



COLLEGE OF HEALTH SCIENCES

DEPARTMENT OF PAEDIATRICS AND CHILD HEALTH

**Quality of Life and Associated Factors among Adolescents with Liquid Cancers in
Remission at Mulago National Referral Hospital, Kampala, Uganda**

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DECLARATION

I hereby declare that, to the best of my knowledge, this is my original work and has never been submitted to this university or any other institution of higher learning for an academic award or publication. I hereby submit it in partial fulfilment for the award of a Master of Medicine in Paediatrics of Makerere University.

Signed  _____

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DEDICATION

I dedicate this dissertation to all the children and adolescent survivors with liquid cancers. Thank you for your courage. Your strength reminds us all that remission extends beyond the clinical status. I hope this research contributes to your continued health and well-being.

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I would like to thank the Almighty God for helping me through the master's program.

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ABBREVIATIONS

ALL	Acute Lymphoblastic Leukaemia
aPR	Adjusted Prevalence Ratio
BMI	Body Mass Index
cPR	crude Prevalence Ratio
GPA	Global Physical Activity Questionnaire
HL	Hodgkin Lymphoma
IQR	Interquartile Range
IRB	Institutional Review Board
LMIC	Low and Middle Income Countries
MaK	Makerere University
MNRH	Mulago National Referral Hospital
MoH	Ministry of Health
NHL	Non-Hodgkin Lymphoma
Peds QL	Paediatric Quality of Life Inventory
PHOU	Paediatric Haematology Oncology Unit
QoL	Quality of Life
RA	Research Assistant
SD	Standard Deviation
SDA	Standard Daily Allowance
SOMREC	School of Medicine Research and Ethics Committee
USA	United States of America
WHO	World Health Organisation

OPERATIONAL DEFINITIONS

Adolescents: any person aged between 10 to 19 years.

Liquid cancers: malignant tumours that originate from hematopoietic or lymphoid cells, these include all types of leukaemias and lymphomas.

Quality of Life: refers to one's perception of the impact that an illness, treatment, or health state has on their psychological, physical, and social well-being.

Remission: the reduction or complete absence of detectable (radiologically or microscopically) malignant cells.

Survivorship: is a complex state of being that includes the perspectives, needs, health, and the physical, psychological, social, and economic challenges experienced by survivors and caregivers after a cancer diagnosis

ABSTRACT

Introduction

In Uganda, leukaemia and lymphoma contribute to 33% and 13% of all childhood cancers, respectively, with improving survival rates. However, data on quality of life (QoL) among adolescents who have achieved remission remain limited. The objective of this study was to determine the quality of life (QoL) among adolescents who were in remission from liquid cancers at Mulago National Referral Hospital (MNRH).

Methods

A cross-sectional study design was used to determine the prevalence of QoL measured as a composite indicator constituted of four domains (Physical, Emotional, Social, and Environmental) using the Pediatric Quality of Life Inventory. Each domain was scored based on a Likert scale ranging from 0(good) to 5(bad), then reverse scored (100 = 0, 0 = 5) and summed for all questions across all 5 domains. An average score was then calculated. QoL was categorised as good (≥ 70) or poor (<70). Data on explanatory variables (demographics, clinical, social, and lifestyle) were collected. The prevalence of QoL was reported as a percentage, and the modified Poisson regression model was used to determine the factors associated with QoL.

Results

The prevalence of Good QoL was 62.6% (95% CI: 53.3 – 71.9). Factors associated with good QoL included being in a relationship (aPR 1.43, 95 % 0.98-2.09, p-value 0.049) and engagement in extracurricular activities (aPR 2.04, 95% CI 1.00-4.14, p-value 0.048). The presence of comorbidities (aPR 0.21, 95% CI 0.21-1.14, p-value 0.043) and persistence of treatment side effects (aPR 0.26, 95% CI 0.13-0.52, p-value 0.000) were associated with poor QoL. The median scores (IQR) per domain were: 78.1 (60.7-93.8), 80 (65-90), 80 (70-100), and 75 (60-85) for Physical, Emotional, Social, and School/work domains, respectively.

Conclusion

Prevalence of good QoL was modest, calling for intervention targeting domains with poor functioning, like school and physical domains should be prioritized. Inclusion of survivorship programs into management of adolescents with liquid cancers in remission should be considered.

CHAPTER 1: INTRODUCTION

1.1 Background

Liquid cancers are the most common childhood cancers globally (1), and they comprise all leukaemias and lymphomas (2). About half of all global cases of leukaemia and lymphomas are recorded from low and middle-income countries (LMICs) (1). In Uganda, leukaemia and lymphoma contribute an estimated 33% and 13% of all childhood cancers, respectively (3).

Worldwide, treatment modalities and supportive care for liquid cancers have greatly advanced over the past 50 years, resulting in improved survival rates (4). In Uganda, the 1-year survival rate for acute lymphoblastic leukaemia (ALL), Hodgkin lymphoma (HL), and non-Hodgkin lymphoma (NHL) among children are 57%, 94%, and 58%, respectively (5), which, if extrapolated, is below the WHO target 5-year survival rate of > 60% by 2030 (6). Regardless, survival rates for liquid cancers among children in Uganda are higher compared to those of other childhood cancers. With more children surviving liquid cancer (7), there is growing concern about their QoL while in complete remission. QoL is an important factor influencing the overall well-being and survival rates among children with cancer after successful treatment (8, 9). Stress of the illness, side effects and adverse effects of treatment, and the duration of the disease have been shown to negatively impact the QoL of these adolescents after successful treatment (10).

In Uganda, literature on the QoL among children with liquid cancers in remission is limited. One study conducted in south-western Uganda (Mbarara Regional Referral Hospital) showed that children with cancer had a good quality of life after treatment. However, this study was limited in that it included all childhood cancers, of whom a small number (n=24) had liquid cancers. Additionally, their approach to assessing QoL was limited to self-reporting, which may overrate QoL (11). The second study, done at the Uganda Cancer Institute (UCI) showed poor quality of life during remission. Like the previous study, this study was underpowered to represent liquid cancers and also represented a younger population of children (12).

With increasing survival rates among children with liquid cancers in Uganda, the objective of this study is to establish the QoL and associated factors among adolescents in remission from liquid cancers at MNRH.

1.2 Problem statement

In Uganda, QoL among an increasing population of adolescents with liquid cancer in remission remains suboptimal. Recent studies have shown that cancer survivors suffer significant mental and functional impairments, including chronic stress (8), negatively impacting their day-to-day living conditions (13). These states interfere with the adolescents' social life, interaction with peers, leading to self-isolation and depression, predisposing them to risky life habits. School attendance and performance are also negatively impacted. Ultimately, low QoL compromises survival among adolescents who have successfully completed treatment. Overemphasis on treatment quality and QoL of life during the treatment phase at the expense of post-treatment care may explain this paradox (14). Additionally, the stressful nature of the disease and its associated treatment, coupled with fear and social developmental drawbacks, may predispose these adolescents to poor outcomes during the post-treatment phase.

1.3 Justification

The Ministry of Health (MOH) has currently developed a National Policy on Cancer (15). . The overall goal of this policy is to enhance policy advocacy to ensure adequate resources, political will, and strategic partnerships are mobilised to support the National Cancer Control Plan, ultimately aiming to reduce cancer-related morbidity and mortality in Uganda (15). This study is going to generate much needed evidence informing this policy, specifically in the area of QoL among adolescents with liquid cancers in remission. In the interim, findings of the study could help in the formulation of local protocols, interventions and guidelines at MNRH Paediatric Cancer Centre, tailored to managing children in remission of liquid cancer, potentially leading to improved post-cancer treatment outcomes. In addition to generating evidence, the study is timely and will abate the likely problem of an increasing population of liquid cancer survivors leading a poor quality of life. This study aims to avoid a related situation seen among patients with sickle cell anaemia who, due to improved paediatric care survive into adulthood but falter because of unmatched adult care (16-18).

1.4 Research questions

1. What is the QoL (physical, social, emotional, and school) among adolescents in remission from liquid cancers at MNRH?
2. What factors are associated with QoL of adolescents in remission from liquid cancers at MNRH?

1.5 Objectives

1.5.1 General objective

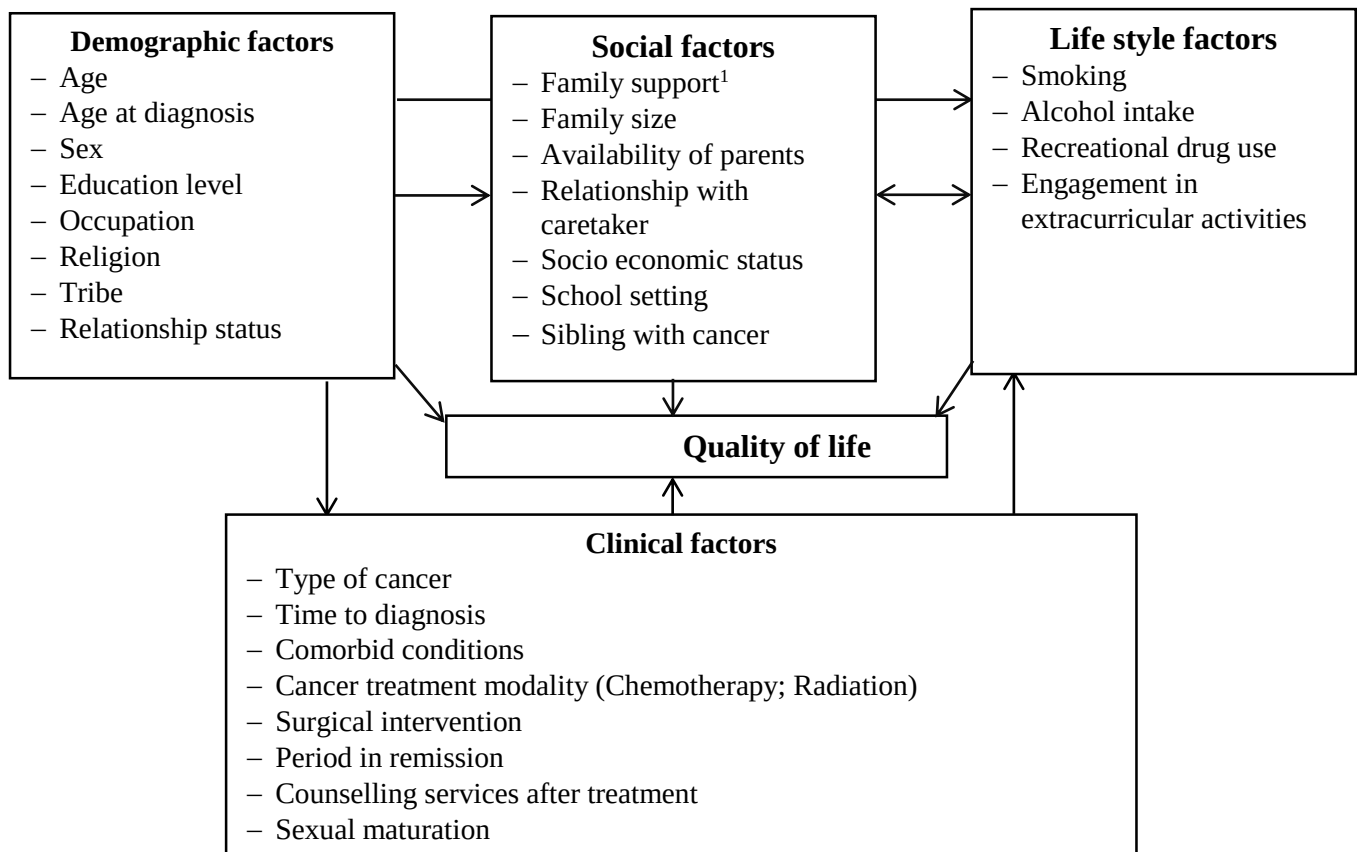
To determine the level and factors associated with the QoL (physical, emotional, and social) among adolescents in remission from liquid cancers at MNRH.

1.5.2 Specific objectives

1. To determine the physical, emotional, school and social quality of life of adolescents in remission from liquid cancers at MNRH.
2. To determine the factors associated with the physical, emotional, and social quality of life of adolescents in remission from liquid cancers at MNRH.

1.6 Conceptual framework

There are four sets of factors which affect quality of life: lifestyle factors, social factors, demographic factors and clinical factors. Though independent these factors may influence each other, which a bidirectional relationship in some factors and yet at the same time influence QoL. The lifestyle factors include: Smoking, alcohol intake, use of recreational drugs and participation in extracurricular activities may represent how an adolescent might cope with the stress of illness with either a positive coping mechanism or negative and hence impacting QoL. The social and demographic factors include: Age, Sex, religion, tribe, education level, occupation, age at diagnosis, years in remission, family support (number of siblings, living with mother/ father/ both), relationship with caretaker, having a sibling with a cancer diagnosis, being in a relationship. The social and demographic factors represent experiences lived and support networks but also further reinforce the adolescent's ability to cope after cancer treatment. The clinical factors include: Comorbid conditions, BMI, cancer treatment regimen (type of chemotherapy, radiation), type of cancer, duration in remission, history of surgical interventions during treatment, and receiving counselling after treatment completion. The clinical factors relate to cancer experience and its medical management and have varying impact on long term health and QoL. Though sexual maturation is an important factor that may influence QoL, because of the sensitivity of assessing it in our study population we have elected not to measure it as a potential explanatory variable.



¹Living with mother, father, both or none

Figure 1: Conceptual framework

1.7 Utility of the study

The purpose of this study is to determine the level and factors contributing to the physical, emotional, and social quality of life of children in remission from liquid cancers at Mulago National Referral Hospital. It will explore the association between social demographic, clinical, and lifestyle factors with the physical, emotional, school and social quality of life.

CHAPTER 2: LITERATURE REVIEW

2.1 Liquid cancer

Liquid cancers refer to the group of cancers, also known as blood or haematological cancers, that have haematopoietic or lymphoid origin (2). It comprises of two types of cancers. First, leukaemias, which are blood cancers that are associated with the production of immature white blood cells. Second, lymphomas are a form of cancer that occurs in the glands or the nodes that make up the lymphatic system in the body.

2.2 Liquid cancers: classification

Leukaemia can be classified based on two approaches: 1) how fast it the cancer develops and 2) the cell types that are affected (19).

2.1.1 Classification based on rate of development

Classification based on rate of growth is as follows:

Acute leukaemia: The aberrant blood cells in acute leukaemia are called immature blood cells, or blasts. The disease progresses swiftly because they are unable to do their regular tasks and proliferate quickly. Treatment for acute leukaemia must be prompt and aggressive(19).

Chronic leukaemia: These come in several forms. Some lead to the production of too few cells, while others create too many. More developed blood cells are involved in chronic leukaemia. For a while, these blood cells can continue to operate correctly despite replicating or accumulating more slowly. For years, some types of chronic leukaemia may go undetected or untreated because they don't show any early symptoms (19).

2.1.2 Classification based on type of white blood cell affected

Under this classification are the following liquid cancer types

1. **Lymphocytic leukaemia.** The lymphoid cells, or lymphocytes, that make up lymphoid or lymphatic tissue are impacted by this type of leukaemia.
2. **Myelogenous leukaemia.** Myeloid cells are impacted by this kind of leukaemia. Red blood cells, white blood cells, and platelet-producing cells are all produced by myeloid cells.

The malignant transformation of pluripotent hematopoietic stem cells, which can produce both myeloid and lymphoid progenitors, is what causes leukaemia (19). On rare occasions, a more devoted stem cell with a restricted potential for self-renewal may also be involved. These cancerous cells in acute leukaemia, which can be either lymphoblasts or myeloblasts, are typically immature, poorly differentiated, aberrant leukocytes (blasts). Clinical symptoms may

result from the replacement and disruption of normal blood cell formation and function caused by these blasts' clonal multiplication and proliferation.

2.3 Pathophysiology

Acute Leukaemia

In ALL, mutations in precursor lymphoid cells that develop into lymphoblasts can be caused by chromosomal translocation or aberrant chromosome numbers. The mutations t(12;21) and t(9;22) are frequently seen. Chromosome rearrangements, translocations, and chromosome gain or loss can result in mutations and aberrant myeloblast formation in AML. One significant translocation is t(15;17), which results in the fusion of a transcription factor for promyelocytic leukaemia (PML) and retinoic acid receptor alpha (RARA). This results in acute promyelocytic leukaemia, which requires immediate all-trans retinoic acid treatment and may exhibit symptoms of disseminated intravascular coagulation (19).

Chronic Leukaemia

Chronic leukaemia is most frequently caused by chromosomal abnormalities in hematopoietic stem cells, which are progenitors to leucocytes. Extra chromosomes, translocations, and deletions are a few examples of anomalies. Mutations primarily impact lymphocytes (particularly B cells) in CLL and granulocytes (most frequently the t(9;22) translocation) in CML. In contrast to acute leukaemias, chronic leukaemias have partially mature cells. These cells divide excessively quickly and provide poor function. They can cause leukopenia, thrombocytopenia, and anaemia by building up in the lymphoid organs and peripheral blood (19).

2.4 Histopathology

Acute leukaemia

More than 20% of the bone marrow or peripheral blood contains blasts in cases of acute leukaemia. Patients with t(8;21)(q22;q22), RUNX1-RUNX1T1, inv(16)(p13.1q22) or t(16;16)(p13.1;q22), CBFB-MYH11 or t(15;17)(q24.1;q21.1), and PML-RARA are treated as having acute leukaemia independent of the blast proportion. Bone marrow biopsies typically show increased cellularity, with blasts, varying numbers of granulocytic or monocytic cells, and erythroid precursors. The evaluation includes the following traditional markers: HLA-DR, CD7, CD11b, CD13, CD14, CD15, CD16, CD33, CD34, CD45, CD56, and CD117. Additionally, a bone marrow aspirate or peripheral smear is submitted for a mutation panel of

several genes, including ASXL1, CEBPA, DNMT3A, FLT3, IDH1, IDH2, NPM1, RUNX1, and TP53, that have therapeutic and prognostic implications (19).

Additionally, B and T lymphoblasts, which make up the bone marrow, have a higher cellularity in ALL. These cells have small nucleoli, scattered chromatin, and uneven, cleft nuclei with invisible cytoplasm. The T-cell lymphoid immunostains TdT, CD2, CD3, CD5, and CD7 are frequently used. Typical B-cell lymphoid immunostains are CD10, CD19, CD22, HLA-DR, PAX5, CD20, and CD79a. To validate the diagnosis of the pure lymphoid lineage, no myeloid markers, such as myeloperoxidase (MPO), should be detected. Mixed phenotype acute leukaemia (MPAL) has both myeloid and lymphoid markers (20).

Chronic Leukaemia

In chronic leukaemia, the white blood cell count is frequently high, and a smear may indicate a marked left shift or granulocyte predominance. Although this type of image is frequently observed during the acute sickness phase, CML should be considered if it continues after repeated lab work. It is possible to diagnose CML by using fluorescence in-situ hybridization (FISH) on peripheral blood to identify the translocation t(9;22).

White blood cells, primarily CD5+ and CD23+ B-lymphocytes, are more prevalent in CLL. For diagnosis, the clonal lymphocyte population must be more than 5,000/mcL. The condition is known as monoclonal B cell lymphocytosis of unknown significance if the population of clonal lymphocytes is less than 5,000/mcL.

In order to choose the best course of treatment, patients would need to have their immunoglobulin heavy chain variable region (IGHV) gene mutation status, del(17p) and TP53 mutation, del(11q), del(13q), and trisomy 12 evaluated (21).

2.5 Aetiology

Multiple genetic and environmental risk factors are identified in the development of leukaemia.

- Exposure to ionising radiation is associated with an increased risk of multiple leukaemia subtypes (22, 23).
- Exposure to benzene is a risk factor for leukaemia in adults, particularly AML (24).
- Previous exposure to chemotherapy, especially alkylating agents and topoisomerase II inhibitors, increases the risk for acute leukaemia later in life (22, 23).

- A history of any hematologic malignancy is a risk factor for subsequently developing another subtype of leukaemia (25).
- Viral infections (e.g., human T-cell leukaemia virus, Epstein-Barr virus) are linked with subtypes of AL (26).
- Several genetic syndromes (e.g., Down syndrome, Fanconi anaemia, Bloom syndrome, Li-Fraumeni syndrome) are associated with an increased risk of AML and ALL (27).
- Male gender and Hispanic race (28).

2.6 Epidemiology of liquid cancers

According to the global cancer observatory trends, GLOBOCAN, there were 474,519 cases worldwide, with 67,784 of those instances occurring in North America (1). The mortality rate is approximately 3.2, and the age-standardised rates are approximately 11 per 100,000. AML and ALL are significant illnesses that affect children (19). Leukaemia is the tenth most prevalent disease in the United States, with an anticipated 61,090 new cases in 2021, contributing to 3.2% of all new cancer cases, according to the Surveillance, Epidemiology, and End Results (2) database. Since 2006, the disease's incidence has grown by 0.6% annually on average, but its fatality rate has dropped by 1.5% annually on average (19, 22, 29). In Uganda, the incidence of leukaemia in children is 10.3 per million children (7). In Uganda, leukaemia and lymphoma contribute an estimated 33% and 13% of all childhood cancers, respectively (3). The cure rates of cancers, including leukaemia and lymphomas, have increased in the last decades, with rates reaching up to 90% for ALL (30, 31). In Uganda, the 1-year survival rates for acute lymphoblastic leukaemia, Hodgkin lymphoma, and non-Hodgkin lymphoma among children are 57%, 94%, and 58%, respectively (5). Although still slightly below WHO targets of > 60% by 2030, survival rates remain high compared to those of other childhood cancers. For this reason, there is a need to ensure strategies for a good quality of life for the survivors (10). Recent research has shown that cancer survivors suffer significant mental and functional impairments that negatively impact their day-to-day living conditions (13), while others suffer from chronic stress (8). Interestingly, some research has found that some cancer survivors from ALL have a better quality of life in some domains, like social and emotional functioning, because they tend to prioritise relationships than the general population (32).

2.7 Quality of life assessment

The Pediatric Quality of Life Inventory (PedsQL) is a widely validated instrument for assessing health-related quality of life (HRQoL) in children and adolescents with chronic illnesses, including cancer. It measures four functional domains—physical, emotional, social, and school functioning—providing a comprehensive assessment of pediatric well-being. Compared with other measures such as the Child Health Questionnaire (CHQ), KINDL-R, and KIDSCREEN, the PedsQL demonstrates superior feasibility, lower respondent burden, shorter administration time, and greater sensitivity to disease-related changes in pediatric cancer populations (Varni et al., 2001; Solans et al., 2008). The instrument includes both generic and disease-specific modules, enabling cross-population comparisons while capturing cancer-specific concerns. Psychometric properties are excellent, with Cronbach's alpha exceeding 0.70 for group comparisons and often surpassing 0.90 for clinical applications (33)

The Ugandan version of the PedsQL was selected for its cultural adaptation and validation among Ugandan children, demonstrating high reliability and acceptability. Internal consistency is excellent (Cronbach's $\alpha \approx 0.95$), with good construct validity supporting its use locally in multiple studies in Uganda (11). Numerous studies have employed the PedsQL to assess quality of life in childhood cancer survivors during remission, identifying persistent functional impairments despite successful treatment. Compared to other HRQoL tools, the PedsQL demonstrates superior responsiveness to treatment effects and survivorship outcomes in pediatric oncology, making it particularly suitable for evaluating children in remission and monitoring longitudinal recovery(13, 34). Thus, the validated Ugandan PedsQL offers a robust, culturally appropriate, and internationally comparable measure for assessing quality of life among adolescents in remission from liquid cancers at Mulago National Referral Hospital.

2.8 Factors contributing to QoL in remission

A recent cohort study to evaluate the effects of chronic illness on the quality of life among 5021 survivors of childhood cancers in the USA reported that comorbid conditions like cardiac conditions, endocrine and pulmonary conditions are related to high stress levels among childhood cancer survivors, hence poor quality of life (10). These conditions usually arise due to complications of the chemotherapy or the cancer itself (35). Additionally, childhood survivors who had undergone surgery in their treatment modalities have reduced functioning, which negatively impacts their quality of life (36, 37). These studies, however included all

childhood cancer survivors and whilst they were adults hence a need to study this effect among paediatric survivors from liquid cancer.

Another cohort study in the USA to determine age-related changes in health status among childhood cancer survivors reported likewise that chronic medical conditions were associated with adverse outcomes. Furthermore, female gender was up to 4 times more likely to have functional impairment as compared to male counterparts (13, 38). Additionally, children who had been diagnosed between 5-10 years had an almost 20% increase in functional impairment (13, 39).

Other factors reported to predispose childhood cancer survivors to impairment and such poor quality of life were: being obese, lymphoma diagnosis, type of cancer treatment (40, 41), and not having attained high school education (13, 42-44). A cross-sectional study of modifiable factors and major cardiac events among 10725 survivors of childhood cancers found that obesity predisposes them to cardiac disease (45).

Age and smoking, alcohol intake, and inactivity are other factors that can impact the quality of life of a childhood cancer survivors, including survival from ALL (46-49). These factors are probably implicated in contributing to the frailty of a cancer survivor, hence poor quality of life (50-52). Furthermore, family dynamics like family support from parents, siblings and their health state impact the quality of life of a cancer survivor (53, 54). Musoro and colleagues studied the quality of life priorities of childhood acute lymphoblastic leukaemia survivors and found that 42% of them generated their happiness from being in relationships (55).

The school setting has been shown to impact the quality of life of adolescents, as many have been away from school for too long and have fallen behind in their classes. The schooling environment has been associated with QoL during remission. Unlike public schools where children have been shown to fail in reintegrating, private schools have been associated with more a positive environment, such as psychological counselling and private tutoring and this has shown to have a good impact on reintegration. The schooling environment is important because when it works well it positively impacts QoL as opposed to staying at home or home schooling(56).

CHAPTER 3: METHODS

3.1 Study design

A cross-sectional study design was used to determine the quality of life among adolescents with liquid cancers in remission.

3.2 Study setting

The study was conducted in the Early Paediatric Haematology Oncology Unit (PHOU) based at MNRH. The unit was established in 2019. The unit provides both inpatient and outpatient care for paediatric blood and cancer disorders, and has a capacity of 48 beds. The unit is run by a team comprised of nine paediatric haematoncologists, four fellows for haemato-oncology, six medical officers, and 16 nurses who provide patient care, which includes patient evaluation (history, examination, and diagnosis), provide treatment, counselling services, and follow-up services. The outpatient oncology clinic runs from Monday to Friday, and patients with active cancer and those in remission are reviewed. On a clinic day, patients' weight, height, blood pressure, and demographic information are taken, entered into the patients' medical records, and then the patients are sent to the medical doctors for review. Medical records at the unit typically detail the following information: past medical history, comorbidities, cancer diagnosis, and treatment regimens. Standards set in the unit over the years have resulted in high-quality medical records. The unit had seen 862 patients with liquid cancers since inception, i.e., 552 with leukaemia and 310 lymphoma patients; 156 patients had completed treatment for at least 6 months. Children are considered to be in complete remission after histological confirmation of the complete absence of malignant cells using bone marrow biopsy and complete blood counts for children with leukaemia. Children with lymphoma are in complete remission when they have complete absence of disease both radiologically and histologically. Children in remission are given appointments for follow-up depending on their duration in remission, either monthly, quarterly, biannually or annually. They are monitored for remission status and also drug side effects. Counselling services are mainly offered to families at diagnosis, and during treatment. Counselling services for adolescents in remission are not offered frequently; only those showing obvious distress see the counsellor, but no remission QoL care programs are available at the clinic yet.

3.3 Population

3.3.1 Target population

All adolescents with liquid cancers in remission upon seeking care at the PHOU at MNRH.

3.3.2 Accessible population

Adolescents aged 10-19 years who were in remission from liquid cancers at Mulago National Referral Hospital, who were around during the study period. Participants who were traceable through clinic visits or via phone call and were available during the study period.

3.3.3 Study population

Adolescents aged 10-19 years who were in remission from liquid cancers at Mulago National Referral Hospital, who were around during the study period, and who fulfilled the eligibility criteria.

3.4 Eligibility criteria

3.4.1 Inclusion criteria

The inclusion included;

1. Adolescents aged 10-19 years.
2. Completed treatment between 2019 to 2025 for at least 6 months at the MNRH PHOU.
3. Were in complete remission from liquid cancers.
4. Adolescents 10 to 17 years who provided assent.
5. Adolescents 10 to 17 whose guardians/parents and study participants age 18 years and above who provided written informed consent.

3.4.2 Exclusion criteria

The exclusion criteria included;

1. Incomplete medical records i.e. were clinical data cannot be ascertained.
2. Patients who were unable to conduct a self-administered questionnaire at the time of enrolment due to severe illness or global development delay like Down syndrome.

3.5 Sample size estimation

3.5.1 Objective 1: Determination of QoL

QoL was categorised as a binary outcome: good or poor. Therefore, the prevalence of good QoL was used to estimate the sample size for objective 1. As recommended for prevalence studies (57), the Kish-Leslie formula (shown below) was used to calculate the sample size for objective 1.

$$n = \frac{Z^2 P(1 - P)}{D^2}$$

Where:

n: The required minimum sample size.

Z: The standard Z-score corresponding to a 95% confidence level, which is = 1.96

P: The expected proportion of adolescents in remission from liquid tumours with good QoL at the PHOU, MNRH will be assumed to be 69.1% (11).

D: precision for the study =0.05

Based on the assumptions above, the study sample size was 324 participants. Upon adjusting for 10% of missing data, the sample size was 364 participants. However, approximately 156 adolescent patients were expected to be in remission since the opening of the unit. On adjusting for the finite population at the PHOU, the final sample size required to estimate the prevalence of QoL among adolescents at the PHOU was:

$$\text{Adjusted sample size } S = \frac{\text{Estimated sample size (N)}}{1 + \frac{\text{Estimated sample size (N)}}{\text{Population size}}}$$

Adjusted sample size *S*= 107 participants

3.5.2 Objective 2: Factors associated with QoL

For objective two, the sample size was calculated using the formula below(57) premised on the calculation formula for difference in means.

$$n = \frac{(Z_{\alpha/2} + Z_{\beta})^2 * 2 * \sigma^2}{d^2}$$

Considering a 95% confidence level and a power of 80%, $Z_{\alpha/2}$ is the standard normal variate corresponding to the 95% confidence interval = 1.96 and Z_{β} = 0.84 variate corresponding to 80% power. d represents the minimum mean difference between two groups (μ_0 - μ_1) where the mean QoL score for termination of treatment less than 12 months (μ_0) = 71, mean QoL score for termination of treatment longer than 12 months (μ_1)= 77 and standard deviation (σ) of 9.6 (58).

After replacing the above formula, the sample size was 41

Adjustment for 10% missing data = 46 participants

Given that the sample size for objective 1 was higher than that for objective 2, the study sample size was based on objective 1. Therefore, the study sample size was 107 participants.

3.6 Sampling technique

The consecutive sampling technique was used to recruit study participants. Medical records in the unit were stored in an orderly manner according to date of enrolment into the unit. Following the order of storage, medical records were consecutively screened for initial (Age 10 to 19; Diagnosis of Liquid cancer in complete remission). Patients whose medical records passed the initial screening criteria were called to the clinic for completion of the eligibility criteria. Patients who fulfilled all the eligibility criteria, including signing of the informed consent form, were enrolled in the study.

3.7 Study variables

3.7.1 Dependent variable

Initially, QoL score was measured a composite indicator measure based on four domains including 1) physical; 8 items assessed; 2) emotional, 3) social, and 4) environment (school or

work). The last three domains were each assessed based on 5 items. Each item in each domain was scored on a Likert scale (range 0 to 4) with most negative experience (almost always) scoring the highest score (4) and the most positive experience (never) scoring the lowest score (0). To determine the total QoL score, the score for each item under each domain were reverse scored (4=0, 3=25, 2=50; 1=75; 0=100). Thereafter, total QoL score was determined by adding all the reversed scores of items answered divided by the number of items answered. Finally, QoL was transformed into a binary variable (Good=1, poor=0) based on a cut of a total QoL score of 70. A good QoL score was equivalent to total QoL score of 70 and above and a poor QoL equivalent to total QoL of less than 70 (11, 59). If more than 50% of all items (all domains) were missing a QoL score was not computed. Each domain was also a scored.

3.7.2 Independent variables

The study consisted of several independent variables under the following categories:

1. Clinical factors

- a. Duration of symptoms before starting treatment
- b. Side effects of medicines (Skin changes, Nail changes, Hair loss)
- c. Treatment types (chemotherapy or radiation)
- d. Comorbid conditions, BMI (height and weight)
- e. Having had Surgical intervention during treatment
- f. Counselling services offered after treatment
- g. Type of cancer – Leukaemia vs lymphoma.
- h. Duration in remission

2. Individual lifestyle factors

- a. Smoking
- b. Alcohol intake.
- c. Use of recreational drugs
- d. Involvement in extracurricular activities

3. Socio-demographic factors

- a. Gender
- b. Age
- c. Age of diagnosis
- d. Religion
- e. Tribe

- f. Level of education of adolescent, primary caretaker and head of household
- g. Family support (number of siblings, living with mother/ father/ both), having a sibling with a cancer diagnosis, and being in a relationship.
- h. Occupation of adolescent
- i. Occupation of caretaker

3.8 Data collection

3.8.1 Study tools

Data collection was done using an interviewer/self-administered semi-structured questionnaire in English. It was pretested on 5 children aged 10-19 years at Mulago National Referral Hospital in English to ascertain whether its items achieve their intended use and if the participants understood the items. Pretesting on the 5 adolescents was done by 2 different interviewers to ensure that scores were close for each participant.

3.8.2 Data collection procedure

Two trained research assistants (RAs) were employed to screen and enrol study participants and administer the E-questionnaire on Red Cap with the help of the principal investigator. RAs were registered nurses.

The RAs and the principal investigator (PI) obtained informed consent or assents as appropriate, filled in the questionnaire with the participants' social demographic characteristics, the clinical and self-care factors as per the questionnaire on Appendix 1, measured and recorded the weight and height of the participants using a well-calibrated weight scale and stadiometer, respectively. The information that was retrieved from the medical records included: cancer treatment, history of surgical resection of a tumour, cancer type, medical history of hypertension and other comorbidities.

The RAs or the PI administered the quality of life using the Paediatric Quality of Life Inventory Uganda version 4.0 (PedsQL; Appendix II) to assess physical, emotional, social, and school functioning of the participant. The 23-item PedsQL encompassed: Physical Functioning (8 items), Emotional Functioning (5 items), Social Functioning (5 items), and School/work Functioning (5 items).

3.9 Data management

At the end of each day, filled out e-questionnaires on Redcap of enrolled study participants were inspected for completeness and correctness by the PI. Data was double entered into

Redcap after which an excel document was exported and cleaned for analysis. Data collected was backed up on an external hard drive to mitigate potential loss.

Data was then exported to STATA version 16 (STATA Corp, College Station, TX) for analysis.

3.10 Data analysis

Continuous normally distributed variables were expressed in means and standard deviations.

Non-normally distributed variables were expressed in medians and interquartile ranges.

Categorical data was summarised in percentages and proportions.

Prevalence of good quality of life was expressed as a percentage of the number of adolescents who scored 70 and above on the PedsQL out of the total number of adolescents recruited.

Modified Poisson regression reporting robust standard errors was used to estimate the association between Quality of Life and the socio-demographic, clinical, and lifestyle factors.

To test the appropriateness of the model, the assumptions of over dispersion/under dispersion and collinearity were checked and not violated.

All variables with a p-value < 0.2 at bivariate analysis were considered for multivariate analysis.

The backward method was used to manually drop the most insignificant variables. Interaction was assessed by introducing product terms of the remaining significant variables in the model and manually removing the ones whose p-value was not < 0.05 . Confounding was assessed by at least a 10% change in the adjusted odds ratios when a variable was reintroduced into the model. Statistical significance for the final model was determined at a p-value < 0.05 .

3.11 Ethical consideration

Before the study, permission to conduct the study was sought from the Makerere University Department of Paediatrics and Child Health. Ethical approval to conduct the study was sought from the School of Medicine Research and Ethics Committee of Makerere University (SoMREC). Administrative clearance was sought from Mulago National Referral Hospital. Written informed consent was obtained from the participants who were 18 years and above, and assent was obtained from adolescents aged 10 - 17 years, and their guardians or parents gave informed consent.

In the community engagement plan, the head of the department and the unit in-charge of the paediatric cancer unit at Mulago National Referral Hospital were approached to express the intention to carry out the research, sought permission to inform the rest of the unit staff about

the research and the recruitment plan. The research was announced to increase awareness among the patients.

For confidentiality reasons, the identities of the participants were not included in the study data. Paper files and records were kept confidential and not shared with any third party without consent from the participant. Data collected was used for research purposes only and may be discarded later.

Participants were given a compensation of ten thousand Uganda shillings.

Participants with poor QoL scores were recommended for the survivorship programme that the unit was in the process of creating, and also their parents, after consents from the participants were advised on how to best support the participants, such as how to help with schooling challenges, for example, after school/ holiday coaching, encouraging the adolescents to be involved in extracurricular activities. Participants with low scores in the emotional domain were given appointments with the unit psychologist/counsellor.

3.12 Quality assurance and control

The research assistants were trained for 2 days before data collection. The study participants were told the objectives of the study to ensure honest responses, and shall be assured of confidentiality. To ensure completeness and accuracy, filled e-questionnaires were reviewed by the research assistants. The PI reviewed the data entered in Redcap and resolved cases of discrepancies by reviewing the tools herself. Both the electronic and hard copies of the data were kept under password and lock and key, respectively, to ensure data safety.

Back translation of the data collection tools, assent and consent forms was done to ensure the reliability of the translated documents.

3.13 Study dissemination

The findings from this study will be presented to the Directorate of postgraduate Studies, Makerere University as a dissertation; a requirement for the partial fulfilment for the award of Master of Medicine in Paediatrics and Child Health. Copies of the dissertation will be availed to the Department of Paediatrics and Child health of Makerere University, Albert Cook Library, the supervisors, and to the paediatric cancer clinic of Mulago National Referral hospital. It may also be shared with authorities at the ministry of health (Uganda) to guide health care policies

on routine screening and education for children in remission and as well as be published in a reputable journal.

3.14 Study limitation

There was likely to be social desirability bias since participants self-reported the comorbid conditions, quality of life parameters and their lifestyle practices and also because QoL was scored on a Likert scale. The participants were told the objectives of the study to ensure honest responses and were assured of confidentiality.

Misclassification bias was anticipated in measurement of the Quality of Life objectively and as well measured in one point in time. To address this, a Pediatric Quality of Life Inventory (PedsQL) was used in the study. The tool was validated for use in children aged 5 years and above to assess physical, social and emotional state of children during and after cancer treatment and was also been used and validated for use in Uganda for cancer patients and other conditions. (8, 11, 33, 60).

CHAPTER 4: RESULTS

4.1 STUDY FLOW

A total of 107 participants were recruited into the study between December 2025 and February 2026. Participants were enrolled at the Paediatric Haematology Oncology Unit of Mulago National Referral Hospital. 4 adolescents with Down syndrome were excluded because of global developmental delay and could not answer the questions. In figure 2.

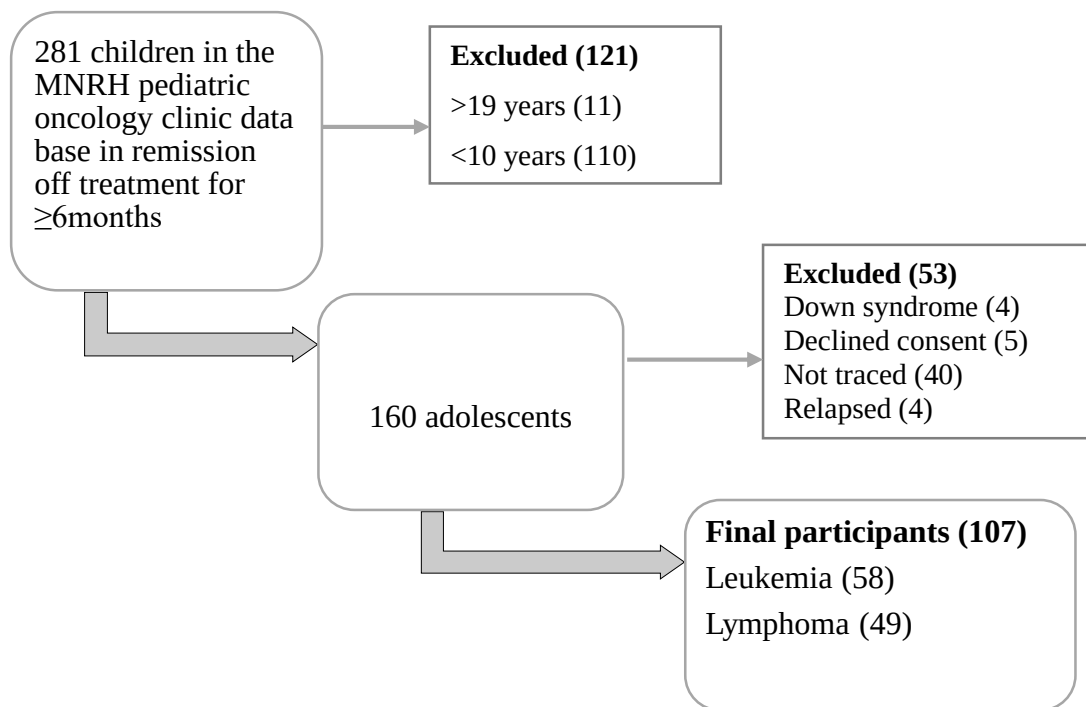


Figure 2: Study flow

4.2 Socio-demographic characteristics

The median age of the 107 participants was 14 years (IQR, 12 - 16), with the majority of participants being of the male gender at 56.1 %. The majority of the participants (74.8%) had been diagnosed with the blood cancer at the age of 10 – 12 years. Nearly all (>95%) participants were students; primary (72); secondary (32). Three participants were not in school.

The socio-demographic and clinical characteristics are shown in Table 1a and 1b below.

Table 1a: Socio-demographic characteristics of 107 patients in remission receiving care at the Paediatric Haematology Oncology Unit of Mulago National Referral Hospital

Variable	Frequency (%)	Median (IQR)
Age in years		14 (12-16)
10-12	37 (34.6)	
13-18	62 (57.9)	
19	8 (7.5)	
Age at diagnosis (years)		10 (8-13)
0-5	9 (8.4)	
6-10	37 (34.6)	
10-13	43 (40.2)	
14 and above	18 (16.8)	
Gender		
Male	60 (56.1)	
Female	47 (43.9)	
Tribe		
Muganda	45 (42.1)	
Musoga	13 (12.1)	
Ankole	8 (7.5)	
Mufumbira	4 (3.7)	
Others	37 (34.6)	
Religion		
Catholic	33 (30.8)	
Muslims	18 (16.8)	
SDA	3 (2.8)	
Born again	24 (22.4)	
Anglican	29 (27.1)	
Education level		
None	3 (2.8)	
Primary level	72 (67.3)	
Secondary Level	32 (29.9)	
School setting		
Government	44 (41.1)	
Private	58 (54.2)	
International	2 (1.9)	
Not applicable	3 (2.8)	
Relationship status		
Single	100 (93.5)	
In a relationship	7 (6.5)	

Table 1b: Socio-demographic characteristics of 107 patients in remission receiving care at the Paediatric Haematology Oncology Unit of Mulago National Referral Hospital

Variable	Frequency (%)	Median (IQR)
Number of siblings		4(3-7)
Has a sibling with cancer		
No	101 (94.4)	
Yes	6 (5.6)	
Living with Parent		
None	22 (20.6)	
Mother only	23 (21.5)	
Father only	6 (5.6)	
Both	56 (52.3)	
Employment of caretaker		
Unemployed	23 (21.5)	
Informal job	58 (54.2)	
Formal job	26 (24.3)	
Education of caretaker		
None	10 (9.3)	
Primary	51 (47.7)	
Secondary	26 (24.3)	
University	20 (18.7)	
Highest level of education for household head		
None	8 (7.4)	
Primary	36 (33.7)	
Secondary	43 (40.2)	
University	20 (18.7)	

4.3 Clinical and lifestyle characteristics

The majority of participants had had Leukaemia (54.2%) and the rest lymphomas. Distribution of the different types of leukaemia and lymphoma participants was follows; B cell-ALL-20, T cell-ALL-10, Acute Promyelocytic Leukaemia-12, Acute Myeloid Leukaemia-16, Burkitt's Lymphoma-28, Classic Hodgkin Lymphoma-14, T-cell Lymphoblastic lymphoma-3, B-cell Lymphoblastic Lymphoma-2, Mature T-cell lymphoma-1, Mature B-cell lymphoma-1. Only 3.7% of the participants having had a relapse. Predominantly (82.2%), the participants had not received counselling on quality of life. Comorbidities included paraplegia/hemi-paralysis, epilepsy, asthma, allergic dermatitis and blindness. Persistent treatment side effects included

back pain, hyperpigmentation, chest pain, forgetfulness and poor concentration. The clinical and life style factors are shown in Table 2 below.

Table 2: Clinical and life style characteristics of 107 patients in remission receiving care at the Paediatric Haematology Oncology Unit of Mulago National Referral Hospital

Variable	Frequency (%)	Median (IQR)
BMI		
Normal	98 (91.6)	
Overweight	9 (8.4)	
Has Comorbidity		
No	97 (90.7)	
Yes	10 (9.3)	
Type of cancer		
Leukaemia	58 (54.2)	
Lymphoma	49 (45.8)	
Duration in remission (years)		2.8 (1.6-4)
Cancer treatment		
Chemotherapy only	93 (86.9)	
Chemo + Radio therapy	14 (13.1)	
History of relapse		
No	103 (96.3)	
Yes	4 (3.7)	
History of surgical intervention		
No	94 (87.8)	
Yes	13 (12.2)	
Persistence of treatment side effects		
No	75 (70.1)	
Yes	32 (29.9)	
Received counselling		
No	88 (82.2)	
Yes	19	
On QoL	11 (10.3)	
Not on QoL	8 (7.5)	
Smoking status		
No	106 (99.1)	
Yes	1 (0.9)	
Alcohol status		
No	106 (99.1)	
Yes	1 (0.9)	
Takes recreational drugs		
No	106 (99.1)	
Yes	1 (0.9)	
Has extracurricular activities		
No	21 (19.6)	
Yes	86 (80.4)	

4.4 Prevalence of Good Quality of Life

Overall, the prevalence of good quality of life was 62.6% (95% CI: 53.3 – 71.9). The majority of the participants with a good quality of life were the teenagers aged 13 to 18 years, and the young adults were the least. A breakdown of quality of life is shown in Table 3 below.

The median scores (IQR) per domain were: 78.1 (60.7-93.8), 80 (65-90), 80 (70-100), and 75 (60-85) for Physical, Emotional, Social, and School/work domains, respectively.

The mean scores (SD) per domain were: 76.8 (19.78), 77.0 (17.73), 81.6 (16.32), 71.7 (18.9) for physical, emotional, social, and school/work domains, respectively. The mean QoL score was 76.8 (14.0)

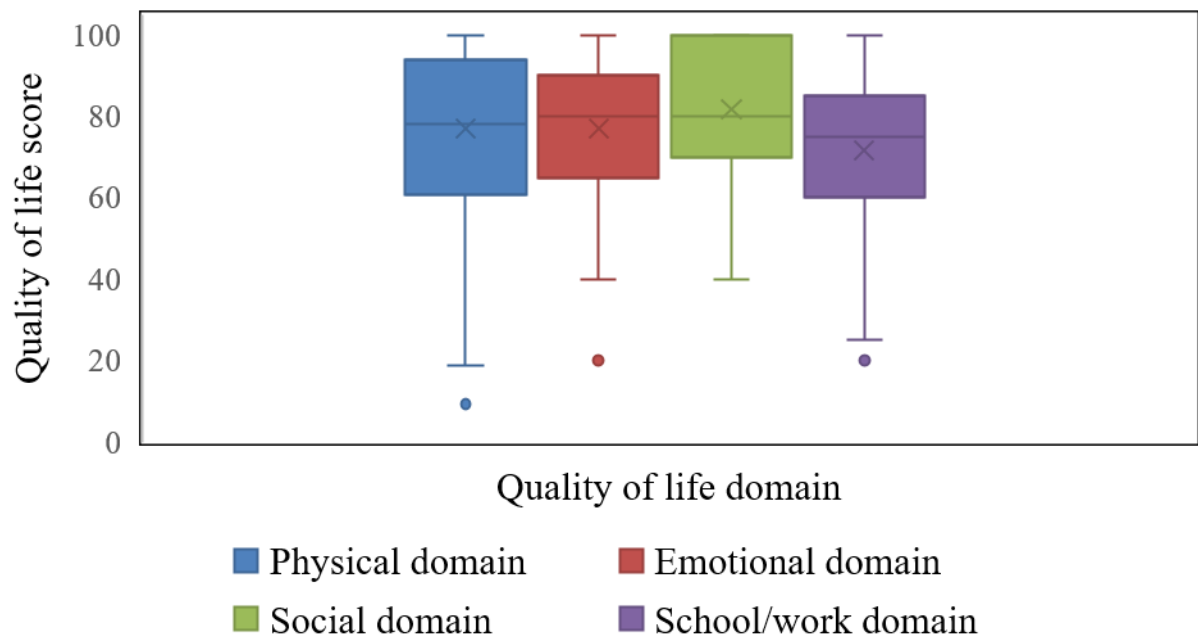


Figure 3: Box and whisker plot of Quality of life scores by domain

Table 3: Prevalence of Good Quality of Life among 107 patients in remission receiving care at the Paediatric Haematology Oncology Unit of Mulago National Referral Hospital

Variable	Frequency	95% CI
	(%)	
QoL status		
Poor	40 (37.4)	28.1 – 46.7
Good	67 (62.6)	53.3 – 71.9
Good QoL by Age Group		
(years)		
10-12	23 (62.2)	
13-18 years	39(62.9)	
19	5 (62.62)	

4.5 Factors associated with Good quality of life

4.5.1 Socio-demographic Factors

The factors that had a p-value less than 0.2 and were considered for multivariate analysis were; Tribe, relationship status, and highest level of education of family members. At multivariate analysis, the socio-demographic factors that was associated with good QoL was being in a relationship (aPR 1.43) was associated with increased likelihood of having good quality of life. The bivariate and multivariate analysis of socio-demographic factors is shown in Table 4a and table 4b.

Table 4a: Bivariable analysis of socio-demographic factors associated with good quality of life among 107 patients in remission receiving care at the Paediatric Haematology Oncology Unit of Mulago National Referral Hospital.

Variable	Quality of Life		cPR	95%CI	P value
	Poor (40) n (%)	Good (67) n (%)			
Age in years					
10-12	14 (37.8)	23 (62.2)	Ref		
13-18	23 (37.1)	39 (62.9)	1.01	0.74-1.39	0.942
19	3 (37.4)	5 (62.6)	1.01	0.55-1.82	0.986
Age at diagnosis					
0-5	3 (7.5)	6 (9.0)	Ref		
6-10	13 (32.5)	24 (35.8)	0.97	0.58-1.64	0.918
10-13	18 (45.0)	25 (37.3)	0.87	0.51-1.48	0.612
14 and above	6 (15.0)	12 (17.9)	1.00	0.57-1.76	1.000
Gender					
Male	20 (50.0)	40 (59.7)	Ref		
Female	20 (50.0)	27 (40.3)	0.86	0.63-1.17	0.340
Tribe					
Muganda	12 (30.0)	33 (49.3)	Ref		
Musoga	6 (15.0)	7 (10.4)	0.73	0.43-1.25	0.258*
Ankole	3 (7.5)	5 (7.5)	0.85	0.48-1.50	0.581*
Mufumbira	3 (7.5)	1 (1.5)	0.34	0.06-1.89	0.219*
Others	16 (40.0)	21 (31.3)	0.77	0.55-1.08	0.132*
Religion					
Catholic	8 (20.0)	25 (37.3)	Ref		
SDA	2 (5.0)	1 (1.5)	0.44	0.09-2.22	0.320*
Muslims	6 (15.0)	12 (17.9)	0.88	0.60-1.29	0.511*
Born again	12 (30.0)	12 (17.9)	0.66	0.42-1.03	0.068*
Anglican	12 (30.0)	17 (25.4)	0.77	0.53-1.11	0.167*
Education					
Primary	23 (57.5)	49 (73.1)	Ref		
None	3 (7.5)	0 (0.0)	**		
Secondary Level	14 (35.0)	18 (26.9)	0.83	0.58-1.17	0.280
School setting					
Government	18 (45.0)	26 (38.8)	Ref		
Private	18 (45.0)	40 (59.7)	1.17	0.86-1.58	0.316
International	1 (2.5)	1 (1.5)	0.85	0.21-3.48	0.817
Not applicable	3 (7.5)	0 (0.0)	**		

*Considered for multivariable analysis. **A few numbers to measure association. PR- prevalence ratio (crude/^aadjusted)

Table 4b: Bivariable analysis of socio-demographic factors associated with good quality of life among 107 patients in remission receiving care at the Paediatric Haematology Oncology Unit of Mulago National Referral Hospital

Oncology Unit of Madang National Referral Hospital					
Variable	Quality of Life		cPR	95% CI	P value
	Poor (40) n (%)	Good (67) n (%)			
Relationship status					
Single	40 (100.0)	60 (89.6)	Ref		
In a relationship	0 (0.00)	7 (10.4)	1.67	1.42-1.96	0.000*
Siblings No.			0.99	0.95-1.04	0.794
Sibling with cancer					
No	38 (95.0)	63 (94.0)	Ref		
Yes	2 (5.0)	4 (6.0)	1.07	0.59-1.93	0.825
Living with Parent					
None	10 (25.0)	12 (17.9)	Ref		
Mother only	9 (22.5)	14 (20.9)	1.12	0.67-1.85	0.670
Father only	2 (5.0)	4 (6.0)	1.22	0.62-2.43	0.566
Both	19 (47.5)	37 (55.2)	1.21	0.79-1.86	0.379
Employment of caretaker					
Unemployed	10 (25.0)	13 (19.4)	Ref		
Informal job	22 (55.0)	36 (53.7)	1.09	0.73-1.66	0.657
Formal job	8 (20.0)	18 (26.9)	1.22	0.79-1.91	0.369
Education of caretaker					
None	3 (7.5)	7 (10.4)	Ref		
Primary	20 (50.0)	31 (46.3)	0.87	0.55-1.38	0.551
Secondary	8 (20.0)	18 (26.9)	0.99	0.61-1.60	0.964
University	9 (22.5)	11 (16.4)	0.79	0.44-1.39	0.407
Highest level of education for house hold head					
None	1 (2.5)	7 (10.4)	Ref		
Primary	16 (40.0)	20 (29.9)	0.63	0.43-0.94	0.024*
Secondary	13 (32.5)	30 (44.8)	0.79	0.57-1.11	0.177*
University	10 (25.0)	10 (14.9)	0.57	0.34-0.95	0.032*

*Considered for multivariable analysis. **A few numbers to measure association. cPR- crude prevalence ratio

4.5.2 Clinical and lifestyle factors

The factors that had a p-value less than 0.2 and were considered for multivariable analysis were: having comorbidity, persistence of side effects of treatment, and having extracurricular activities. At multivariable analysis, the clinical and lifestyle factors that were included in the final model were: having comorbidity (aPR 0.21), persistence of side effects of treatment (aPR 0.26) were associated with less likelihood of having good quality of life. Having extracurricular activities (aPR 2.04) was associated with an increased likelihood of having good quality of life. The bivariate and multivariate analysis of socio-demographic factors is shown in Table 5 and table 6 respectively.

Table 5: Bivariable analysis of clinical and lifestyle factors associated with good quality of life among 107 patients in remission receiving care at the Paediatric Haematology Oncology Unit of Mulago National Referral Hospital

Variable	Quality of Life		cPR	95%CI	P value
	Poor (40) n (%)	Good (67) n (%)			
BMI					
Normal	38 (95.0)	60 (89.5)	Ref		
Overweight	2 (5.0)	7 (10.5)	1.27	0.86-1.87	0.223
Has Comorbidity					
No	31 (77.5)	66 (98.5)	Ref		
Yes	9 (22.5)	1 (1.5)	0.20	0.02-0.96	0.045*
Type of cancer					
Leukaemia	19 (47.5)	39 (58.2)	Ref		
Lymphoma	21 (52.5)	28 (41.8)	0.85	0.63-1.15	0.293
Duration in remission (years)			1.00	0.93-1.08	0.935
Cancer treatment					
Chemotherapy only	34 (85.0)	59 (88.1)	Ref		
Chemo + Radio therapy	6 (15.0)	8 (11.9)	0.90	0.56-1.46	0.670
History of relapse					
No	36 (90.0)	67 (100.0)	Ref		
Yes	4 (10.0)	0 (0.0)	**		
History of surgical intervention					
No	34 (85.0)	60 (89.6)	Ref		
Yes	6 (15.0)	7 (10.4)	0.84	0.49-1.43	0.528
Persistence of treatment side effects					
No	14 (35.0)	61 (91.0)	Ref		
Yes	26 (65.0)	6 (9.0)	0.23	0.11-0.48	0.000*
Received QoL counselling					
No	36 (90.0)	60 (89.5)	Ref		
Yes	4 (10.0)	7 (10.5)	1.02	0.63-1.64	0.941
Smoking status					
No	40 (100.0)	66 (98.5)	Ref		
Yes	0 (0.0)	1 (1.5)	**		
Alcohol status					
No	40 (100.0)	66 (98.5)	Ref		
Yes	0 (0.0)	1 (1.5)	**		
Takes recreational drugs					
No	40 (100.0)	66 (98.5)	Ref		
Yes	0 (0.0)	1 (1.5)	**		
Has extracurricular activities					
No	16 (40.0)	5 (7.5)	Ref		
Yes	24 (60.0)	62 (92.5)	3.03	1.39-6.61	0.005*

* Considered for multivariable analysis. **Few numbers to measure association. cPR- crude prevalence ratio

Table 6: Multivariable analysis of clinical, socio-demographic and lifestyle factors associated with good quality of life among 107 patients in remission receiving care at the Paediatric Haematology Oncology Unit of Mulago National Referral Hospital

Variable	cPR (95%CI)	aPR	95%CI	P value
Has Comorbidity				
No	Ref	Ref		
Yes	0.20 (0.02-0.96)	0.21	0.03-1.14	0.043
Persistence of treatment side effects				
No	Ref	Ref		
Yes	0.23 (0.11-0.48)	0.26	0.13-0.52	0.000
Relationship status				
Single	Ref	Ref		
In a relationship	1.67 (1.42-1.96)	1.43	0.98-2.09	0.049
Has extracurricular activities				
No	Ref	Ref		
Yes	3.03 (1.31-6.61)	2.04	1.00-4.14	0.048

cPR- crude prevalence ratio, aPR- adjusted prevalence ratio

CHAPTER 5: DISCUSSION

5.1 Introduction

Quality of life is an important outcome among adolescents with liquid cancers in remission in this study, we found a modest proportion of adolescents with good QoL, with 2 in 5 participants still living a poor quality of life, implying that even when in remission, the adolescents struggle with other aspects of quality of life, undermining the successes of cancer treatment. Factors associated with good QoL included being in a relationship and participation in extracurricular activities. Not surprisingly, persistence of treatment side effects and the presence of comorbidities were associated with poor QoL. These findings provide direction as to where interventions targeting improvement of QoL can be directed.

5.2 Prevalence of QoL

The prevalence of good QoL was modest, with about 2 in 5 adolescents in remission living with a poor QoL. These study findings are consistent with other studies conducted in western Uganda, Sudan, and Europe (11, 58, 61). These studies included children with all cancers, therefore undermining our ability to draw conclusions. However, a meta-analysis of the same study population in China reported lower QoL scores (62). These differences may be explained by the different cultural factors that might influence QoL (62). In our setting, strong family networks, including extended family support, may explain the relatively higher QoL scores as determined by mixed study carried out in western Uganda(11). Adolescents aged 19 years had a poorer overall QoL compared to younger adolescents in other groups. Albeit not statistically significant, this finding is consistent with findings from other studies, a pointer that all adolescents have unique needs. Indeed, it has been suggested that the role of family support decreases in older adolescents.

5.3 Functioning by the QoL domain

QoL was also assessed based on functioning in each domain to create an understanding of variation in functioning by domain. Findings indicated that median scores in the different domains were good, but associated with wide interquartile ranges and outliers in all domains except the social domain. This may reflect that functioning levels varied greatly within domains and could be explained by differences in participants' attributes. suggesting some participants may still experience limitations in those domains, especially in the physical and school

domains, likely due to the persistence of treatment side effects, commodities, or not participating in extracurricular activities

The highest scores were found in the social domain, consistent with studies that indicate children and adolescents easily regain social functioning, a fact explained by strong family, peer support, and the extended family structures in Uganda (11, 35, 63). Lower scores were found in the school functioning domain, a finding consistent with other studies (34, 63). The negative impact of cancer and its treatment on schooling likely explains these findings. Cancer treatment, side effects grossly disrupt school attendance but may also lead to cognitive impairment characterised by forgetfulness, poor concentration, and reduced academic performance, regardless of cancer type, and also linked to young age at diagnosis (34, 63), and the majority of the participants in this study were diagnosed below the age of 14years (40.2%). Scores in the emotional functioning demonstrated a relatively stable emotional well-being, but the lowest interquartile range was 65.0, with outliers in this domain, which may indicate subsets still experienced emotion deficits like depression, comparable to a study in Spain comparing QoL in adolescent cancer survivors and other adolescents (63). However, a study in the USA noted that adolescent cancer survivors had a higher perceived positive view of self and viewed themselves in a positive light, making them more resilient, which may improve their emotional wellbeing (64).

5.4 Factors associated with QoL

Being in a relationship was associated with a borderline likelihood of good QoL (aPR 1.43). This finding aligns with the systematic review of quantitative studies done in Europe that emphasised that relationship status during remission improved QoL because relationships may foster social reintegration, resilience, and growth, but also compensate for deficits in some domains like school (55). However, many of the adolescent were hesitant to disclose their relationship status, and but this variable had a small sample size with a wide confidence interval weakening association. Participants who had comorbidities (aPR 0.21) were less likely to have a good QoL. This was consistent with a study that showed chronic physical health conditions, whether pre-existing or caused by the cancer, were primary drivers of poor functional outcomes, especially in the physical and school domains (10). This finding is not surprising given the nature of comorbidities (epilepsy, paraplegia, blindness) that can be quite debilitating although this variable had a small sample size this variable still has biological plausibility. Persistence of treatment side effects (aPR 0.26, $p < 0.000$) was a strong predictor of poor QoL.

This aligned with other studies that showed early and late effects of treatment may impact physical, cognitive functioning, and body image, and, in the long run, affect physical and school functioning(11, 65). Lastly, engagement in extracurricular activities was a positive predictor of QoL, and this was consistent with studies that showed physical activity and peer engagement improve both physical, emotional, and social domains of QoL (63).

Sex was not found to be a statistically significant predictor of QoL in both bivariate and multivariate analysis. This was consistent with a study comparing QoL of cancer patients in Khartoum on and off treatment, which showed no variation in QoL among males and females (58). However, another study found females had a lower QoL, but their study population mainly comprised adolescents aged 18 to 19 and young adults (35). Bivariate analysis showed no significant association between age at diagnosis and QoL. This contrasted with a study in the Netherlands looking at the life course of young adults, which found poor QoL in survivors, especially those diagnosed during adolescence, having poor social and emotional functioning (66). This difference may be attributed to resilience in this age group or the extended family nature in Uganda, which provides easier reintegration (11, 64). In addition, adolescents aged 19years had a poorer overall QoL compared with other adolescents; however, this difference was not statistically significant. The type of liquid cancer and most of the social demographic factors were not associated with the quality of life, which correlated with a study done in Norway (67). The lack of association between QoL and other factors, such as sex and socioeconomic factors, commonly associated with health outcomes, may be explained by the fact that cancer is a complex illness. Cancer survivors develop resilience due to their lived experience.

5.5 Limitations and strengths

The small sample size limited our ability to detect some associations; this also weakened the association of some factors, like the presence of comorbidities, and being in a relationship, and further explains why the prevalence of good QoL was associated with wide confidence intervals. This is a limitation we could not overcome, given the low numbers of eligible participants at MNRH, but the study was carried out at a tertiary hospital that gets referrals from across the country and neighbouring countries.

Being a cross-sectional design, we were unable to measure change in QoL over time and assessment of causality. Self-reporting and the use of a Likert scale score created social

desirability bias, and this was mitigated by training the interviewers and a validated Peds QoL tool for use in Uganda was used to assess QoL

5.6 Conclusion

The prevalence of good QoL was modest in this study. Modifiable factors, including extracurricular activities a good QoL. Persistence of treatment side effects and presence of comorbid conditions were associated with a poor QoL. Although relationship status had a borderline statistically significant association with QoL, the association was weak and based on a small number of participants; therefore, it should be interpreted cautiously

5.7 Recommendations

1. There is a need for the MOH to update cancer management guidelines by catering to QoL while in remission
2. Set up integrated survivorship programs at different cancer treatment centres that focus on long-term side effects management and address comorbid conditions, and provide more psychosocial support with the development of school reintegration programs to support academic recovery.
3. More research is needed to understand the changes in QoL over the life course of liquid cancer survivors.

REFERENCES

1. WHO GLOBAL CANCER OBSERVATORY. Absolute numbers, Incidence, Both sexes, age [0-19], in 2022 Hodgkin lymphoma + Non-Hodgkin lymphoma + Leukaemia: WHO; 2025 [cited 2025 03/April/2025]. Available from: https://gco.iarc.fr/today/en/dataviz/pie?mode=population&group_populations=0&populations=987_988_989_990&age_end=3&cancers=36_33_34&group_cancers=1&multiple_cancers=1&age_start=0.
2. National Cancer Institute SEER. Cancer classification: National Cancer Institute; 2025 [cited 2025 03/April/2025]. Available from: <https://training.seer.cancer.gov/disease/categories/classification.html>.
3. Haematoncology P. Internal data on the incidence of paediatric cancers 2019 to 2025 (unpublished data). 2025.
4. Phillips SM, Padgett LS, Leisenring WM, Stratton KK, Bishop K, Krull KR, et al. Survivors of childhood cancer in the United States: prevalence and burden of morbidity. *Cancer Epidemiol Biomarkers Prev*. 2015;24(4):653-63.
5. Liu B, Youlden DR, Wabinga H, Nambooz S, Amulen PM, Aitken JF, et al. Survival from childhood cancer in Kampala, Uganda. *Pediatr Blood Cancer*. 2021;68(3):e28876.
6. CureAll Framework: WHO Global Initiative for Childhood Cancer. Increasing Access, Advancing Quality, Saving Lives. 1st ed. Geneva: World Health Organization; 2021 2021. 1 p.
7. Mutyaba I, Wabinga HR, Orem J, Casper C, Phipps W. Presentation and Outcomes of Childhood Cancer Patients at Uganda Cancer Institute. *Glob Pediatr Health*. 2019;6:2333794x19849749.
8. Racine NM, Khu M, Reynolds K, Guilcher GMT, Schulte FSM. Quality of life in pediatric cancer survivors: contributions of parental distress and psychosocial family risk. *Curr Oncol*. 2018;25(1):41-8.
9. Brand S, Wolfe J, Samsel C. The Impact of Cancer and its Treatment on the Growth and Development of the Pediatric Patient. *Curr Pediatr Rev*. 2017;13(1):24-33.
10. Vuotto SC, Krull KR, Li C, Oeffinger KC, Green DM, Patel SK, et al. Impact of chronic disease on emotional distress in adult survivors of childhood cancer: A report from the Childhood Cancer Survivor Study. *Cancer*. 2017;123(3):521-8.
11. Longes DF, Tibaijuka L, Muwanguzi M, Kalubi P, Asiimwe S, Schwartz K, et al. Self-Reported Quality of Life and Lived Experiences of Adolescent Cancer Survivors Aged 10-19 in Southwestern Uganda: A Mixed-Methods Study in a Resource-Limited Setting. *Cancer Rep (Hoboken)*. 2025;8(3):e70163.
12. Stella Maleni. Health Related Quality of Life in Children 2-15 years at Diagnosis, During Cancer Treatment, and Post-Treatment in Uganda Cancer Institute (unpublished master's thesis). 2016.
13. Hudson MM, Oeffinger KC, Jones K, Brinkman TM, Krull KR, Mulrooney DA, et al. Age-dependent changes in health status in the Childhood Cancer Survivor cohort. *J Clin Oncol*. 2015;33(5):479-91.
14. Hamner T, Latzman RD, Latzman NE, Elkin TD, Majumdar S. Quality of life among pediatric patients with cancer: Contributions of time since diagnosis and parental chronic stress. *Pediatr Blood Cancer*. 2015;62(7):1232-6.
15. Uganda Cancer Society. Policy Brief On National Cancer Control Planning In Uganda. Policy Brief. Uganda Uganda Cancer society; 2023.

16. Aronson PL, Nolan SA, Schaeffer P, Hieftje K, Ponce KA, Calhoun C. Perspectives of Adolescents and Young Adults with Sickle Cell Disease and Clinicians on Improving Transition Readiness and a Videogame Intervention. *Blood*. 2023;142(Supplement 1):5116-.
17. Prussien KV, Faust HL, Smith-Whitley K, Barakat LP, Schwartz LA. Barriers to Transition from Pediatric to Adult Care in Adolescents and Young Adults with Sickle Cell Disease: A Mixed-Method Study on the Impact of Systems of Inequity. *Blood*. 2022;140(Supplement 1):2173-4.
18. Treadwell M, Telfair J, Gibson RW, Johnson S, Osunkwo I. Transition from pediatric to adult care in sickle cell disease: establishing evidence-based practice and directions for research. *Am J Hematol*. 2011;86(1):116-20.
19. Chennamadhavuni A, Lyengar V, Mukkamalla SKR, Shimanovsky A. *Leukemia*. StatPearls. Treasure Island (FL): StatPearls Publishing, Copyright © 2025, StatPearls Publishing LLC.; 2025.
20. Leszczenko P, Borek-Dorosz A, Nowakowska AM, Adamczyk A, Kashyrskaya S, Jakubowska J, et al. Towards Raman-Based Screening of Acute Lymphoblastic Leukemia-Type B (B-ALL) Subtypes. *Cancers (Basel)*. 2021;13(21).
21. Looi W, Zargari A, Dun K, Grigoriadis G, Fedele P, Gregory GP, et al. Concomitant diagnosis of chronic myeloid leukaemia and myeloma. *Pathology*. 2022;54(4):493-5.
22. Bispo JAB, Pinheiro PS, Kobetz EK. Epidemiology and Etiology of Leukemia and Lymphoma. *Cold Spring Harb Perspect Med*. 2020;10(6).
23. Miranda-Filho A, Piñeros M, Ferlay J, Soerjomataram I, Monnereau A, Bray F. Epidemiological patterns of leukaemia in 184 countries: a population-based study. *Lancet Haematol*. 2018;5(1):e14-e24.
24. Snyder R. Leukemia and benzene. *Int J Environ Res Public Health*. 2012;9(8):2875-93.
25. Friedman DL, Whitton J, Leisenring W, Mertens AC, Hammond S, Stovall M, et al. Subsequent neoplasms in 5-year survivors of childhood cancer: the Childhood Cancer Survivor Study. *J Natl Cancer Inst*. 2010;102(14):1083-95.
26. Davis AS, Viera AJ, Mead MD. Leukemia: an overview for primary care. *Am Fam Physician*. 2014;89(9):731-8.
27. Stieglitz E, Loh ML. Genetic predispositions to childhood leukemia. *Ther Adv Hematol*. 2013;4(4):270-90.
28. Lim JY, Bhatia S, Robison LL, Yang JJ. Genomics of racial and ethnic disparities in childhood acute lymphoblastic leukemia. *Cancer*. 2014;120(7):955-62.
29. Siegel RL, Miller KD, Jemal A. Cancer Statistics, 2017. *CA Cancer J Clin*. 2017;67(1):7-30.
30. Juliusson G, Hough R. Leukemia. *Prog Tumor Res*. 2016;43:87-100.
31. Pui CH, Mullighan CG, Evans WE, Relling MV. Pediatric acute lymphoblastic leukemia: where are we going and how do we get there? *Blood*. 2012;120(6):1165-74.
32. Chantziara S, Musoro J, Rowsell AC, Sleurs C, Coens C, Pe M, et al. Quality of life of long-term childhood acute lymphoblastic leukemia survivors: Comparison with healthy controls. *Psychooncology*. 2022;31(12):2159-68.
33. Varni JW, Burwinkle TM, Katz ER, Meeske K, Dickinson P. The PedsQL in pediatric cancer: reliability and validity of the Pediatric Quality of Life Inventory Generic Core Scales, Multidimensional Fatigue Scale, and Cancer Module. *Cancer*. 2002;94(7):2090-106.
34. Tremolada M, Taverna L, Bonichini S, Pillon M, Biffi A. Psychological Well-Being, Cognitive Functioning, and Quality of Life in 205 Adolescent and Young Adult Childhood Cancer Survivors Compared to Healthy Peers. *Frontiers in Psychology*. 2022;Volume 13 - 2022.

35. Hudson MM, Ness KK, Gurney JG, Mulrooney DA, Chemaitilly W, Krull KR, et al. Clinical ascertainment of health outcomes among adults treated for childhood cancer. *Jama*. 2013;309(22):2371-81.
36. Gawade PL, Hudson MM, Kaste SC, Neglia JP, Wasilewski-Masker K, Constine LS, et al. A systematic review of selected musculoskeletal late effects in survivors of childhood cancer. *Curr Pediatr Rev*. 2014;10(4):249-62.
37. Interiano RB, Kaste SC, Li C, Srivastava DK, Rao BN, Warner WC, Jr., et al. Associations between treatment, scoliosis, pulmonary function, and physical performance in long-term survivors of sarcoma. *J Cancer Surviv*. 2017;11(5):553-61.
38. Armstrong GT, Sklar CA, Hudson MM, Robison LL. Long-term health status among survivors of childhood cancer: does sex matter? *J Clin Oncol*. 2007;25(28):4477-89.
39. Ernst M, Hinz A, Brähler E, Merzenich H, Faber J, Wild PS, et al. Quality of life after pediatric cancer: comparison of long-term childhood cancer survivors' quality of life with a representative general population sample and associations with physical health and risk indicators. *Health Qual Life Outcomes*. 2023;21(1):65.
40. Chemaitilly W, Mertens AC, Mitby P, Whitton J, Stovall M, Yasui Y, et al. Acute ovarian failure in the childhood cancer survivor study. *J Clin Endocrinol Metab*. 2006;91(5):1723-8.
41. Green DM, Kawashima T, Stovall M, Leisenring W, Sklar CA, Mertens AC, et al. Fertility of female survivors of childhood cancer: a report from the childhood cancer survivor study. *J Clin Oncol*. 2009;27(16):2677-85.
42. Cooke R, Jones ME, Cunningham D, Falk SJ, Gilson D, Hancock BW, et al. Breast cancer risk following Hodgkin lymphoma radiotherapy in relation to menstrual and reproductive factors. *Br J Cancer*. 2013;108(11):2399-406.
43. Friedman DL, Chen L, Wolden S, Buxton A, McCarten K, FitzGerald TJ, et al. Dose-intensive response-based chemotherapy and radiation therapy for children and adolescents with newly diagnosed intermediate-risk hodgkin lymphoma: a report from the Children's Oncology Group Study AHOD0031. *J Clin Oncol*. 2014;32(32):3651-8.
44. Kelly KM. Hodgkin lymphoma in children and adolescents: improving the therapeutic index. *Blood*. 2015;126(22):2452-8.
45. Armstrong GT, Oeffinger KC, Chen Y, Kawashima T, Yasui Y, Leisenring W, et al. Modifiable risk factors and major cardiac events among adult survivors of childhood cancer. *J Clin Oncol*. 2013;31(29):3673-80.
46. Cox CL, Nolan VG, Leisenring W, Yasui Y, Ogg SW, Mertens AC, et al. Noncancer-related mortality risks in adult survivors of pediatric malignancies: the childhood cancer survivor study. *J Cancer Surviv*. 2014;8(3):460-71.
47. Gibson TM, Liu W, Armstrong GT, Srivastava DK, Hudson MM, Leisenring WM, et al. Longitudinal smoking patterns in survivors of childhood cancer: An update from the Childhood Cancer Survivor Study. *Cancer*. 2015;121(22):4035-43.
48. Ness KK, Krull KR, Jones KE, Mulrooney DA, Armstrong GT, Green DM, et al. Physiologic frailty as a sign of accelerated aging among adult survivors of childhood cancer: a report from the St Jude Lifetime cohort study. *J Clin Oncol*. 2013;31(36):4496-503.
49. Wilson CL, Chemaitilly W, Jones KE, Kaste SC, Srivastava DK, Ojha RP, et al. Modifiable Factors Associated With Aging Phenotypes Among Adult Survivors of Childhood Acute Lymphoblastic Leukemia. *J Clin Oncol*. 2016;34(21):2509-15.
50. Ariffin H, Azanan MS, Abd Ghafar SS, Oh L, Lau KH, Thirunavakarasu T, et al. Young adult survivors of childhood acute lymphoblastic leukemia show evidence of chronic inflammation and cellular aging. *Cancer*. 2017;123(21):4207-14.

51. Ness KK, Leisenring WM, Huang S, Hudson MM, Gurney JG, Whelan K, et al. Predictors of inactive lifestyle among adult survivors of childhood cancer: a report from the Childhood Cancer Survivor Study. *Cancer*. 2009;115(9):1984-94.
52. Oancea SC, Gurney JG, Ness KK, Ojha RP, Tyc VL, Klosky JL, et al. Cigarette smoking and pulmonary function in adult survivors of childhood cancer exposed to pulmonary-toxic therapy: results from the St. Jude lifetime cohort study. *Cancer Epidemiol Biomarkers Prev*. 2014;23(9):1938-43.
53. Bruce M. A systematic and conceptual review of posttraumatic stress in childhood cancer survivors and their parents. *Clin Psychol Rev*. 2006;26(3):233-56.
54. Gilbert LK, Breiding MJ, Merrick MT, Thompson WW, Ford DC, Dhingra SS, et al. Childhood adversity and adult chronic disease: an update from ten states and the District of Columbia, 2010. *Am J Prev Med*. 2015;48(3):345-9.
55. Musoro J, Sleurs C, Rowsell A, Suci S, Kicinski M, Chantziara S, et al. Quality of Life Priorities of Childhood Acute Lymphoblastic Leukemia Survivors Enrolled in EORTC Studies, and a Comparison of Instruments. *Pediatr Blood Cancer*. 2025;72(2):e31446.
56. Parrillo E, Petchler C, Jacobson LA, Ruble K, Paré-Blagoev EJ, Nolan MT. Integrative review of school integration support following pediatric cancer. *J Cancer Surviv*. 2024;18(2):325-43.
57. Charan J, Biswas T. How to calculate sample size for different study designs in medical research? *Indian J Psychol Med*. 2013;35(2):121-6.
58. Abdelkarim MA, AwadElseed RH, Alsanosi MA, Badi S, Abdulraheem MA, Nasser NM, et al. Assessment of Quality of Life Among Pediatric Patients with Cancer in Khartoum Oncology Hospital: A Cross-Sectional Pilot Study. *Matrix Science Medica*. 2022;6(3):75-9.
59. Kartawijaya A, Nugroho H, Nur FT. Quality of Life in Children with Nephrotic Syndrome at Dr. Moewardi Hospital. *Journal of Maternal and Child Health*. 2021;6:344-52.
60. Limbers C, Larson M. A systematic review of psychometric properties of the Pediatric Quality of Life Inventory™ 4.0 generic core scales: in pediatric cancer patients and survivors. *Expert Review of Quality of Life in Cancer Care*. 2016;1:1-8.
61. Larsen PA, Amidi A, Ghith N, Winther JF, Pedersen C. Quality of life of adolescent and adult survivors of childhood cancer in Europe-A systematic review. *Int J Cancer*. 2023;153(7):1356-75.
62. Shuai J, Cui Y, Zhou F, Yang W, Ma Y, Yan Y. Health related quality of life in pediatric hematological malignancies patients and survivors: A meta-analysis of comparative studies. *Journal of Psychosomatic Research*. 2024;177:111568.
63. Redondo-Tébar A, Rodriguez-Solana A, Gracia-Marco L, Marmol-Perez A, Gil-Cosano JJ, Cadenas-Sánchez C, et al. Physical Activity, Fitness, and Health-Related Quality of Life in Children and Adolescent Cancer Survivors: A Cross-Sectional Study (iBoneFIT Project). *Cancers (Basel)*. 2025;17(6).
64. Zebrack BJ, Landier W. The perceived impact of cancer on quality of life for post-treatment survivors of childhood cancer. *Qual Life Res*. 2011;20(10):1595-608.
65. Seth R, Singh A, Seth S, Sapra S. Late effects of treatment in survivors of childhood cancers: A single-centre experience. *Indian J Med Res*. 2017;146(2):216-23.
66. Stam H, Grootenhuys MA, Last BF. The course of life of survivors of childhood cancer. *Psycho-Oncology*. 2005;14(3):227-38.
67. Kanellopoulos A, Hamre HM, Dahl AA, Fosså SD, Ruud E. Factors associated with poor quality of life in survivors of childhood acute lymphoblastic leukemia and lymphoma. *Pediatr Blood Cancer*. 2013;60(5):849-55.

APPENDICES

APPENDIX I: DATA COLLECTION TOOL

Topic: Quality of life and factors contributing to good quality of life among adolescents in remission from liquid cancers at Mulago National Referral Hospital.

Section A: Demographic and social information

ID Number:

1. Gender: Male ☐ ₁ Female ☐ ₂
2. Age in years:
3. Age at diagnosis of cancer:
4. Tribe:
5. Religion: Catholic ☐ ₁ SDA ☐ ₂ Muslim ☐ ₃ Other ☐ ₄
6. Occupation: Student ☐ ₁ Unemployed ☐ ₂ Informal job ☐ ₃ Formal job ☐ ₄
7. Highest level of education: None ☐ ₁ Primary ☐ ₂ Secondary ☐ ₃ University ☐ ₄
8. School setting: Government ☐ ₁ Private ☐ ₂ International ☐ ₃
9. Relationship status: Single ☐ ₁ In a relationship ☐ ₂
10. Number of siblings:
11. Any sibling with a cancer diagnosis: No ☐ ₁ Yes ☐ ₂
12. Living with parents: None ☐ ₁ Mother only ☐ ₂ Father only ☐ ₃ Both ☐ ₄
13. Occupation of caretaker: Unemployed ☐ ₁ Informal job ☐ ₂ Formal job ☐ ₃
14. Level of education of primary caretaker: None ☐ ₁ Primary ☐ ₂ Secondary ☐ ₃
University ☐ ₄
15. Level of education of head of household: None ☐ ₁ Primary ☐ ₂ Secondary ☐ ₃
University ☐ ₄

Section B: Clinical and life style factors

16. Weight in kilograms.....
17. Height in cms

18. BMI.....

19. History of comorbidities: ☐ ☐₁ Yes ☐₂ If yes
specify.....

20. Type of cancer: Leukaemia ☐₁ Lymphoma ☐₂

Specify cancer subtype:

21. Duration in remission:

22. Cancer treatment: Chemotherapy ☐₁ Radiation ☐₂

Specify chemotherapy:

23. History surgical intervention during treatment: No ☐₁ Yes ☐₂

If yes specify.....

24. Persistent or permanent side effect of cancer treatment No ☐₁ Yes ☐₂

If yes specify.....

25. Counselling services after treatment: No ☐₁ Yes ☐₂

If yes was quality of life talked about: No ☐₁ Yes ☐₂

26. Smoking status: No ☐₁ Yes ☐₂

27. Alcohol intake status: No ☐₁ Yes ☐₂

28. Use of any recreational drugs: No ☐₁ Yes ☐₂

29. Extracurricular activities done: No ☐₁ Yes ☐₂

**APPENDIX II: PEDIATRIC QUALITY OF LIFE INVENTORY (PEDSQL)
QOL INVENTORY FOR 10 TO 12 YEARS OLD**

ID#
Date:

PedsQL™
Pediatric Quality of Life
Inventory

Version 4.0

CHILD REPORT (ages 8-12)

DIRECTIONS

On the following page is a list of things that might be a problem for you.
Please tell us how much of a problem each one has been for you
during the past ONE month by circling:

- 0 if it is never a problem
- 1 if it is almost never a problem
- 2 if it is sometimes a problem
- 3 if it is often a problem
- 4 if it is almost always a problem

There are no right or wrong answers.
If you do not understand a question, please ask for help.

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PedsQL-4.0-Core-C_AU4.0_eng-UG_nonMapi.docx

*In the past **ONE month**, how much of a **problem** has this been for you ...*

ABOUT MY HEALTH AND ACTIVITIES (problems with...)	Never	Almost Never	Sometimes	Often	Almost Always
1. It is hard for me to walk more than 200m	0	1	2	3	4
2. It is hard for me to run	0	1	2	3	4
3. It is hard for me to do sports activity or exercise	0	1	2	3	4
4. It is hard for me to lift something heavy	0	1	2	3	4
5. It is hard for me to take a bath or shower by myself	0	1	2	3	4
6. It is hard for me to do chores around the house	0	1	2	3	4
7. I hurt or ache	0	1	2	3	4
8. I have low energy	0	1	2	3	4

ABOUT MY FEELINGS (problems with...)	Never	Almost Never	Sometimes	Often	Almost Always
1. I feel afraid or scared	0	1	2	3	4
2. I feel sad or blue	0	1	2	3	4
3. I feel angry	0	1	2	3	4
4. I have trouble sleeping	0	1	2	3	4
5. I worry about what will happen to me	0	1	2	3	4

HOW I GET ALONG WITH OTHERS (problems with...)	Never	Almost Never	Sometimes	Often	Almost Always
1. I have trouble getting along with other kids	0	1	2	3	4
2. Other kids do not want to be my friend	0	1	2	3	4
3. Other kids tease me	0	1	2	3	4
4. I cannot do things that other kids my age can do	0	1	2	3	4
5. It is hard to keep up when I play with other kids	0	1	2	3	4

ABOUT SCHOOL (problems with...)	Never	Almost Never	Sometimes	Often	Almost Always
1. It is hard to pay attention in class	0	1	2	3	4
2. I forget things	0	1	2	3	4
3. I have trouble keeping up with my schoolwork	0	1	2	3	4
4. I miss school because of not feeling well	0	1	2	3	4
5. I miss school to go to the doctor or hospital	0	1	2	3	4

QOL INVENTORY FOR 13 TO 18 YEARS

ID# _____
Date: _____

PedsQLTM

Pediatric Quality of Life Inventory

Version 4.0

TEEN REPORT (ages 13-18)

DIRECTIONS

On the following page is a list of things that might be a problem for you.
Please tell us **how much of a problem** each one has been for you
during the **past ONE month** by circling:

- 0 if it is **never** a problem
- 1 if it is **almost never** a problem
- 2 if it is **sometimes** a problem
- 3 if it is **often** a problem
- 4 if it is **almost always** a problem

There are no right or wrong answers.
If you do not understand a question, please ask for help.

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PedsQL-4.0-Core-A_AU4.0_eng-UG_nonMapi.docx

*In the past **ONE** month, how much of a **problem** has this been for you ...*

ABOUT MY HEALTH AND ACTIVITIES (problems with...)	Never	Almost Never	Some- times	Often	Almost Always
1. It is hard for me to walk more than 200m	0	1	2	3	4
2. It is hard for me to run	0	1	2	3	4
3. It is hard for me to do sports activity or exercise	0	1	2	3	4
4. It is hard for me to lift something heavy	0	1	2	3	4
5. It is hard for me to take a bath or shower by myself	0	1	2	3	4
6. It is hard for me to do chores around the house	0	1	2	3	4
7. I hurt or ache	0	1	2	3	4
8. I have low energy	0	1	2	3	4

ABOUT MY FEELINGS (problems with...)	Never	Almost Never	Some- times	Often	Almost Always
1. I feel afraid or scared	0	1	2	3	4
2. I feel sad or blue	0	1	2	3	4
3. I feel angry	0	1	2	3	4
4. I have trouble sleeping	0	1	2	3	4
5. I worry about what will happen to me	0	1	2	3	4

HOW I GET ALONG WITH OTHERS (problems with...)	Never	Almost Never	Some- times	Often	Almost Always
1. I have trouble getting along with other teens	0	1	2	3	4
2. Other teens do not want to be my friend	0	1	2	3	4
3. Other teens tease me	0	1	2	3	4
4. I cannot do things that other teens my age can do	0	1	2	3	4
5. It is hard to keep up with my peers	0	1	2	3	4

ABOUT SCHOOL (problems with...)	Never	Almost Never	Some- times	Often	Almost Always
1. It is hard to pay attention in class	0	1	2	3	4
2. I forget things	0	1	2	3	4
3. I have trouble keeping up with my schoolwork	0	1	2	3	4
4. I miss school because of not feeling well	0	1	2	3	4
5. I miss school to go to the doctor or hospital	0	1	2	3	4

QOL INVENTORY FOR 19 YEAR OLDS

ID#	_____
Date:	_____

PedsQLTM

Young Adult Quality of Life Inventory

Version 4.0 - English (United Kingdom)

YOUNG ADULT REPORT (ages 18-25)

INSTRUCTIONS

On the following page is a list of things that might be a problem for you. Please tell us **how much of a problem** each one has been for you during the **past ONE month** by circling:

- 0 if it is **never** a problem
- 1 if it is **almost never** a problem
- 2 if it is **sometimes** a problem
- 3 if it is **often** a problem
- 4 if it is **almost always** a problem

There are no right or wrong answers.
If you do not understand a question, please ask for help.

In the past ONE month, how much of a problem has this been for you ...

ABOUT MY HEALTH AND ACTIVITIES (problems with...)	Never	Almost Never	Some- times	Often	Almost Always
1. It is hard for me to walk more than a couple of streets (about 100 metres)	0	1	2	3	4
2. It is hard for me to run	0	1	2	3	4
3. It is hard for me to do sports activities or exercise	0	1	2	3	4
4. It is hard for me to lift heavy things	0	1	2	3	4
5. It is hard for me to have a bath or shower by myself	0	1	2	3	4
6. It is hard for me to do chores around the house	0	1	2	3	4
7. I have aches or pains	0	1	2	3	4
8. I feel tired	0	1	2	3	4

ABOUT MY FEELINGS (problems with...)	Never	Almost Never	Some- times	Often	Almost Always
1. I feel afraid or scared	0	1	2	3	4
2. I feel sad	0	1	2	3	4
3. I feel angry	0	1	2	3	4
4. I have trouble sleeping	0	1	2	3	4
5. I worry about what will happen to me	0	1	2	3	4

HOW I GET ALONG WITH OTHERS (problems with...)	Never	Almost Never	Some- times	Often	Almost Always
1. I have trouble getting along with other young adults	0	1	2	3	4
2. Other young adults do not want to be friends with me	0	1	2	3	4
3. Other young adults tease me	0	1	2	3	4
4. I cannot do things that others my age can do	0	1	2	3	4
5. It is hard to keep up with other people my age	0	1	2	3	4

ABOUT MY WORK/STUDIES (problems with...)	Never	Almost Never	Some- times	Often	Almost Always
1. It is hard to pay attention at work or college/university	0	1	2	3	4
2. I forget things	0	1	2	3	4
3. I have trouble keeping up with my work or studies	0	1	2	3	4
4. I miss work or college/university because of not feeling well	0	1	2	3	4
5. I miss work or college/university to go to the doctor or hospital	0	1	2	3	4

APPENDIX III: CONSENT FORMS

CONSENT FORM (ENGLISH) FOR ADOLESCENTS AGED 18 AND 19

Title of the study: Quality of Life and Associated Factors Among Adolescents with Liquid Cancers in Remission at Mulago National Referral Hospital, Kampala, Uganda

Name	Contact	Institution
Dr. Victoria Faith Zalwango (PI)	0704644085	Makerere University

Background and rationale for the study

Cancer of the blood diagnosis and management in children and adolescents is often a hard diagnosis on the child and the parents, with treatment lasting for as long as 3 years. This might continue to affect the well-being of the child either physically, emotionally, socially or affect school and work functioning even after completion of treatment. Findings from this study will help inform interventions on how best to support children and adolescents after completing treatment for these cancers.

This study is funded by the principal investigator, Dr. Victoria Faith Zalwango, and no external or outside financial support has been obtained.

Purpose of the study

The study aims to understand the quality of life of adolescents with blood cancers who are cured at MNRH and factors associated with their quality of life.

Study procedure

On accepting to participate in the study, you will be asked to answer questions about the adolescents' quality of life, looking at the adolescent's physical, emotional, social, school and work functioning. We will also review the medical records. The answers will be recorded on paper.

Who will participate in the study?

Adolescents aged 10 to 19 years who have completed treatment between 2019 to 2025 for at least 6 months at the Mulago National Referral Hospital, children's cancer ward, and are in complete remission from blood cancers.

We expect to involve at least 109 adolescents who will be asked questions from two standardized questionnaires.

Risks and discomforts

Some questions may cause emotional distress to you. In case that happens, we shall link you to a counsellor in the hospital. If you do not want to continue with the questions, you are free to withdraw from the study or continue with the questions when you are comfortable or ready.

Benefits

There may be no direct benefit to you as a participant in this study. However, the findings will be used to advocate for services that are responsive to the needs of adolescents who have been managed for cancer.

Confidentiality

Whatever we ask the adolescent will only be used for this research, and a special number will be assigned to you. Your name will not appear on the papers used to collect information. While the study results may be published, the participant's identity will not be disclosed. Additionally, the Makerere University School of Medicine Research and Ethics Committee and Uganda National Council for Science and Technology may request access to identifying information for ethical review purposes, but this information will not be made public.

Costs

You will not be told to pay any money for participating in this study.

Compensation for participation in the study:

There will be compensation of 10,000 Ugandan shillings as compensation for the time taken to participate in this study.

Questions about the study

In case of any questions or concerns about this study, feel free to call the principal investigator, Victoria Faith Zalwango on 0704644085.

Questions about participants' rights

For more information about your rights as a participant in this study, feel free to contact the chairman of the SOMREC (School of Medicine Research and Ethics Committee) Professor Ocama Ponsiano, on telephone number 0772-421190

Statement of voluntariness:

Participation in this study is voluntary, and participants may join on their own free will. Participants also have the right to withdraw from the study at any time without penalty.

Dissemination of results:

Any new information that affects you will be made available to you, your parent/guardian and/or your health care providers. The findings of this study will also be disseminated in form of a report that will be submitted to the department of pediatrics and child health of Makerere University. The findings will also be disseminated in conferences, abstract presentations and a peer-reviewed journal.

Ethical approval:

This study has been reviewed and approved by the Makerere University School of Medicine and Ethics Committee (SOMREC).

STATEMENT OF CONSENT

..... has described to me what is going to be done, the risks, the benefits involved, and my rights regarding this study. I understand that my decision to participate in this study will not alter my (child's) medical care. In the use of this information, my identity will be concealed. I am aware that I may withdraw at any time. I understand that by signing this form, I do not waive any of my legal rights but merely indicate that I have been informed about the research study in which I am voluntarily agreeing to participate. A copy of this form will be provided to me.

Name Signature/thumbprint of participant Date

Name Signature of research assistant Date.....

Witness (if applicable)

Name Signature of witness.....Date.....

**FOOMU Y'OKUKKIRIZA EY'ABAVUBUKA AB'EMYAKA 18 NE 19,
N'ABALABIRIRA ABAANA.**

Omutwe gw'okunoonyereza: Omutindo gw'obulamu n'ensonga ezikwatagana ku bavubuka abalina kookolo womusaayi abamaliriza obujjanjabi mu ddwaaliro ekulu ely'e Mulago.

Ttiimu y'okunoonyereza:

Erinnya	Essimu	Ekitongole
Dr. Victoria Faith Zalwango (PI)	0704644085	Makerere University

Ensibuka yo'kunonyereza: Obulwadde bwa kookolo womusaayi mu baana ne mubavubuka butera okuba obuzibu okuzuula ku mwana n'abazadde, era obujjanjabi buwangaala okumala emyaka esaatu (3). Kino kiyinza okusigala nga kikosa obulamu bw'omwana obw'omubiri, obw'ebirowoozo, obw'embeera z'abantu oba okukosa ebye ssomero n'emirimu ne bwaba yamaliliza obujjanjabi. Ebizuuliddwa okuva mu kunoonyereza kuno bijja kuyamba okumanyisa ebiyinza okolebwa okuyambako abaana n'abavubuka oluvannyuma lw'okumaliriza obujjanjabi bwa kookolo ow'omusaayi.

Okunoonyereza kuno kussibwamu ssente omunoonyereza omukulu, Dr. Victoria Faith Zalwango, era tewali buyambi bwa nsimbi bwa bweru bufunibwa.

Ekigendererwa ky'okunoonyereza: Okunoonyereza kuno kugenderera okutegeera omutindo gw'obulamu bw'abavubuka abalina ekilwadde kya kookolo womusaayi abamaliriza obujjanjabi ku ddwaaliro ekulu elya Mulago n'ensonga ezikwatagana n'omutindo gw'obulamu bwabwe.

Enkola y'okunoonyereza: Bwokkiriza okwetaba mu kunoonyereza, ojja kusabibwa okuddamu ebibuuzo ebikwata ku mutindo gw'obulamu bw'abavubuka, ng'otunuulira enkola y'omuvubuka ey'omubiri, ey'ebirowoozo, ey'embeera z'abantu, ey'essomero n'emirimu, tujja kwetegereza n'ebiwandiiko byo eby'eddwaaliro. Eby'okuddamu bijja kuwandiikibwa ku lupapula.

Ani agenda okwetaba mu kunoonyereza kuno? Abavubuka abali wakati w'emyaka 10 ne 19 abamaze okujjanjabibwa wakati wa 2019 ne 2025 okumala emyezi egitakka wansi wa 6 mu ddwaaliro e Mulago National Referral Hospital, waadi y'abaana eya kookolo, era nga bawonye ddala kookolo w'omusaayi. Tusubira okukozesa abavubuka 109 abagenda okubuuzibwa ebibuuzo okuva mu lupapula lw'ebibuuzo.

Obulabe: Ebimu ku bibuuzo biyinza okukuleetera okunyigirizibwa mu nneewulira yo. Singa mbeera nga eyo ebaawo, tujja kukuyunga ku kansala mu ddwaaliro. Bw'oba toyagala kugenda mu maaso na bibuuzo, oli wa ddembe okuva mu kunoonyereza oba okugenda mu maaso n'ebibuuzo ng'oli weeyagaza oba nga weetegese.

Emigaso: Tewayinza kubaawo mugaso gwa butereevu gy'oli ng'omuntu eyeetabye mu kunoonyereza kuno, naye ebizuuliddwa bijja kukozezebwa okulwanirira obuweereza obuddamu ebyetaago by'abavubuka abajjanjabwa kookolo.

Ebyama: Kyonna kyetusaba omuvubuka kijja kukozezebwa mu kunoonyereza kuno kwokka, era ennamba ey'enjawulo ejja kukuweebwa. Erinnya lyo terijja kulabika ku mpapula ezikozezebwa okukungaanya amawulire. Wadde ng'ebiva mu kunoonyereza biyinza okufulumizibwa, omuntu eyeetabye mu kunoonyereza kuno tebijja kwogerwako. Okugatta ku ekyo, akakiiko ka Makerere University School of Medicine Research and Ethics Committee ne Uganda National Council for Science and Technology bayinza okusaba okufuna amawulire agazuulibwa okusobola okwekenneenya empisa, naye amawulire gano tegajja kufulumizibwa mu lujjudde.

Ebisale: Tojja kugambibwa kusasula ssente zonna olw'okwetaba mu kunoonyereza kuno.

Akasimo akokwetaba mu kunoonyereza kuno: Wajja kubaawo akasimo aka siringi za Uganda 10,000 okuliyirira obudde bwonatwala okwetaba mu kunoonyereza kuno.

Ebibuuzo ebikwata ku kusoma: Bwoba olina ekibuuzo kyonna oba ebikweraliikiriza ku kunoonyereza kuno, oli waddembe okukubira omunonyereza omukulu Victoria Faith Zalwango ku nnamba y'essimu 0704644085.

Ebibuuzo ebikwata ku ddembe ly'a ayetabye mu kunonyereza: Okumanya ebisingawo ku ddembe lyo mu kunoonyereza kuno nga eyeetaba mu kunoonyereza kuno, oli waddemebe okutukirira Ssentebe w'ekitongole ky'okunoonyereza ku by'obusawo n'akakiiko akavunaanyizibwa ku kunoonyereza n'obulamu, Professor OCAMA PONSIANO ku nnamba y'essimu 0772-421190.

Ekiwandiiko ky'obwannakyewa: Okwetaba mu kunoonyereza kuno kwa kyeyagalire, era abeetabye mu kunoonyereza kuno bayinza okwegatta mu kunonyerza kuno ku ddembe lyabwe

ery'okwesalirawo. Abeetabyemu era balina eddembe okuva mu kunonyereza kuno ekiseera kyonna awatali kibonerezo.

Okusaasaanya ebivudde mu kunonyereza: Amawulire gonna amapya agakukosa gajja kuweebwa omuzadde, ne/oba abajjanjabi bo. Ebizuuliddwa mu kunoonyereza kuno era byakusaasaanyizibwa mu ngeri ya lipoota egenda okuweebwa ekitongole ky'abaana n'ebyobulamu by'abaana mu yunivasite y'e Makerere. Ebizuuliddwa era bigenda kusaasaanyizibwa mu nkunjaana, ennyanjula ezitaliimu n'ekitabo ekitunuulirwa bannaabwe.

Okukkirizibwa mu ngeri ey'obwannannyini: Okunoonyereza kuno kwekenneenyeddwa era ne kukkirizibwa akakiiko k'eby'obusawo n'empisa mu yunivasite y'e Makerere (SOMREC)..

EKITABO KY'OKUKKIRIZIGANYA

.....annyonnyodde ekigenda okukolebwa, akabi, emigaso, n'eddembe lyange erikwata ku kunoonyereza kuno. Ntegedde nti okusalawo kwange okwetaba mu kunoonyereza kuno tekijja kukyusa bujjanjabi bwange (obw'omwana). Mu nkozesa y'amawulire gano, endagamuntu yange ejja kukwekebwa. Nkimanyi nti nnyinza okuva mu kunonyereza kuno ekiseera kyonna. Ntegedde nti nga nzisa omukono ku ffoomu eno, siwaayo ddembe lyange lyonna ery'amateeka wabula nambika nti ntegeezeddwa ku kunoonyereza kuno kwe nzikiriza kyeyagalire okwetabamu. Kopi ya ffoomu eno ejja kuweebwa gyendi.

Erinnya ly'omuntu eyeetabye mu.....

Omukono oba ekinkumu:

Ennaku z'omwezi:.....

Erinya lya'buza ebibuzo.....

Omukono gw'oyo abuuza ebibuuzo.....

Ennaku z'omwezi:.....

Omujuulizi

Erinnya

O mukono oba ekinkumu:

Ennaku z'omwezi:.....

ASSENT FORM (ENGLISH) FOR ADOLESCENTS AGED 10-17

Title of the study: Quality of Life and Associated Factors Among Adolescents with Liquid Cancers in Remission at Mulago National Referral Hospital, Kampala, Uganda

Name	Contact	Institution
Dr. Victoria Faith Zalwango (PI)	0704644085	Makerere University

Background and rationale for the study

Blood cancer diagnosis and management in children and adolescents is often a hard diagnosis on the child and the parents, with treatment lasting for as long as 3 years. This might continue to affect the well-being of the child either physically, emotionally, socially or affect school and work functioning even after completion of treatment. Findings from this study will help inform interventions on how best to support children and adolescents after completing treatment for these blood cancers.

This study is funded by the principal investigator, Dr. Victoria Faith Zalwango, and no external or outside financial support has been obtained.

Purpose of the study

The study intends to understand the quality of life of adolescents with blood cancers who are cured at MNRH and factors associated with the quality of life.

Study procedure

On accepting to be part of the study, you will be asked to answer questions about your quality of life, looking at your physical, emotional, social, school and work functioning. We will also look at your medical records. The answers will be recorded on paper.

Who will participate in the study?

Adolescents aged 10 to 19 years who have completed treatment between 2019 to 2025 for at least 6 months at the Mulago National Referral Hospital, children's cancer ward, and are in complete remission from blood cancers.

We expect to involve at least 109 adolescents who will be asked questions from two standardized questionnaires.

Risks and discomforts

Some questions may cause emotional distress to you. In case that happens, we shall link you to a counsellor in the hospital. If you do not want to continue with the questions, you are free to withdraw from the study or continue with the questions when you are comfortable or ready.

Benefits

There may be no direct benefit to you as a participant in this study. However, the findings will be used to advocate for services that are responsive to the needs of adolescents who have been managed for cancer.

Confidentiality

Whatever we ask you will only be used for this research, and a special number will be assigned to you. Your name will not appear on the papers used to collect information. While the study results may be published, the participant's identity will not be disclosed. Additionally, the Makerere University School of Medicine Research and Ethics Committee and Uganda National Council for Science and Technology may request access to identifying information for ethical review purposes, but this information will not be made public.

Costs

You will not be told to pay any money for participating in this study.

Compensation for participation in the study:

You will be given 10,000 Ugandan shillings as compensation for your time for participating in this study.

Questions about the study

In case of any questions or concerns about this study, feel free to call the principal investigator, Victoria Faith Zalwango on 0704644085.

Questions about participants' rights

For more information about your rights as a participant in this study, feel free to contact the chairman of the SOMREC (School of Medicine Research and Ethics Committee), Professor Ocamo Ponsiano, on telephone number 0772-421190

Statement of voluntariness:

Participation in this study is voluntary, and you may join at your own free will. Participants (you) also have the right to withdraw from the study at any time without penalty.

Dissemination of results:

Any new information that affects you will be made available to you, your parent/guardian and/or your health care providers. The findings of this study will also be disseminated in form of a report that will be submitted to the department of pediatrics and child health of Makerere University. The findings will also be disseminated in conferences, abstract presentations and a peer-reviewed journal.

Ethical approval:

This study has been reviewed and approved by the Makerere University School of Medicine and Ethics Committee (SOMREC).

STATEMENT OF ASSENT

..... has described to me what is going to be done, the risks, the benefits involved and my rights regarding this study. I understand that my decision to participate in this study will not alter my medical care. In the use of this information, my identity will be concealed. I am aware that I may withdraw at any time. I understand that by signing this form, I do not waive any of my legal rights but merely indicate that I have been informed about the research study in which I am voluntarily agreeing to participate. A copy of this form will be provided to me.

Name Signature/thumbprint of participant Date

Name Signature of parent/guardian Date

Name Signature of research assistant..... Date.....

Witness (if applicable)

Name Signature Date.....

**OKUKKIRIZA OKUTEGEEREKESE ERI ABAVUBUKA AB'EMYAKA KUMI (10)
PAKA KU MYAKA KUMI NAMUSANVU (17)**

Omutwe gw'okunoonyereza: Omutindo gw'obulamu n'ensonga ezikwatagana ku bavubuka abalina kookolo womusaayi abamaliriza obujjanjabi mu ddwaaliro ekulu ely'e Mulago.

Ttiimu y'okunoonyereza:

Erinnya	Essimu	Ekitongole
Dr. Victoria Faith Zalwango (PI)	0704644085	Makerere University

Ensibuko yo'kunonyereza: Obulwadde bwa kookolo womusaayi n'okuzuula mu baana ne mubavubuka butera okuba obuzibu okuzuula ku mwana n'abazadde, era obujjanjabi buwangaala okumala emyaka esaatu (3). Kino kiyinza okusigala nga kikosa obulamu bw'omwana obw'omubiri, obw'ebirowoozo, obw'embeera z'abantu oba okukosa ebye ssomero n'emirimu ne bwaba yamaliliza obujjanjabi. Ebizuuliddwa okuva mu kunoonyereza kuno bijja kuyamba okumanyisa ebiyinza okolebwa okuyambako abaana n'abavubuka oluvannyuma lw'okumaliriza obujjanjabi bwa kookolo ow'omusaayi.

Okunoonyereza kuno kussibwamu ssente omunoonyereza omukulu, Dr. Victoria Faith Zalwango, era tewali buyambi bwa nsimbi bwa bweru bufunibwa.

Ekigendererwa ky'okunoonyereza: Okunoonyereza kuno kugenderera okutegeera omutindo gw'obulamu bw'abavubuka abalina ekilwadde kya kookolo womusaayi abamaliriza obujjanjabi ku ddwaaliro ekulu elya Mulago n'ensonga ezikwatagana n'omutindo gw'obulamu bwabwe.

Enkola y'okunoonyereza: Bwokkiriza okwetaba mu kunoonyereza, ojja kusabibwa okuddamu ebibuuzo ebikwata ku mutindo gw'obulamu bw'abavubuka, ng'otunuulira enkola y'omuvubuka ey'omubiri, ey'ebirowoozo, ey'embeera z'abantu, ey'essomero n'emirimu, tujja kwetegereza n'ebiwandiiko byo eby'eddwaaliro. Eby'okuddamu bijja kuwandiikibwa ku lupapula.

Ani agenda okwetaba mu kunoonyereza kuno? Abavubuka abali wakati w'emyaka 10 ne 19 abamaze okujjanjabibwa wakati wa 2019 ne 2025 okumala emyezi egitakka wansi wa 6 mu ddwaaliro e Mulago National Referral Hospital, waadi y'abaana eya kookolo, era nga bawonye ddala kookolo w'omusaayi. Tusubira okukozesa abavubuka 109 abagenda okubuuzibwa ebibuuzo okuva mu lupapula lw'ebibuuzo.

Obulabe: Ebimu ku bibuuzo biyinza okukuleetera okunyigirizibwa mu nneewulira yo. Singa mbeera nga eyo ebaawo, tujja kukuyunga ku kansala mu ddwaaliro. Bw'oba toyagala kugenda mu maaso na bibuuzo, oli wa ddembe okuva mu kunoonyereza oba okugenda mu maaso n'ebibuuzo ng'oli weeyagaza oba nga weetegese.

Emigaso: Tewayinza kubaawo mugaso gwa butereevu gy'oli ng'omuntu eyeetabye mu kunoonyereza kuno, naye ebizuuliddwa bijja kukozezebwa okulwanirira obuweereza obuddamu ebyetaago by'abavubuka abajjanjabwa kookolo.

Ebyama: Kyonna kyetusaba omuvubuka kijja kukozezebwa mu kunoonyereza kuno kwokka, era ennamba ey'enjawulo ejja kukuweebwa. Erinnya lyo terijja kulabika ku mpapula ezikozezebwa okukungaanya amawulire. Wadde ng'ebiva mu kunoonyereza biyinza okufulumizibwa, omuntu eyeetabye mu kunoonyereza kuno tebijja kwogerwako. Okugatta ku ekyo, akakiiko ka Makerere University School of Medicine Research and Ethics Committee ne Uganda National Council for Science and Technology bayinza okusaba okufuna amawulire agazuulibwa okusobola okwekenneenya empisa, naye amawulire gano tegajja kufulumizibwa mu lujjudde.

Ebisale: Tojja kugambibwa kusasula ssente zonna olw'okwetaba mu kunoonyereza kuno.

Akasimo akokwetaba mu kunoonyereza kuno: Wajja kubaawo akasimo aka siringi za Uganda 10,000 okuliyirira obudde bwonatwala okwetaba mu kunoonyereza kuno.

Ebibuuzo ebikwata ku kusoma: Bwoba olina ekibuuzo kyonna oba ebikweraliikiriza ku kukunoonyereza kuno, oli waddembe okukubira omunonyeleza omukuulu, Victoria Faith Zalwango ku nnamba y'essimu 0704644085.

Ebibuuzo ebikwata ku ddembe ly'a ayetabye mu kunonyereza: Okumanya ebisingawo ku ddembe lyo mu kunoonyereza kuno nga eyeetabye mu kunoonyereza kuno, oli waddemebe okutukirira Ssentebe w'ekitongole ky'okunoonyereza ku by'obusawo n'akakiiko akavunaanyizibwa ku kunoonyereza n'obulamu, Professor OCAMA PONSIANO ku nnamba y'essimu 0772-421190.

Ekiwandiiko ky'obwannakyewa: Okwetaba mu kunoonyereza kuno kwa kyeyagalire, era abeetabye mu kunoonyereza kuno bayinza okwegatta mu kunonyerza kuno ku ddembe lyabwe

ery'okwesalirawo. Abeetabyemu era balina eddembe okuva mu kunonyereza kuno ekiseera kyonna awatali kibonerezo.

Okusaasaanya ebivudde mu kunonyereza: Amawulire gonna amapya agakukosa gajja kuweebwa omuzadde, ne/oba abajjanjabi bo. Ebizuuliddwa mu kunoonyereza kuno era byakusaasaanyizibwa mu ngeri ya lipoota egenda okuweebwa ekitongole ky'abaana n'ebyobulamu by'abaana mu yunivasite y'e Makerere. Ebizuuliddwa era bigenda kusaasaanyizibwa mu nkunjaana, ennyanjula ezitaliimu n'ekitabo ekitunuulirwa bannaabwe.

Okukkirizibwa mu ngeri ey'obwannannyini: Okunoonyereza kuno kwekenneenyeddwa era ne kukkirizibwa akakiiko k'eby'obusawo n'empisa mu yunivasite y'e Makerere (SOMREC).

EKITABO KY'OKUKKIRIZIGANYA

.....annyonnyodde ekigenda okukolebwa, akabi, emigaso, n'eddembe lyange erikwata ku kunoonyereza kuno. Ntegedde nti okusalawo kwange okwetaba mu kunoonyereza kuno tekijja kukyusa bujjanjabi bwange. Mu nkozesa y'amawulire gano, endagamuntu yange ejja kukwekebwa. Nkimanyi nti nnyinza okuva mu kunonyereza kuno ekiseera kyonna. Ntegedde nti nga nzisa omukono ku ffoomu eno, siwaayo ddembe lyange lyonna ery'amateeka wabula nambika nti ntegeezeddwa ku kunoonyereza kuno kwe nzikiriza kyeyagalire okwetabamu. Kopi ya ffoomu eno ejja kuweebwa gyendi.

Erinnya ly'omwana.....

Omukono oba ekinkumu:

Ennaku z'omwezi:.....

Erinnya ly'omuzadde.....

Omukono oba ekinkumu:

Ennaku z'omwezi:.....

Erinya lya'buza ebibuzo.....

Omukono gw'oyo abuuza ebibuuzo.....

Ennaku z'omwezi:.....

Omujuulizi

Erinnya

Omukono oba ekinkumu:

Ennaku z'omwezi:.....

CONSENT FORM (ENGLISH) FOR CARETAKERS OF ADOLESCENTS AGED 10-17 YEARS

Title of the study: Quality of Life and Associated Factors Among Adolescents with Liquid Cancers in Remission at Mulago National Referral Hospital, Kampala, Uganda

Name	Contact	Institution
Dr. Victoria Faith Zalwango (PI)	0704644085	Makerere University

Background and rationale for the study

Cancer of the blood diagnosis and management in children and adolescents is often a hard diagnosis on the child and the parents, with treatment lasting for as long as 3 years. This might continue to affect the well-being of the child either physically, emotionally, socially or affect school and work functioning even after completion of treatment. Findings from this study will help inform interventions on how best to support children and adolescents after completing treatment for these cancers.

This study is funded by the principal investigator, Dr. Victoria Faith Zalwango, and no external or outside financial support has been obtained.

Purpose of the study

The study aims to understand the quality of life of adolescents with blood cancers who are cured at MNRH and factors associated with their quality of life.

Study procedure

On accepting for your child to participate in the study, the child and you will be asked to answer questions about the adolescents' quality of life, looking at the adolescent's physical, emotional, social, school and work functioning, we will also review the medical records. The answers will be recorded on paper.

Who will participate in the study?

Adolescents aged 10 to 19 years who have completed treatment between 2019 to 2025 for at least 6 months at the Mulago National Referral Hospital, children's cancer ward, and are in complete remission from blood cancers.

We expect to involve at least 109 adolescents who will be asked questions from two standardized questionnaires.

Risks and discomforts

Some questions may cause emotional distress to you or your child. In case that happens, we shall link you and the child to a counsellor in the hospital. If the child does not want to continue with the questions, you are free to withdraw from the study or continue with the questions when the child is comfortable or ready.

Benefits

There may be no direct benefit to you as a participant in this study. However, the findings will be used to advocate for services that are responsive to the needs of adolescents who have been managed for cancer.

Confidentiality

Whatever we ask the adolescent will only be used for this research, and a special number will be assigned to the adolescent. Your name/ adolescent's name will not appear on the papers used to collect information. While the study results may be published, the participant's identity will not be disclosed. Additionally, the Makerere University School of Medicine Research and Ethics Committee and Uganda National Council for Science and Technology may request access to identifying information for ethical review purposes, but this information will not be made public.

Costs: You will not be told to pay any money for participating in this study.

Compensation for participation in the study:

There will be compensation of 10,000 Ugandan shillings as compensation for the time taken to participate in this study.

Questions about the study

In case of any questions or concerns about this study, feel free to call the principal investigator, Faith Zalwango on 0704644085.

Questions about participants' rights

For more information about your rights as a participant in this study, feel free to contact the chairman of the SOMREC (School of Medicine Research and Ethics Committee) Professor Ocamia Ponsiano, on telephone number 0772-421190

Statement of voluntariness:

Participation in this study is voluntary, and participants may join on their own free will. Participants also have the right to withdraw from the study at any time without penalty.

Dissemination of results:

Any new information that affects you will be made available to you, your parent/guardian and/or your health care providers. The findings of this study will also be disseminated in form of a report that will be submitted to the department of pediatrics and child health of Makerere University. The findings will also be disseminated in conferences, abstract presentations and a peer-reviewed journal.

Ethical approval:

This study has been reviewed and approved by the Makerere University School of Medicine and Ethics Committee (SOMREC).

STATEMENT OF CONSENT

..... has described to me what is going to be done, the risks, the benefits involved and my rights regarding this study. I understand that my decision to participate in this study will not alter my (child's) medical care. In the use of this information, my identity and that of the child will be concealed. I am aware that I and the child may withdraw at any time. I understand that by signing this form, I do not waive any of my and my child's legal rights but merely indicate that I have been informed about the research study in which I am voluntarily agreeing to participate. A copy of this form will be provided to me.

Name Signature/thumbprint of participant Date

Name Signature of parent/guardian Date

Name Signature of research assistant.....Date.....

Witness (if applicable)

Name Signature Date.....

**FOOMU Y'OKUKKIRIZA EY'ABAVUBUKA AB'EMYAKA 18 NE 19,
N'ABALABIRIRA ABAANA.**

Omutwe gw'okunoonyereza: Omutindo gw'obulamu n'ensonga ezikwatagana ku bavubuka abalina kookolo womusaayi abamaliriza obujjanjabi mu ddwaaliro ekulu ely'e Mulago.

Ttiimu y'okunoonyereza:

Erinnya	Essimu	Ekitongole
Dr. Victoria Faith Zalwango (PI)	0704644085	Makerere University

Ensibuka yo'kunonyereza: Obulwadde bwa kookolo womusaayi mu baana ne mubavubuka butera okuba obuzibu okuzuula ku mwana n'abazadde, era obujjanjabi buwangaala okumala emyaka esaatu (3). Kino kiyinza okusigala nga kikosa obulamu bw'omwana obw'omubiri, obw'ebirowoozo, obw'embeera z'abantu oba okukosa ebye ssomero n'emirimu ne bwaba yamaliliza obujjanjabi. Ebizuuliddwa okuva mu kunoonyereza kuno bijja kuyamba okumanyisa ebiyinza okolebwa okuyambako abaana n'abavubuka oluvannyuma lw'okumaliriza obujjanjabi bwa kookolo ow'omusaayi.

Okunoonyereza kuno kussibwamu ssente omunoonyereza omukulu, Dr. Victoria Faith Zalwango, era tewali buyambi bwa nsimbi bwa bweru bufunibwa.

Ekigendererwa ky'okunoonyereza: Okunoonyereza kuno kugenderera okutegeera omutindo gw'obulamu bw'abavubuka abalina ekilwadde kya kookolo womusaayi abamaliriza obujjanjabi ku ddwaaliro ekulu elya Mulago n'ensonga ezikwatagana n'omutindo gw'obulamu bwabwe.

Enkola y'okunoonyereza: Bwokkiriza okwetaba mu kunoonyereza, omwana nawe ojja kusabibwa okuddamu ebibuuzo ebikwata ku mutindo gw'obulamu bwomwana wo, ng'otunuulira enkola y'omuvubuka ey'omubiri, ey'ebirowoozo, ey'embeera z'abantu, ey'essomero n'emirimu, tujja kwetegereza n'ebiwandiiko byo eby'eddwaaliro. Eby'okuddamu bijja kuwandiikibwa ku lupapula.

Ani agenda okwetaba mu kunoonyereza kuno? Abavubuka abali wakati w'emyaka 10 ne 19 abamaze okujjanjabibwa wakati wa 2019 ne 2025 okumala emyezi egitakka wansi wa 6 mu ddwaaliro e Mulago National Referral Hospital, waadi y'abaana eya kookolo, era nga bawonye ddala kookolo w'omusaayi. Tusubira okukozesa abavubuka 109 abagenda okubuuzibwa ebibuuzo okuva mu lupapula lw'ebibuuzo.

Obulabe: Ebimu ku bibuuzo biyinja okukuleetera okunyigirizibwa mu nneewulira yo. Singa mbeera nga eyo ebaawo, tujja kukuyunga gwe nomwana ku kansala mu ddwaaliro. Omwana bw'aba tayagala kugenda mu maaso na bibuuzo, oli wa ddembe okuva mu kunoonyereza oba okugenda mu maaso n'ebibuuzo ng'omwana yeeyagaza oba nga mwetegefu.

Emigaso: Tewayinza kubaawo mugaso gwa butereevu gy'oli ng'omuntu eyeetabye mu kunoonyereza kuno, naye ebizuuliddwa bijja kukozezebwa okulwanirira obuweereza obuddamu ebyetaago by'abavubuka abajjanjabwa kookolo.

Ebyama: Kyonna kyetusaba omuvubuka kijja kukozezebwa mu kunoonyereza kuno kwokka, era ennamba ey'enjawulo ejja kukuweebwa. Erinnya lyo/ erinnya ly'omuvubuka terijja kulabika ku mpapula ezikozezebwa okukungaanya amawulire. Wadde ng'ebiva mu kunoonyereza biyinja okufulumizibwa, omuntu eyeetabye mu kunoonyereza kuno tebijja kwogerwako. Okugatta ku ekyo, akakiiko ka Makerere University School of Medicine Research and Ethics Committee ne Uganda National Council for Science and Technology bayinza okusaba okufuna amawulire agazuulibwa okusobola okwekenneenya empisa, naye amawulire gano tegajja kufulumizibwa mu lujjudde.

Ebisale: Tojja kugambibwa kusasula ssente zonna olw'okwetaba mu kunoonyereza kuno.

Akasimo akokwetaba mu kunoonyereza kuno: Wajja kubaawo akasimo aka siringi za Uganda 10,000 okuliyirira obudde bwonatwala okwetaba mu kunoonyereza kuno.

Ebibuuzo ebikwata ku kusoma: Bwoba olina ekibuuzo kyonna oba ebikweraliikiriza ku kunoonyereza kuno, oli waddembe okukubira omunonyereza omukulu Faith Zalwango ku nnamba y'essimu 0704644085.

Ebibuuzo ebikwata ku ddembe ly'a ayetabye mu kunonyereza: Okumanya ebisingawo ku ddembe lyo mu kunoonyereza kuno nga eyeetabye mu kunoonyereza kuno, oli waddemebe okutukirira Ssentebe w'ekitongole ky'okunoonyereza ku by'obusawo n'akakiiko akavunaanyizibwa ku kunoonyereza n'obulamu, Professor OCAMA PONSANO ku nnamba y'essimu 0772-421190.

Ekiwandiiko ky'obwannakyewa: Okwetaba mu kunoonyereza kuno kwa kyeyagalire, era abeetabye mu kunoonyereza kuno bayinza okwegatta mu kunonyerza kuno ku ddembe lyabwe

ery'okwesalirawo. Abeetabyemu era balina eddembe okuva mu kunonyereza kuno ekiseera kyonna awatali kibonerezo.

Okusaasaanya ebivudde mu kunonyereza: Amawulire gonna amapya agakukosa gajja kuweebwa omuzadde, ne/oba abajjanjabi bo. Ebizuuliddwa mu kunoonyereza kuno era byakusaasaanyizibwa mu ngeri ya lipoota egenda okuweebwa ekitongole ky'abaana n'ebyobulamu by'abaana mu yunivasite y'e Makerere. Ebizuuliddwa era bigenda kusaasaanyizibwa mu nkunjaana, ennyanjula ezitaliimu n'ekitabo ekitunuulirwa bannaabwe.

Okukkirizibwa mu ngeri ey'obwannannyini: Okunoonyereza kuno kwekenneenyeddwa era ne kukkirizibwa akakiiko k'eby'obusawo n'empisa mu yunivasite y'e Makerere (SOMREC).

EKITABO KY'OKUKKIRIZIGANYA

.....annyonnyodde ekigenda okukolebwa, akabi, emigaso, n'eddembe lyange erikwata ku kunoonyereza kuno. Ntegedde nti okusalawo kwange okwetaba mu kunoonyereza kuno tekijja kukyusa bujjanjabi bwange oba obw'omwana wange. Mu nkozesa y'amawulire gano, endagamuntu yange ejja kukwekebwa. Nkimanyi nti nnyinza okuva mu kunonyereza kuno ekiseera kyonna. Ntegedde nti nga nzisa omukono ku ffoomu eno, siwaayo ddembe lyange lyonna ery'amateeka wabula nambika nti ntegeezeddwa ku kunoonyereza kuno kwe nzikiriza kyeyagalire okwetabamu. Kopi ya ffoomu eno ejja kuweebwa gyendi.

Erinnya ly'omuntu eyeetabye mu (omulabirizi).....

Omukono oba ekinkumu:

Ennaku z'omwezi:.....

Erinya lya'buza ebibuzo.....

Omukono gw'oyo abuuza ebibuuzo.....

Ennaku z'omwezi:.....

Omujiizi

Erinya

Omukono

Ennaku z'omwezi:.....

APPENDIX IV: TIMELINE

Activity	05/ 25	06/ 25	07/ 25	08/ 25	09/ 25	10/ 25	11/ 25	12/ 25	01/ 26	02/ 26	03/ 26	04/ 26	05/ 26	06/ 26
Proposal presentation														
IRB approval and administrative clearance														
Pre-testing of data collection Tools														
Data collection														
Data entry & analysis														
Dissertation writing														
Dissertation defence														

APPENDIX V: BUDGET

No	Item and description	Units	Unit cost (UGX)	Amount (UGX)	Justification
1	IRB fees	NA		100,000	
2	Printing and stationery	NA		600,000	Printing study tools and stationary
3	Compensation for participants	110	10000	1,100,000	Compensation of study participants
4	Data analysis	NA		1,500,000	Remuneration of biostatistician
6	Publication fees	NA		500,000	Publication fees to a peer-reviewed journal
7	Research assistant	2	500,000	1,000,000	
	Total			4,800,000	

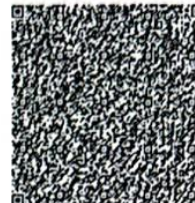
The study did not have any external funding, and all costs were covered by the principal investigator.

APPENDIX VI: SOMREC APPROVAL



21/09/2025

To: VictoriaFaith Zalwango
Makerereuniversity



Review Type: Initial Review

Re:Mak-SOMREC-2025-580: Quality of Life and Associated Factors Among Adolescents with Liquid Cancers in Remission at Mulago National Referral Hospital, Kampala, Uganda

I am pleased to inform you that at the 206 convened meeting on 22/07/2025, the MAK School of Medicine REC (Mak-SOMREC) meeting voted to approve the above referenced application.
Approval of the research is for the period of 21/09/2025 to 21/09/2026.

As Principal Investigator of the research, you are responsible for fulfilling the following requirements of approval:

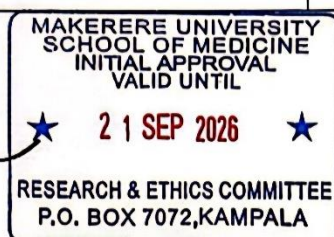
1. All co-investigators must be kept informed of the status of the research.
2. Changes, amendments, and addenda to the protocol or the consent form must be submitted to the REC for re-review and approval **prior** to the activation of the changes.
3. Reports of unanticipated problems involving risks to participants or any new information which could change the risk benefit: ratio must be submitted to the REC.
4. Only approved consent forms are to be used in the enrollment of participants. All consent forms signed by participants and/or witnesses should be retained on file. The REC may conduct audits of all study records, and consent documentation may be part of such audits.
5. Continuing review application must be submitted to the REC **eight weeks** prior to the expiration date of 21/09/2026 in order to continue the study beyond the approved period. Failure to submit a continuing review application in a timely fashion may result in suspension or termination of the study.
6. The REC application number assigned to the research should be cited in any correspondence with the REC of record.
7. You are required to register the research protocol with the Uganda National Council for Science and Technology (UNCST) for final clearance to undertake the study in Uganda.

The following is the list of all documents approved in this application by MAK School of Medicine REC (Mak-SOMREC):

No.	Document Title	Language	Version Number	Version Date
1	study plan	English	2.0	2025-09-10
2	Community Engagement plan	English	2.0	2025-09-10
3	Informed Consent forms	english and	parents 1	2025-09-10

		luganda		
4	Informed Consent forms	english and luganda	Adolscents 1	2025-09-10
5	Assent form	english and luganda	2.0	2025-09-10
6	Protocol	English	2.0	2025-09-10
7	Data collection tools	english	1.0	2025-06-06
8	COVID-19 & EBOLA risk management plan	english	1.0	2025-06-06

Yours sincerely,

Prof. Ponsiano Ocama

For: MAK School of Medicine REC (Mak-SOMREC)

APPENDIX VII: ADMINISTRATIVE CLEARANCE

TELEPHONE: +256-41554008/1
FAX: +256-414-5325591
E-mail: admin@mulago.or.ug
Website: www.mulago.or.ug

IN ANY CORRESPONDENCE ON THIS
SUBJECT PLEASE QUOTE NO.....



MULAGO NATIONAL REFERRAL HOSPITAL
P. O. Box 7051
KAMPALA, UGANDA

4th November 2025.

Dr. Zalwango Victoria Faith
Principal Investigator
Department of Paediatrics and Child Health
Makerere University

Dear Dr. Zalwango,

RE: ADMINISTRATIVE CLEARANCE TO CONDUCT A STUDY AT MULAGO NATIONAL REFERRAL HOSPITAL.

The Mulago Hospital Management is pleased to inform you that you have been offered clearance to conduct the study titled MHREC 3040: "Quality of life and associated factors among Adolescents with Liquid cancers in remission at Mulago National Referral Hospital, Kampala, Uganda".

The above clearance is granted to you on the following conditions;

- That you will follow the research ethical processes
- Agreed to comply with all institutional policies and regulations of Mulago National Referral Hospital
- Agreed to provide end of study report and acknowledge Mulago hospital in all publications
- Submit a copy of filled in participant compensation log after recruiting one quarter of the approved research sample size.

Administrative clearance is valid for one (1) year effective from 31st October 2025 to 30th October 2026.

By copy of this letter, we reiterate our commitment to support this study.


DR. BYANYIMA ROSEMARY
EXECUTIVE DIRECTOR
MULAGO NATIONAL REFERRAL HOSPITAL

Copied to;

1. Incharge – Pediatric Haematology Oncology Unit-MNRH

Vision: "To be the leading centre of Health Care Services"