| **4. Friends** | | | | | |
| 16.my child played with friends | | | | | |
| 17.my child did things together with friends | | | | | |
| 18.my child was liked by other kids | | | | | |
| 19.my child got along well with his friends | | | | | |
| 20.my child felt different from other children | | | | | |
| **5. Everyday Functioning (School)** | | | | | |
| 21.my child easily coped with schoolwork | | | | | |
| 22.my child enjoyed the school lessons | | | | | |

| | | | | | |
|---|---|---|---|---|---|
| 23. My child worried about his future | | | | | |
| 24. my child made lots of mistakes when doing minor assignments or homework | | | | | |
| 25. my child was afraid of bad marks or grades | | | | | |
| **II. Factors Influencing Peds HRQOL** | Fill in according to questions | | | | |
| 26.Age of Your Child impact HRQOL | | | | | |
| 27.Gender of Your Child impact HRQOL | | | | | |
| 28.Your habits(Addictions-If any) | | | | | |
| 29.Pain of Chemotherapy administration | | | | | |
| 30.Length of treatment | | | | | |
| 31.Fear of Relapse, untreated or side effects | | | | | |

## አባሪዎች

**አባሪ 1፡የመረጃሉህ**

**አዲስአበባዩኒቨርሲቲ፣የጤናሳይንስኮሌጅ**

ስሜመገርቱቀልበሳበአዲስአበባዩኒቨርሲቲየጤናሳይንስኮሌጅለሚካሄደውጥናትመረጃሰብሳቢሆኜእየሰራሁ ነውስለጥናቱለማስረዳትትኩረትእንድትሰጡኝበትህትናእጠይቃለሁ።

**የጥናቱርዕስ፡**የህይወትጥራትግምገማ (HRQOL)
በአዲስአበባኢትዮጵያጥቁርአንበሳስፔሻላይዝድሆስፒታልየህጻናትህክምናየደምካንሰርካለባቸውታካሚዎች መካከል።

**የጥናቱዓላማ፡**የጥራትሕይወትግምገማ (HRQOL)
በአዲስአበባ፣ኢትዮጵያውስጥበሚገኘውጥቁርአንበሳስፔሻላይዝድሆስፒታልየሕፃናትሕክምናደምካንሰርያለ ባቸውታካሚዎችመካከል።

**የጥናቱዓላማ/ዓላማ፡-**
የዚህጥናትግኝቶችየካንሰርክብካቤአገልግሎትንለማጠናከርለሆስፒታልሥራአስኪያጅእናለጤናእንክብካቤአ ቅራቢዎችየመሠረታዊመስመርመረጃንይሰጣል።

**የአሰራርሂደትእናየቆይታጊዜ፡-**
መረጃሰብሳቢዎቹከተሳታፊዎችጋርበመጀመርያቋንቋየቃለመጠይቅመመሪያንበመጠቀምቃለመጠይቅያደ ርጋሉእናከ25-30 ደቂቃዎችይወስዳል።

**ስጋትእናጥቅም፡**ተሳታፊዎቹበዚህጥናትውስጥየመሳተፍምንምአይነትስጋትአይኖራቸውም።በዚህጥናት ውስጥለመሳተፍምንምአይነትቀጥተኛጥቅምየለም,
ነገርግንየእርስዎተሳትፎየካንሰርአገልግሎቱንለማጠናከርመሰረታዊመረጃንለማመንጨትይረዳል.

**ምስጢራዊነት**፡የተሳታፊውመረጃሚስጥራዊይሆናል።የእርስዎስምእናሌሎችየግልመለያዎችበመረጃአሰባሰ ብፎርማትላይአይመዘገቡምእናእርስዎየሚሰጡንመረጃበሚስጥርይጠበቃልእናለዚህጥናትዓላማብቻጥቅ ምላይይውላል።

**መብቶች**፡ተሳታፊዎችተሳትፎውንአለመቀበልወይምምኞትየሚሰማቸውንማንኛውንምጥያቄየመመለስመ
ብትአላቸው።እናስለተካሄደውጥናትማንኛቸውምጥያቄዎችካሉዎት፣ዋናመርማሪዎችንበሚከተለውአድራሻ
መጠየቅይችላሉ።ስልክ -

በዚህጥናትላይእንደተሳታፊለመሳተፍፈቃደኛነዎት?

1. አዎ 2. አይደለም

አባሪ 2፡መጠይቅ

የጥራትህይወትግምገማ (HRQOL)
በአዲስአበባ፣ኢትዮጵያውስጥበሚገኘውጥቁርአንበሳስፔሻላይዝድሆስፒታልየህፃናትህክምናደምካንሰርካለ
ባቸውታካሚዎችመካከል።

የሆስፒታልስም ----

**መግቢያእናበመረጃየተደገፈየስምምነትቅጽ**

ጤናይስጥልኝ:
ስሜመገርቱቀልበሳበአዲስአበባዩኒቨርሲቲየጤናሳይንስኮሌጅየምርምርቡድንስምመጥቻለሁ።በህጻናትህክ
ምናክፍልውስጥሉኪሚያካለባቸውታካሚዎችመካከልየጥራትህይወትን (HRQOL)
መገምገምእንፈልጋለን።እንዲሁም፣የደምካንሰርካለባቸውየሕፃናትሕክምናታማሚዎችመካከልየጥራትሕይ
ወትግምገማ (HRQOL)
ምንያህልእንደሆነማወቅእንፈልጋለን።ይህንንመረጃለማግኘት፣በዚህሆስፒታልውስጥምርምርእያደረግንነው
።ይህየዳሰሳጥናትፖሊሲአውጪዎችንእናሌሎችኃላፊነትየሚሰማቸውአካላትየካንሰርእንክብካቤአገልግሎት
ንእንዲያሻሽሉለመርዳትይጠቅማል።ልጠይቃቸውየምፈልጋቸውጥያቄዎችጊዜህን 30
ደቂቃያህልይወስዳሉ።የነገርከኝነገርበጥብቅሚስጥራዊይሆናል፣ስምህአይመዘገብምእናመረጃህለሌላአካልአ
ይተላለፍምወይምበስህተትአይተረጎምም።የእርስዎተሳትፎበፈቃደኝነትነው,

እናማንኛውንምጥያቄለመመለስአይገደዱም;

መልስመስጠትካልፈለጉበማንኛውምጊዜቃለመጠይቁንማቆምይችላሉ።

ስለዚህልቀጥል? 1. አዎ 2. የለምበቃለመጠይቅየተረጋገጠበመረጃየተደገፈስምምነት_____

ፊርማ___ የቃለመጠይቁቀን _____ ጊዜየጀመረው_____ የተጠናቀቀውጊዜ_____

የቃለመጠይቁውጤት - 1. የተጠናቀቀ 2.ተጠሪአይገኝም 3.እምቢተኛ

4.ያልተሟላ።በሱፐርቫይዘርየተረጋገጠ_____ ፊርማ _____ ቀን _____

ለማንኛውምምኞትእናችግርየዋናውንመርማሪስልክማግኘትይችላሉ -0920886029

አማካሪ-፣

አድራሻ- ኤ/ኤ፣

ስልክቁጥር፡-

## ለህጻናትሉኪሚያበሽተኞች-የወላጆችስሪትየተዋቀረመጠይቅ

የጥናቱርዕስ፡የጥራትህይወትግምገማ (QoL)

በአዲስአበባ፣አዲስአበባ፣ጥቁርአንበሳስፔሻላይዝድሆስፒታልየህፃናትህክምናየደምካንሰርካለባቸውታካሚዎ ችመካከል።

ዋናመርማሪ፡መገርቱቀልቤሳ (ቢኤስሲ)

ዋናሱፐርቫይዘር፡ዮሐንስአየለው (ረ/ፕሮፌሰር)

ዋናተባባሪተቆጣጣሪ፡ቦካ፣ቢ (ኤምኤስሲ)

ውድጌታ/እመቤት፣

የዚህጥናትአላማበጥቁርአንበሳስፔሻላይዝድሆስፒታልየሚማሩሉኪሚያያለባቸውህጻናትንህይወትጥራትለ መገምገምነው።ጥናቱበተጨማሪምየህፃናትሉኪሚያበሽተኛየህይወትጥራትላይአሉታዊተጽእኖየሚያሳድሩ

ትንነገሮችለመለየትቃልገብቷልበመሠረቱበሉኪሚያህክምናላይበማስረጃላይየተመሰረተውሳኔመስጠትንለ ማሻሻል።ይህጥናትለአካዳሚክዓላማነውእናያቀረቡትመረጃምስጢራዊነትበቅንነትይጠበቃል።

ለጥያቄዎች፣በሚከተለውአድራሻዋናውንመርማሪማነጋገርይችላሉ።

የተንቀሳቃሽስልክቁጥር: +251920886029

ኢሜል፡ Magartu44@gmail.com

## መመሪያዎች

 እባክዎሁሉንምመረጃለመሙላትይሞክሩ

 የተሰጠውንበታሞልተውበተመረጡበታዎችላይምልክትያድርጉ

 ኤስኤ-በጣምእስማማለሁ፣ኤስዲ- በጣምአልስማማም፣ N-ገለልተኛ፣ A-እስማማለሁ፣እና D-አልስማማም

I. የወላጆችስነ-ሕዝብባህሪያት

1. ጸታ. _____ 4. ትምህርት_____

2. ዕድሜ (በዓመታት) _____ 5. ሙያ_____

3. የጋብቻሁኔታ፡ _____

II. የህይወትጥራትመደበኛጥያቄዎች በጣምተስማማ ተስማማ መደበኛአልስማማም። በጣምአልስማማም

| II. የህይወትጥራትመደበኛጥያቄዎች | በጣምተስማማ | ተስማማ | መደበኛ | አልስማማም። | በጣምአልስማማም |
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| 1. አካላዊደህንነት | | | | | |
| 1. ልጄታምሞነበር | | | | | |
| 2. ልጄራስምታትወይምሆድነበረበት- | | | | | |
| 3. ልጄደክሞእናደክሞነበር። | | | | | |
| 4. ልጄጠንካራእናሙሉጉልበትተሰማኝ | | | | | |
| 2. ስሜታዊደህንነት | | | | | |
| 5. ልጄተዝናናእናበጣምሳቀ 6. ... ልጄምንምነገርለመስራትብዙምአይወድምነበር። | | | | | |
| 6. ልጄብቸኝነትተሰማው | | | | | |
| 7. ልጄፍርሃትተሰምቶትነበርወይምስለራሱእርግጠኛያልሆነ | | | | | |
| 3. ለራስክብርመስጠት | | | | | |
| 8. ልጄበራሱይኮራነበር። | | | | | |

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| 9. ልጄበአለምአናትላይተሰማኝ | | | | | |
| 10. ልጄበራሱተደስቷል | | | | | |
| 11. ልጄብዙጥሩሀሳቦችነበረውቤተሰብ | | | | | |
| 12. ልጄእንደወላጅከእኛጋርተግባብቷል። | | | | | |
| 13. ልጄበቤትውስጥጥሩስሜትተሰማው | | | | | |
| 14. ቤትውስጥተጨቃጨቅን። | | | | | |
| 15. ልጄበዙሪያውእንደምመራውተሰማው። | | | | | |
| 4. ጓደኞች | | | | | |
| 16. ልጄከጓደኞችጋርተጫውቷል | | | | | |
| 17. ልጄከጓደኞችጋርአንድላይነገሮችንአድርጓል | | | | | |

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| 18. ልጄበሌሎችልጆችይወድነበር | | | | | |
| 19. ልጄከጓደኞቹጋርበደንብተስማምቷል | | | | | |
| 20. ልጄከሌሎችልጆችየተለየስሜትተሰማው | | | | | |
| 5. የዕለትተዕለትተግባር (ትምህርትቤት) | | | | | |
| 21. ልጄየትምህርትቤትስራንበቀላሉይቋቋማል | | | | | |
| 22. ልጄበትምህርትቤትትምህርቶችተደስቷል | | | | | |
| 23. ልጄስለወደፊቱይጨነቃል | | | | | |
| 24. ልጄጥቃቅንስራዎችንወይምየቤትስራንሲሰራብዙስህተቶችንአድርጓል | | | | | |
| 25. ልጄመጥፎምልክቶችንወይምደረጃዎችንይፈራነበር | | | | | |
| 6. የበሽታሞዴል | | | | | |
| 26. ልጅዎአሁንበሆስፒታልውስጥተቀምጧልወይንስየረዥምጊዜህመምአለበት? | | | | | |
| 27. ልጄሕመሙሊባባስእንደሚችልፈራ | | | | | |
| 28. ልጄበህመምምክንያትአዝኖነበር | | | | | |
| 29. ልጄህመሙንበደንብመቋቋምችሏል | | | | | |

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| 30. ልጃችንንበሕመምምክንያትእንደታናሽአድርገንነበር | | | | | |
| 31. ልጄህመሙንለመገንዘብከሌሎችይርቃል | | | | | |
| 32. ልጄበህመምምክንያትበትምህርትቤትየሆነነገርአምል ጦታል። | | | | | |
| III. በህጸነትላይተጽዕኖየሚያሳድሩምክንያቶች QoL አዎአይሙላ | | | | | |
| 33. የልጅዎዕድሜበQoL ላይተጽዕኖያሳድራል። | | | | | |
| 34. የልጅዎጸታበQoL ላይተጽዕኖያሳድራል። | | | | | |
| 35. ልምዶችዎ (ሱሶች - ካለ) | | | | | |
| 36. የእርስዎማህበራዊኢኮኖሚያዊሁኔታ(ጋብቻ፣ገቢ፣ስራ እናየመኖሪያሁኔታ) | | | | | |
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| 37. የሕክምናውርዝመት | | | | | |
| 38 .የማገገምፍርሃት,<br>ያልታከመወይምየጎንዮሽጉዳቶች | | | | | |
| 39. የበሽታደረጃ(1-4) | | | | | |

አመሰግናለሁ