DEPRESSION AMONG ADOLESCENTS WITH SICKLE CELL ANEMIA IN DAR-ES-SALAAM, TANZANIA: PREVALENCE, ASSOCIATED FACTORS, AND LIVED EXPERIENCES.

Linda Paul Athman, MD

Mmed Pediatrics and Child Health dissertation
Muhimbili University of Health and Allied Sciences
October, 2024

Muhimbili university of health and allied sciences

Department of Pediatrics and Child Health



DEPRESSION AMONG ADOLESCENTS WITH SICKLE CELL ANEMIA IN DAR-ES-SALAAM, TANZANIA: PREVALENCE, ASSOCIATED FACTORS, AND LIVED EXPERIENCES.

By

Linda Paul Athman

A Dissertation submitted in (partial) Fulfillment of the Requirements for the Degree of Masters of Medicine (Pediatrics and child health) of

Muhimbili University of Health and Allied sciences

October, 2024

CERTIFICATION

The undersigned certify that they have read and hereby recommend for examination of dissertation entitled "**Depression among adolescents with sickle cell anemia in Dar-es-salaam, Tanzania: Prevalence, associated factors, and lived experiences"**, in fulfillment of the requirements for the degree of Master of Medicine (Pediatrics and Child health) of Muhimbili University of Health and Allied Sciences.

……

DR FATIMA MUSSA

(Supervisor)

Date: ……

……

DR HONESTA KIPASIKA

(Co-supervisor)

Date: ……

DECLARATION AND COPYRIGHT

I, **Linda Paul Athman**, declare that this **dissertation** is my own original work and that it has not been presented and will not be presented to any other University for a similar or any other degree award.

Signature……. Date……

The dissertation if a copyright material protected under the Berne convention, The Copyright Act 1999 and other international and national enactments, in that behalf, on intellectual property. It may not be reproduced by any means, in full or in part, except for short extracts in fair dealing, for research or private study, critical scholarly review or discourse with an acknowledgement, without the written permission of the directorate of postgraduate studies, on behalf of both the author and the Muhimbili University of Health and Allied Sciences.

ACKNOWLEDGEMENT

I would like to express my gratitude to all who have contributed towards the success of this dissertation. First and foremost, I am grateful to GOD for giving me strength, will power and guidance towards accomplishing this work.

Special thanks to my supervisors, Dr. Fatima Mussa and Dr. Honesta Kipasika for their tireless constructive criticism and guidance that made completion of this dissertation successful. Thank you both, for mentoring me throughout making of this dissertation.

Sincere thanks to MUHAS Sickle cell programme SPARCO, for the technical support during the entire study duration; your support made the process of data collection process smooth and all the constructive inputs have contributed towards improving the outcome of my work.

My family was a great source of support and encouragement from the beginning. I am grateful for your prayers and patience for the times that I couldn't be there as I was working on my dissertation.

Last but not least, I am thankful for my classmates (pediatrics MMED class of 2024), our team work, togetherness and solidarity remain remarkable throughout our study duration.

ABSTRACT

Background: Depression is a mood disorder that affects how a person feels, thinks, and conducts daily activities. Sickle Cell Anaemia (SCA), like other chronic diseases, has been associated with an increased likelihood of neuropsychiatric complications (including depression) and reduced quality of life due to the chronicity of the disease and the occurrence of painful crisis. Studies have revealed that adolescents with SCA are found to have higher rates of depressive symptoms compared to children who do not have SCA.

Broad Objective: To assess the magnitude of depression, associated factors, and lived experiences among adolescents 10-19 years with SCA attending sickle cell clinic in Dar es salaam from October 2023 to March 2024.

Materials and Methodology: A sequential dominance mixed method research study. Socio-demographic and SCA severity data were collected using pre-structured and pre-tested questionnaires and in-depth interviews were conducted among participants with depression to explore their experiences. Descriptive statistics were summarized as mean and standard deviation for continuous variables. Categorical variables were described using frequencies and proportions with the difference in proportions analyzed using the chi-squared or Fisher's exact test, as appropriate. Univariate and multivariable analysis were used for the associated factors. A P-value of less than 0.05 was considered statistically significant. Qualitative data was analyzed using NVivo 11 pro; codes, themes and subthemes were derived and final write-up was made.

Results: Among 326 adolescents, 216 (53.7 %) had depressive symptoms; where by 167 (38.7%) had mild symptoms, 48 (14.7 %) had moderate symptoms and 1 (0.3%) had severe symptoms. Fifteen percent of adolescents had clinical depression (moderate and severe depression). Various factors including age, gender, education level, health insurance, use of hydroxyurea, hospital admission, and blood transfusion showed no significant association with depression, p >0.05. Painful episodes experienced within previous 12 months were significantly associated with depression (aOR = 2.49) (95% CI: 1.17 - 5.29, p = 0.01). The majority of adolescents experienced loneliness and isolation and had not fully accepted the reality of living with SCA. Adaptive and maladaptive behaviors were observed as the coping mechanisms when depressed. Family and community social support was from parents,

friends and teachers. However, some reported mistrust from friends, bullying and name-calling.

Conclusion: Depression is common among adolescents with SCA in our setting. Painful episodes experienced by these adolescents were significantly associated with depression. Depressed adolescents commonly experienced loneliness and isolation. Social support, coping mechanisms, and acceptance play pivotal roles in their well-being. Understanding these experiences can inform targeted interventions and support systems for this vulnerable population

Recommendations

This study highlights the need for screening adolescents with SCA for depression and integration of mental health services in sickle cell clinics. Prevention and adequate management of frequent painful episodes is crucial for these adolescents. Targeted interventions should focus on good coping strategies, acceptance and strengthening social support systems

MUHTASARI

Utangulzi; Sosona ni ugonjwa wa kihisia unaoathiri jinsi mtu anavyohisi, kufikiri, na kufanya shughuli za kila siku. Seli mundu, kama yalivyo magonjwa mengine sugu, imehusishwa na kuongezeka kwa uwezekano wa matatizo ya kiakili (ikiwa ni pamoja na sonona) na kupunguza ubora wa maisha kutokana na usugu wa ugonjwa huo na maumivu ya muda mrefu. Uchunguzi umeonyesha kuwa vijana walio na Seli mundu wanapatikana kuwa na viwango vya juu vya dalili za sonona ikilinganishwa na watoto ambao hawana Seli mundu.

Lengo la utafiti; Kutathmini ukubwa wa ugonjwa wa sonona, sababu zinazohusiana, na uzoefu wa maisha kati ya vijana rika wa miaka 10-19 wenye seli mundu wanaohudhuria kliniki za seli mundu jijini Dar es salaam kuanzia Oktoba 2023 hadi Machi 2024.

Mbinu; Utafiti wa mbinu mchanganyiko unaofuatana. Takwimu za kijamii-demografia na ukali wa seli mundu ilikusanywa kwa kutumia dodoso zilizopangwa awali na zilizojaribiwa awali. Mahojiano ya kina yalifanyika kati ya washiriki wenye sonona ili kuchunguza uzoefu wao. Takwimu za maelezo zilifupishwa kama wastani na mkengeuko wa kawaida kwa vigeu vingi vinavyoendelea. Vigezo vya kategoria vilielezewa kwa kutumia masafa na uwiano na tofauti katika uwiano uliochanganuliwa kwa kutumia kipimo cha "chi-square" au "Fisher exact test", inavyofaa. Uchambuzi usio na tofauti na unaoweza kubadilika ulitumiwa kwa sababu zinazohusiana. "P value" ya chini ya 0.05 ilizingatiwa kuwa muhimu kitakwimu. Data ya ubora ilichambuliwa kwa kutumia NVivo 11 pro; misimbo, mada na mada ndogo zilitolewa na uandishi wa mwisho ukafanywa.

Matokeo; Miongoni mwa vijana 326, 216 (53.7%) walikuwa na dalili za huzuni; ambapo kufikia 167 (38.7%) walikuwa na dalili kidogo, 48 (14.7%) walikuwa na dalili za wastani na 1 (0.3%) alikuwa na dalili kali. 15% walikuwa na sonona yenye dalili (sonona ya wastani na kali). Mambo mbalimbali yakiwemo umri, jinsia, kiwango cha elimu, bima ya afya, matumizi ya hydroxyurea, kulazwa hospitalini, na kuongezewa damu hayakuonyesha uhusiano wowote na sonona, p >0.05.vipindi vya maumivu makali ndani ya miezi 12 iliyopita vilihusishwa kwa kiasi kikubwa na sonona (aOR = 2.49) (95% CI: 1.17 - 5.29, p = 0.01). vijana rika wengi walikua na upweke na kujisikia kutengwa na hawakuwa wamekubali kikamilifu hali ya kuishi na ugonwa wa seli mundu. Tabia zinazofaa na

zisizofaa zilionekana kama njia za kukabiliana wakati wa huzuni. Msaada wa kijamii kutoka kwa familia na jamii ulitoka kwa wazazi, marafiki, na walimu. Hata hivyo, baadhi yao waliripoti kutokuaminiana kutoka kwa marafiki, vitendo vya uonevu, na kuitwa majina mabaya..

Hitimisho; Ugonwa wa sonona upo kwa wingi kati ya vijana rika walio na Seli mundu katika eneo letu. Vipindi vya maumivu makali vilivyowapata vijana rika hawa vilihusishwa sana na ugonjjwa wa sonona. Upweke na kutengwa viliwakumba vijana rika wengi wenye sonona. Usaidizi wa kijamii, mbinu za kukabiliana na hali hiyo, na kujikubali ni hatua muhimu zinazopaswa kutiliwa mkazo ili kuboresha ustawi wao. Kuelewa maisha wanayopitia vijana hawa kunaweza kufahamisha vitengo husika kupanga mifumo ya usaidizi kwa vijana rika walio hatarini.

Mapendekezo; Utafiti huu unaonyesha hitaji la kuwachunguza vijana rika wenye seli mundu kugundua dalili za sonona mapena na kujumuisha huduma za afya ya akili katika kliniki za seli mundu. Kinga na udhibiti wa kutosha wa maumivu ya mara kwa mara ni muhimu kwa vijana hawa. Afua zinazolengwa zinapaswa kuzingatia mikakati mizuri ya kukabiliana, kujikubali na kuimarisha mifumo ya usaidizi wa kijamii kwa vijana rika.

CONTENTS

CERTIFICATION i
DECLARATION AND COPYRIGHT ii
ACKNOWLEDGEMENT iii
ABSTRACT iv
MUHTASARI vi
LIST OF TABLES xi
LIST OF FIGURES xi
DEFINITION OF KEY TERMS xiii
1.0 INTRODUCTION 1
1.1 Background 1
1.1.1 Depression 1
1.1.2 Sickle cell anemia and depression 1
1.2 Problem statement 2
1.3 Conceptual framework 3
1.4 Rationale/Justification 4
1.5 Research questions 5
1.5.1 Main research question 5
1.5.2 Specific research questions 5
1.6 Objective 5
1.6.1 Broad objective 5
1.6.2 Specific objective 5
2.0 LITERATURE REVIEW 6
2.1 Prevalence of depression in adolescents with SCA. 6
2.3 Factors associated with depression in adolescents with SCA 7
2.4 Lived experiences of depression among adolescents 7
3.0 METHODOLOGY 9
3.1 Study design 9
3.2 Study setting 9
3.3 Study population 9
3.4 Quantitative method 10
3.4.1 Inclusion criteria 10
3.4.2 Exclusion criteria 10
3.4.3. Sampling technique 10

3.4.4 Sample size and selection 10
3.4.5 Variables to be measured; 10
Dependent variables 10
Independent variables 10
3.4.6 Data collection methods 11
3.4.7 Data collection tools 11
3.4.8 Data analysis 12
3.5 Qualitative method 12
3.5.1 Purposive sampling 12
3.5.2 Sample size 12
3.5.3 Themes 13
3.5.4 Data collection 13
3.5.5 Data collection tools 13
3.5.6 Data analysis 13
3.6 Ethical consideration 14
4.0 RESULTS 15
4.1. Participant's socio-demographic characteristics 15
4.1.1 Participant's clinical profile 16
4.1.2 Prevalence of depression among adolescents with SCA 18
4.1.3 Factors associated with clinical depression. 20
4.2 Qualitative study respondent characteristics. 21
4.3 Health related stigma 22
4.3.1 Isolation 22
4.3.2 Loneliness 23
4.4 Acceptance 23
4.5 Coping mechanisms 24
4.5.1 Maladaptive coping mechanism 24
4.5.2 Adaptive coping mechanisms 24
4.6 Social support system 25
4.6.1 Family social support 25
4.6.2 Community social support 25
5.0 DISCUSSION 26
6.0 STRENGTHS, STUDY LIMITATIONS, CONCLUSION AND RECOMMENDATIONS 29
6.1 Strengths 29

6.2 Study Limitations and mitigation 29
6.3 Conclusion.....29
6.3 Recommendations 30
REFFERENCES 31
APPENDICES 34
Appendix 1: Questionnaire.....34
Appendix 2: Dodoso.....37
Appendix 3: - Interview guide.....40
Appendix 4: Muongozo wa mahojiano.....41
Appendix 5: Consent form 42
Appendix 6. Fomu ya ridhaa 44
Appendix 7: Assent form 46
Appendix 8: - Fomu ya ridhaa kwa mtoto 47
Appendix 9: - Ethical Clearance.....48
Appendix 10: - Permission Letters for data collection.....50

LIST OF TABLES

Table 1: Socio-demographic characteristics of adolescents with SCA 16

Table 2: Participant's clinical profile 17

Table 4: Factors associated with clinical depression (moderate and severe) by chi-square or fisher exact test..... 19

Table 5: Logistic regression factors associated with clinical depression 20

Table 6: Qualitative study respondent characteristics. 21

Table 7: Summary of themes and subthemes studied..... 22

LIST OF FIGURES

Figure 1: Conceptual framework showing interaction between dependent and independent variables..... 4

Figure 2: Flow chart showing recruitment of participants 15

Figure 4: Showing prevalence of depression among adolescents with SCA 18

Figure 5: Showing prevalence and severity of depression among adolescents with SCA.20

ABREVIATION

AVN - Avascular Necrosis

cOR - Crude Odds Ratio

aOR - Adjusted Odds Ratio

Hb - Hemoglobin

HbS - Sickled hemoglobin

HbAS - Heterozygous sickled hemoglobin

HbSS - Homozygous sickled hemoglobin

HPLC - High-Performance Liquid Chromatography

IDI - In Depth Interview

MUHAS- Muhimbili University of Health and Allied Sciences

MNH - Muhimbili National Hospital

NBS - Newborn Screening

PHC - Primary Healthcare

RBC - Red Blood Cells

PHQ - Patient Health Questionnaire

RRH - Regional Referral Hospital

SCA - Sickle Cell Anemia

SCD - Sickle Cell Disease

SPSS - Statistical Package for Social Sciences.

SSS - Sickle cell anemia Severity Score

VOC - Vaso-occlusive crisis

WHO - World Health Organization

DEFINITION OF KEY TERMS

Depression (Major depressive disorder or Clinical depression) - a mental health disorder presenting with at least 2 weeks of a depressed and/or irritable mood that is present for most of the day, nearly every day and/or loss of interest or pleasure in doing nearly all activities. Clinical depression was also defined with a PHQ-9 score of ≥10.

Sickle cell Anemia – Defined as those individuals confirmed to have homozygous HbS gene (HbSS) by Hb electrophoresis or High-Performance Liquid Chromatography (HPLC)

Adolescents- Defined as those in a transitional phase from childhood to adulthood with age range of 10-19 years according to this study which is similar to WHO's definition.

1.0 INTRODUCTION.

1.1 Background

1.1.1 Depression

Depression also known as major depressive disorder or clinical depression, is a mood disorder that affects how a person feels, thinks, and conducts daily activities. Globally, it has been estimated that 1 in every 7 (14%) 10-19-year-olds experience mental health conditions, including; depression, anxiety, and behavioral disorders. Depression affects 1.1% of adolescents aged 10-14 years and 2.8% of those aged 15-19 years. (1)

The Diagnostic and Statistical Manual of Mental Disorders (DSM V) is a universal tool designed for diagnosing depression. (2) An individual must have 5 or more of the 9 clinical symptoms (including 1 of depressed mood and loss of interest or pleasure) in the same 2-week period. These clinical symptoms include, depressed mood, loss of interest or pleasure, change in weight or appetite, insomnia or hypersomnia, psychomotor retardation or agitation, loss of energy or fatigue, worthlessness or guilt, impaired concentration or indecisiveness and thoughts of death or suicidal ideation or suicidal attempt.

Experts have predicted that by 2030 depression alone is likely to be the 3rd leading cause of disease burden in low-income countries and 2nd highest in middle-income countries. (3) The majority of depressive disorders arise in adolescents who have experienced long-standing psychosocial difficulties including physical or sexual abuse, emotional abuse, neglect, chronic illness, school difficulties (bullying, academic failure), social isolation, parental psychopathology, family or marital disharmony, and domestic violence.

1.1.2 Sickle cell anemia and depression

Sickle cell Anemia (SCA), is an autosomal recessive hemoglobin S mutation (HbSS) which has been linked to significant mortality and morbidity in African and Mediterranean ancestry.(4)

Tanzania is among the top 5 countries in Sub-Saharan Africa and the top leading in East Africa with the highest prevalence of SCD estimated at 11,000 per year in 2018. Nearly half (47.4%) of sickle cell anemia (SCA) patients fall within the 5-17 year age group, indicating a significant disease burden among children and adolescents. However, the severity of the

condition varies based on the level of anemia, the frequency of crises, and the extent of multiorgan damage. (5)

With improved care and advanced treatment modalities, there has been reduced mortality due to sickle cell disease. Widespread use of screening tests, rapid tests, and early newborn screening has led to early detection and timely management of sickle cell disease. Advancements in therapy including the use of hydroxyurea and hematopoietic stem cell transplant have significantly increased survival rates, transforming SCA into a chronic illness, accompanied with psychosocial and mental health burden.

Tanzania is still on the move to improve knowledge, resources, and availability of treatment modalities in various levels of health care facilities. In Tanzania, the primary causes of increased hospitalizations for sickle cell anemia (SCA) were identified as severe anemia, fever, and painful crises. (5) Along with other complications, the occurrence of acute and chronic painful episodes has been strongly associated with the development of depressive symptoms in adolescents. Depression rates are found to be high in adolescents with SCA compared to general population of adolescence. (6)

Similarly, depression has negative effects on the progression of a chronic illness. Patients with chronic illness and depressive symptoms have reported an increased frequency of medical symptoms as compared to patients with chronic illness alone.(7),(8)

1.2 Problem statement

Adolescents 10-19 years make up approximately 26% of the total population in Tanzania.(9) This being a critical age of transitioning between childhood and adulthood, the biological and psychological changes place them at a unique risk of psychopathology.

Studies have revealed that adolescents with a chronic illness like SCA have a higher risk of developing psychological problems like depression than their healthy counterparts due to its impact on physical, social, and sexual development with resultant effects like isolation, poor relationships, and poor performance in school. (6),(10)

The transition of care from pediatric to adult SCA clinics during adolescence increases vulnerability. (11) Any unsmooth transition increases the risks for depression due to an inconsistent continuum of care and dropout of clinics.

Despite the huge burden of SCA in Sub-Saharan Africa very few studies have been done to explore the burden of depression among adolescents with SCA. Depression rates were high in some African countries like Congo and other resource limited settings with prevalence ranging from 22% to 84 %. (12) The magnitude of depression among adolescents with SCA in Tanzania is unknown.

Studies done in Nigeria and other resource limited settings have identified some factors that may be associated with occurrence of depression. These include; painful episodes, age, gender, level of education and socio-economic status.(12)-(13) Similar studies have been conducted for adult patients with SCA. (14) However, there is no data in Tanzania showing prevalence, severity and factors associated with depression in adolescents with SCA.

This gap of knowledge calls for further research in this area hence, this study will attempt to cover that gap. Furthermore, this study will explore the lived experiences of adolescents with depression and SCA.

1.3 Conceptual framework

Studies have linked several factors to be associated with depression among adolescents with SCA. Socio-demographic factors like age, gender and level of education will be studied, to determine how they affect the prevalence and severity of depression.

Recurring complications of SCA, determines the severity and directly affects psychosocial functioning. Most authors have studied this, in relation to the severity and prevalence of depression. All these variables combined increase severity of the SCA which in turn contributes to occurrence of depressive symptoms. Assessing factors that lead to depression in our setting, will aid in the early identification of these factors, and designing of interventions focused on prevention and hence reduction in the prevalence of depression.

Understanding the experiences of depression among adolescents will enlighten us on how depression affects psychosocial functioning and adaptability. The study will explore experiences of loneliness and isolation, struggles towards acceptance of the illness, coping mechanisms to deal with depressive symptoms, and social support to overcome depressive symptoms.

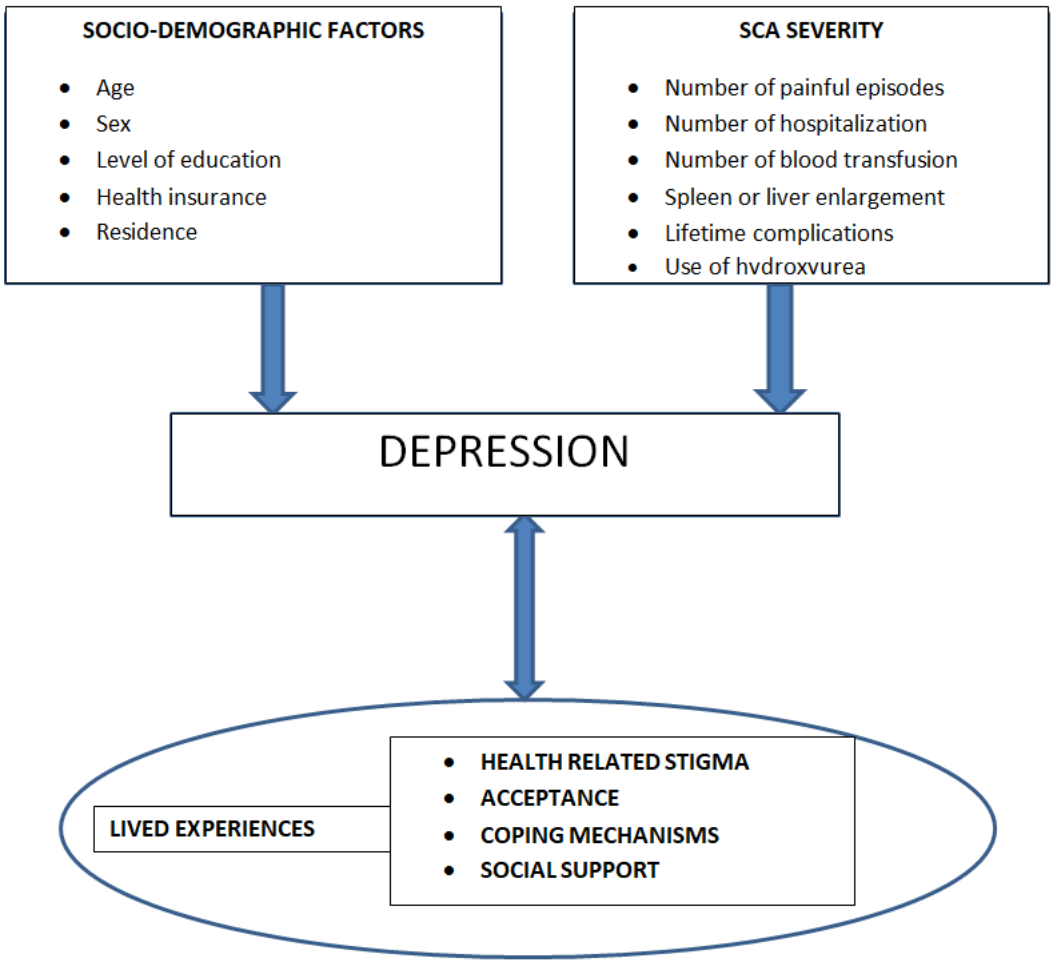


Figure 1: Conceptual framework showing the interaction between dependent and independent variables

1.4 Rationale/Justification

Data from this study aims to provide an understanding of the magnitude and severity of depression in adolescents with SCA. This will help to raise awareness among primary care physicians to pay extra attention to the mental health of adolescents attended in clinics.

It will also provide general emphasis on the importance of screening for depression in clinics using the available and validated tools, to ensure early detection of depression and timely referral of high-risk adolescents for appropriate therapy and treatment.

This study will further enlighten healthcare workers on the factors influencing depression among adolescents with sickle cell anemia and lead to determining the predictors of depression in future studies.

1.5 Research questions

1.5.1 Main research question

What is the prevalence, associated factors and lived experiences of depression among adolescents 10-19 years with SCA attending sickle cell clinics in Dar es salaam from October 2023 to March 2024?

1.5.2 Specific research questions

1. What is the prevalence of depression among adolescents 10-19 years with SCA attending sickle cell clinics in Dar es salaam from October 2023 to March 2024?
2. What are the factors associated with depression among adolescents 10-19 years with SCA attending sickle cell clinics in Dar es salaam from October 2023 to March 2024?
3. What are the lived experiences of depression among adolescents 10-19 years with SCA diagnosed to have moderate and severe depression?

1.6 Objective

1.6.1 Broad objective

To determine the prevalence of depression, associated factors and lived experiences among adolescents 10-19 years with SCA attending sickle cell clinics in Dar es salaam from October 2023 to March 2024

1.6.2 Specific objective

1. To determine the prevalence of depression among adolescents 10-19 years with SCA attending sickle cell clinics in Dar es salaam from October 2023 to March 2024.
2. To determine the factors associated with depression among adolescents 10-19 years with SCA attending sickle cell clinics in Dar es salaam from October 2023 to March 2024.
3. To explore the lived experiences of depression among adolescents 10-19 years with SCA diagnosed to have moderate and severe depression.

2.0 LITERATURE REVIEW

2.1 Prevalence of depression in adolescents with SCA.

Prevalence estimates for depression in the population vary widely across different studies and between different countries. This could be attributed to the different diagnostic tools, different adopted classifications, and study methods. Children and adolescents with SCA have higher rates of depressive symptoms compared to those who do not have SCA. (7)(15)

Globally, as per the WHO fact sheet, depression is estimated to occur in 1.1% of adolescents with the age of 10-14 years, and 2.8% of 15-19-year-olds. (1) In the USA, there are various studies with variable prevalence rates. A study done by Jerrell et al in America showed 46% of adolescents in the sickle cell disease cohort, were diagnosed with a depressive disorder. An integrative review by Kimberly et al also depicted a depression prevalence of 26-64% among children with SCD in the United States. (15)(16)

In view of other studies done in various continents and countries, there is a significant rise in depression prevalence. A cross-sectional study in Saudi Arabia by Alhomoud et al revealed 48% of sickle cell patients attending clinics had depression which (17) A similar study that was done in India by Singh et al, depicted a depression prevalence of 40% among school-aged adolescents.

Depression varies in severity and this has implications when it comes to treatment approaches for a patient. Severe depression has been associated with an increased risk of suicide attempts and hence warrants prompt management. Aljumah et al did a cross-sectional study in Saudi Arabia that assessed various levels of depression severity using the Beck Depression Inventory tool. He discovered that the prevalence of mild, moderate and severe depression were 23.2%, 20.6%, and 6.8% respectfully. (18)

In comparison with another study in Malaysia, where depression was classified using PHQ-9 tool and the prevalence of mild, moderate, and severe depression was found to be 16.6%, 12.8%, and 3.8% respectively.(19)

Compared to studies done in other continents, the prevalence of depression was found to be high in Africa. A study done by Lukoo et al in Congo showed that 86.4% of children and adolescents with SCA had depressive symptoms and among them mild, moderate and severe

depression was observed with prevalence of 14.3%, 77.1%, 8.6% respectively (12) This study showed the highest prevalence of depression in comparison to the few studies done in Africa. There is no published study done in Tanzania to assess the overall depression rates among adolescents, few studies looked at depression rates in chronic illness other than SCA.

2.3 Factors associated with depression in adolescents with SCA

Determining the predictors of depression, aids in tackling the core root of the problem. Despite the fact that no global studies have been done, factors associated with depression among adolescents with sickle cell anemia have been studied by various researchers worldwide and can be grouped into socio-demographic factors (e.g., age, sex and socio-economic status) and SCA disease severity factors.

Alhamoud et al in Saudi Arabia and Mallicka et al in India did studies that revealed socio-demographic factors like gender, low level of education, low socio-economic status were significantly associated with depression. (17),(20) However, Asnani et al in Jamaica, revealed that higher level of education was associated with higher odds of depression. This difference could be due to different settings and cultural environment of subjects.(21)

On the basis of SCA disease severity, the prevalence of depression is higher in patients with frequent admissions and frequent painful crisis as demonstrated by Aljumah et al, in Saudi Arabia.(18) Asnani et al, in Jamaica, showed that; patients with frequent painful crises had 2.5 times higher odds of developing depression CI (1.1-5.8). Other patient-related factors like leg ulcers, frequent visits to the hospital, low socio-economic status, and a higher level of education were significantly associated with higher odds of depression. (21)

2.4 Lived experiences of depression among adolescents

Adolescents with SCA who have developed depressive symptoms experience various challenges in their day to day lives. A good understanding of their life experiences as they try to cope with the double burden of disease and fit in the society is necessary to develop targeted interventions. They are predisposed to experience loneliness and social isolation, and most of them struggle to accept living with the illness. Social support especially from parents and peers is very crucial in helping these adolescents to thrive and heal from depression.

There is still paucity of global data, however a cross-sectional study done in the Denmark by Christiansen et al in 2021, demonstrated that feelings of loneliness and social isolation were strongly associated with mental illness and depressive symptoms among adolescents and young adults. He further discussed that employing strategies to help alleviate loneliness and social isolation greatly improved mental and physical health in adolescents.(22)

A descriptive qualitative study done in Jamaica by Forrester et al, showing experiences among adolescents with SCA, reported that strong family, school, and peer support made them feel accepted in their community despite their illness. It was also reported that prayer and spiritual activities were among the major coping mechanism in dealing with the illness and other diversion activities like watching TV, surfing the net, and talking to others were also found to be helpful. (23)

3.0 METHODOLOGY

3.1 Study design

Sequential dominant status, Mixed Method Research (MMR) design, where by the quantitative phase preceded the qualitative phase.

3.2 Study setting

Study sites were sickle cell clinics at Muhimbili National Hospital (MNH), Temeke Regional Referral hospital (TRRH), Amana Regional Referral Hospital (ARRH) and Mwananyamala Regional Referral Hospital (MRRH) found in Dar es salaam city. Dar es salaam is one among the largest and fastest growing cities in Tanzania with estimated population of 7.4 million residents as per 2022. The inhabitants receive health services form public and private health facilities. It comprises of four referral hospitals including a Muhimbili National Hospital (MNH) and three Regional Referral Hospitals (Mwananyamala, Amana and Temeke).

MNH functions as a national referral hospital, research centre and university teaching hospital. MNH attends to 2000 outpatients per day while the sickle cell clinic conducted once per week tends to around 120 clients weekly. Mwananyamala RRH is a public facility serving a population of around 2.2 million covering Ubungo and Kinondoni districts in Dar-es-salaam. The hospital tends to 1,500 to 1,800 clients per day and the sickle cell clinic in Mwananyamala attends to average of 30 children and adolescents per week. Amana RRH serves a population of about 1.2 million people and the outpatient attendances range from 800-1200 daily. The sickle cell clinic at Amana attends to average of 30 children and adolescents per week. Temeke RRH which serves Temeke district attends to average of 35 children and adolescents with SCA. All these four clinics offered comprehensive sickle cell care.

3.3 Study population

Adolescents 10-19 years attending Sickle cell clinics at MNH, Amana RRH, Temeke RRH, and Mwanyamala RRH in Dar es salaam, from October 2023 to March 2024 with the criteria mentioned below were recruited in the study.

3.4 Quantitative method

3.4.1 Inclusion criteria

All adolescents with the age of 10-19 years, who attended sickle cell clinics at the four health facilities, were included. They were confirmed to have SCA by Hb electrophoresis or HPLC.

3.4.2 Exclusion criteria

All adolescents who declined consent or assent were excluded from this study. In addition, adolescents who had painful crisis at that time or comorbid illness which could further contribute to depression were excluded as these could be among the confounders.

3.4.3. Sampling technique

Convenience sampling was used to obtain participants. Adolescents who arrived at clinic on that particular day being eligible for the study were recruited then assent and consent were obtained.

3.4.4 Sample size and selection

The sample size (N) was calculated using the formula for proportion

$$N=\frac{Z^2P(1-P)}{E^2}$$

Where; N= minimum sample size required, P= 86% - mean prevalence of depression in adolescence with SCA in Congo.(14); E= Maximum allowable error of the study, which is 5%; Z= Standard normal distribution that corresponds to 95% level of confidence, which is 2.85. The statistical power of the study is 99%

$$N=\frac{2.58^2 \times 0.86 \times (1-0.86)}{0.05^2}$$

Therefore, the minimum sample size required was 320 participants. 5% non-respondent was 16 participants.

3.4.5 Variables to be measured;

Dependent variables

- Depression

Independent variables

- Social demographic data (age, sex, level of education, residence, health insurance)
- Use of hydroxyurea

- SCA disease severity;
    - In the past 12 months- no of hospitalizations, no of blood transfusions, no of painful crises,
    - In present state- splenic and liver enlargement
    - Lifetime complications of SCA including; Leg ulcers, stroke, priapism, respiratory complications, arthritis, gallstones, osteomyelitis, sickle cell nephropathy.

3.4.6 Data collection methods

Data was collected by the principal investigator with the help of 2 research assistants who were trained on the entire data collection process and had good understanding of the study. The study was conducted using pre-structured and pre-tested questionnaire to assess the prevalence, severity and factors associated with depression. The questionnaire had three sections including socio-demographic data, severity of SCA and Patient Health Questionnaire (PHQ-9) tools.

The interviews took place during the time at which clients waited to see the attending doctor or after they were done with their visit. This did not affect their access to necessary services during their clinic visit. Eligible adolescents who attended clinic on that particular day were asked to participate in the study.

Those who were ready to participate signed the assent and consent forms respectively. In a separate room, the researcher administered the questionnaire due to the sensitivity of data and ease of obtaining data from participants who can't read or write. The researcher ensured the questions were well elaborated and the responses were filled appropriately.

3.4.7 Data collection tools

Designed questionnaires were used to capture independent variables (severity of SCA and social demographic characteristics). The questionnaire for assessing sickle cell disease severity was adopted from a study by Ezenwosu et al where a total of thirteen parameters were evaluated. (13)

The (PHQ-9) tool modified for adolescent's age 11-19 years was readily available for use, in Swahili version. It was tested and found that a PHQ-9 score >10 has a specificity of 88

and sensitivity of 88 for major depression. It was both valid and reliable in identifying sound psychometric properties. (24)

3.4.8 Data analysis

Parameters from the SCA disease severity tool were analyzed as follows. Items in the previous 12 months (number of hospitalizations, number of blood transfusions, and number of painful crises) were scored according to the frequency of their occurrence (0-3). Items in present state- splenic and liver enlargement were scored by severity (0=<5cm, 1=5-10cm, 2>10cm) while lifetime complications of SCA, leg ulcers, stroke, priapism, respiratory complications, arthritis, osteomyelitis, gall stones, sickle cell nephropathy (0=absent, 1=present). Total possible score was 21, whereby; a score ≤ 6 (mild), score 7-12 (moderate), and score >12 (severe).

The severity of depression was obtained from the PHQ-9 tool scores whereas the total score from the 9 items ranged from 0 to 27. Major depressive disorder was suggested if of the 9 items, 5 or more are checked as, “at least more than half the days” or each item 1 or 2 was checked as, “at least more than half the days” a score of 0-4 (none-minimal depression), 5-9 (mild depression), 10-14 (moderate depression), 15-19 (moderately severe depression), 20-27 (severe depression).

Quantitative data was entered in SPSS V23 and data cleaning was done. For numerical variables, mean and standard deviation were used. Categorical variables were described using frequencies and proportions with difference in proportions analyzed using the chi squared or Fishers exact test, as appropriate. Univariate and multivariate analysis were used for the associated factors. A P-value of less than 0.05 was considered statistically significant.

3.5 Qualitative method

3.5.1 Purposive sampling

Adolescents from the quantitative study found to have moderate to severe depression were purposefully selected by the researcher to join the qualitative study. Assent and consent were obtained and they were interviewed by the researcher

3.5.2 Sample size

Participants for in-depth interviews were recruited until saturation point was attained. A total of 6 participants were interviewed.

3.5.3 Themes

Themes that were studied to ascertain the experience of adolescents living with depression included, health related stigma, acceptance of living with SCA, coping mechanisms in dealing with depression, and social support systems.

3.5.4 Data collection

Data collection was conducted using in-depth interviews (IDI) by the principal investigator in a convenient place to maintain confidentiality and ensure participants are comfortable enough to open up. Prior to interviews, consent and assent forms were obtained from adolescents and their parents after explaining to them about purpose of the study and ensuring confidentiality. Interviews were conducted in Swahili with pre-structured open-ended questions and they took 20-30 minutes to be completed.

Interview sessions were recorded using a digital voice recorder and hand written notes were taken. During interviews participants were given time to reflect then respond, and for some cases where concepts were not well understood, the researcher rephrased the questions to ensure correct understanding. Data collection stopped when data was saturated.

3.5.5 Data collection tools

Qualitative data was conducted using pre-structured open ended interview guide questions.

3.5.6 Data analysis

Verbatim transcription was done in Swahili and then the research team reviewed the transcription to ensure the words of informants were not manipulated. This was followed by translation into English language. Thematic analysis was made using NVivo 11 Pro, qualitative data management software developed by QSR international in 2015. The researcher familiarized themselves with the data and generated initial codes. Coded data were organized into themes and subthemes as per research objectives. Categorized themes and subthemes were reviewed again to assess meaning and relationship between them and lastly, the final write up was made.

3.6 Ethical consideration

Ethical approval from the Muhimbili University of Health and Allied sciences Ethical Board Committee was obtained (MUHAS-REC-06-2023-1770). Permission letter for data collection were also obtained from each health facility. The data collected did not interfere with the routine care provided at the clinic. A clear informed consent and assent were sought from the caregiver and the adolescent respectively after providing clear information about the study. Participants had a free will to participate in the study.

In case a participant was diagnosed to have moderate to severe depressive symptoms, he/she was channeled to a clinical psychologist for further evaluation and therapy at the Muhimbili National hospital Psychiatry department or respective nearby health facility for further review.

4.0 RESULTS

A total of 341 adolescents were recruited from the four (4) sickle cell clinics of which 326 were enrolled in the study. 15 candidates did not meet the eligibility criteria (13 declined consent and 2 were not confirmed to have SCA by Hb electrophoresis or HPLC).

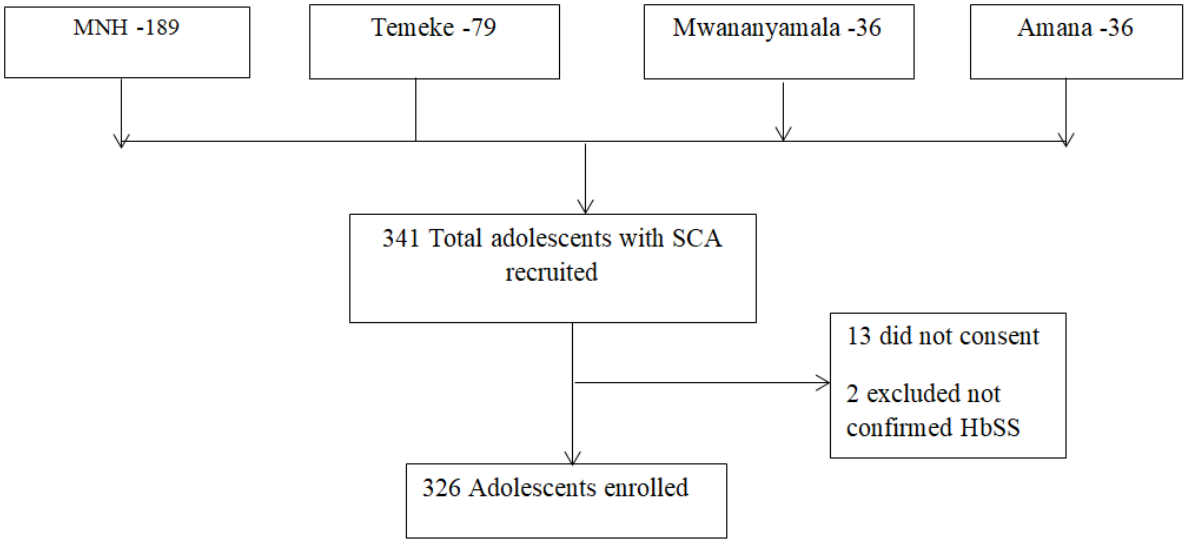


Figure 2: Flow chart showing recruitment of participants

4.1. Participant's socio-demographic characteristics

Participant's socio-demographic characteristics on table 1 revealed that the majority (64.7%) of participants were 10-14 years of age, with the mean age of 13.9 years, standard deviation of 2.35. There was equal gender distribution. Nearly half of participants (49.1%) were from the tertiary referral clinic (MNH clinic), followed by the regional hospital clinics; Temeke (23.6%) and almost equal proportion were from Mwananyamala (10.1%) and Amana (10.4%). Almost all participants had either primary level education (48.2%) or secondary level education (46.9%), with a small proportion (4.9%) having no formal education at all. The majority of participants were from Dar es salaam (urban and rural) (87.7%) and few (12.3%) were from Up-country (other regions in Tanzania). Sixty five (65%) of participants had health insurance coverage.

Table 1: Socio-demographic characteristics of adolescents with SCA

		No of participants-326	**Percentage (%)**
Age(years)	10-14	211	64.7
	15-19	115	35.3
Sex	Male	160	49.1
	Female	166	50.9
Clinic	MNH	182	55.8
	Temeke	77	23.6
	Mwananyamala	33	10.1
	Amana	34	10.4
Education	No formal education	16	4.9
	Primary	157	48.2
	Secondary	153	46.9
Address	Dar es salaam	286	87.7
	Up-country	40	12.3
Health insurance	present	212	65
	absent	114	35

4.1.1 Participant's clinical profile

Table 2 and 3 shows the clinical profile of recruited participants. Three quarters of adolescents (74.5%) with SCA were on hydroxyurea. Sickle cell disease Severity Score (SSS) was used to determine severity of SCA among participants classifying them as mild, moderate and severe disease category. It was observed that (96.3%) had mild disease severity, (3.7%) had moderate disease severity and none of them had severe disease. When looking at painful episodes in the past 12 months, 39.6% of the adolescents reported to be pain-free while the remaining had either one painful episode (26.4%), two to three painful episodes (22.7%), or more than three painful episodes(11.3%). In the past 12 months Most participants in the study had not received blood transfusions (85.0%) or required hospitalization (66.3%), and the majority showed no current signs of hepatomegaly or splenomegaly (97.9% and 91.1% of participants, respectively).

Table 2: Participant's clinical profile

		No of participants-326	Percentage (%)
Hydroxyurea use	No	80	24.5
	yes	246	75.5
SCA severity	Mild	341	96.3
	Moderate	12	3.7
Events in the past 12 months.			
Painful Episodes	none	129	39.6
	once	89	26.4
	2-3	74	22.7
	>3	37	11.3
Hospital admission	none	216	66.3
	once	69	21.2
	2-3	32	9.8
	>3	9	2.8
Blood transfusion	none	277	85.0
	once	34	10.4
	2-3	13	4.0
	>3	2	0.6
Spleen enlargement	<5cm	319	97.9
	5-10 cm	6	1.8
	>10cm	1	0.3
Liver enlargement	<5cm	323	99.1
	5-10cm	3	0.9

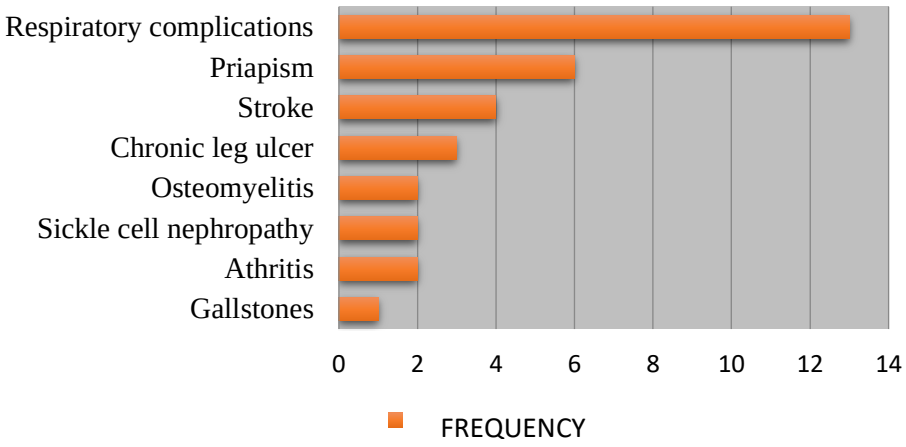


Figure 3: Clinical profile: Complications of SCA among participants

When looking at the complication profile of the participants, majority of adolescents in this study had no complications of SCA (table 3). Of the few that reported complications, the most commonly observed complication was respiratory complications (pneumonia or acute chest syndrome) (figure 3).

4.1.2 Prevalence of depression among adolescents with SCA

Out of the 326 adolescents screened, 216 exhibited depressive symptoms, resulting in an overall prevalence rate of 53.7%. (Figure 4). These symptoms were categorized as mild in 167 (38.7%) adolescents, moderate in 48 (14.7%) adolescents, and severe in 1(0.3%) adolescent (figure 5). Moreover, the study identified that clinical depression, encompassing moderate to severe symptoms, was prevalent in 49(15%) adolescents.

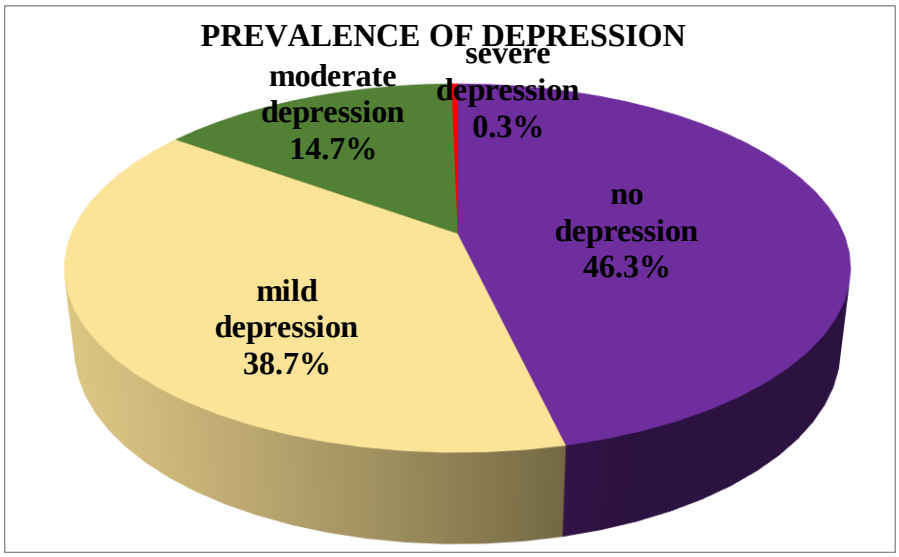


Figure 4: Prevalence of depression among adolescents with SCA

Table 3: Factors associated with clinical depression (moderate and severe).

		No Depression	Clinical depression (moderate and severe)	P-value
	Overall	277 (84.7)	49 (15.03)	
Age(years)	10-14	183 (86.7)	28 (13.3)	0.228
	15-19	94(81.7)	21 (18.3)	
Gender	Male	139 (86.9)	21 (13.1)	0.345
	Female	138 (83.1)	28 (16.9)	
Education level	No formal education	13 (81.3)	3 (18.8)	0.359
	primary	138 (87.2)	19 (12.1)	
	secondary	126 (82.4)	27 (17.6)	
Health insurance	Insured	177 (83.5)	35 (16.5)	0.308
	Non-insured	100 (87.7)	14 (12.3)	
Address	Dar-es-salaam	240 (83.9)	46 (16.1)	0.155
	Up-country	37 (92.5)	3 (7.5)	
Clinic	MNH	150 (82.4)	32(17.6)	0.551
	Temeke	68 (88.3)	9 (11.7)	
	Mwananyamala	29 (87.9)	4 (12.1)	
	Amana	30 (88.2)	4 (11.8)	
Use of hydroxyurea	No use	72 (90.0)	8 (10.0)	0.147
	use	205 (83.3)	41(16.7)	
SCA severity***	mild	267 (84.8)	48 (15.2)	1.000
	moderate	10 (90.9)	1 (9.1)	
Painful episodes	none	118 (91.5)	11 (8.5)	0.008
	present	159 (80.7)	38 (19.3)	
Hospital admission	none	186 (86.1)	30 (13.9)	0.399
	present	91 (82.6)	19 (17.4)	
Blood transfusion	none	234 (84.5)	43 (87.8)	0.554
	present	43 (15.5)	6 (12.2)	
Splenomegaly	≤5 cm	271 (85.0)	48 (15.0)	1.000
	>5cm	6 (85.7)	1 (14.3)	
Hepatomegaly***	≤5 cm	275 (85.1)	48 (14.9)	0.388
	>5 cm	2 (66.7)	1 (33.3)	

***Fischer exact test used. P value < 0.05- statistically significant

4.1.3 Factors associated with clinical depression.

The association between socio demographic factors and clinical profile of participants, in relation to clinical depression in this study, were evaluated using Chi-square and Fischer exact test (Table 4), we note that experiencing painful episodes within the last 12 months appeared to be the only factor that was significant for clinical depression (p-value 0.008). Other factors like age, gender, education level, address, clinic, SCA disease severity, use of hydroxyurea, blood transfusion, hospital admission, and organomegaly had no significant associations.

Table 4: Logistic regression factors associated with clinical depression

		Univariate analysis			**Multivariable analysis**		
		cOR	**95% CI**	**P-value**	**aOR**	**95% CI**	**P-value**
Age(years)	10-14	ref					
	15-19	1.46	0.79 - 2.71	0.23	1.29	0.56 - 2.97	0.54
Gender	Male	ref					
	Female	1.34	0.73 - 2.48	0.34	1.35	0.70 – 2.58	0.37
Education level	No formal education	ref					
	Primary	0.59	0.16 - 2.29	0.45	0.60	0.14 – 2.50	0.48
	Secondary	0.93	0.25 - 3.48	0.91	0.74	0.19 - 2.90	0.69
Health insurance	Non insured						
	Insured	1.41	0.73-2.75	0.31	1.47	0.72 - 3.02	0.29
SCA severity	Mild	ref					
	Moderate	0.58	0.07 - 4.44	0.56	0.35	0.04 - 3.39	0.36
Painful episodes	No	ref					
	Yes	2.56	1.25 - 5.23	0.01	2.49	1.17 - 5.29	0.01
Hospital admission	No	ref					
	Yes	1.30	0.69 - 2.42	0.42	1.14	0.53 – 2.43	0.73
Blood transfusion	No	ref					
	Yes	0.76	0.30 - 1.89	0.555	0.79	0.26 – 2.39	0.69
Use of hydroxyurea	No use						
	Use	1.80	0.80 - 4.02	0.15	1.65	0.70 - 3.87	0.25

cOR- crude odds ratio, aOR –adjusted odds ratio.

The logistic regression analysis investigated factors associated with clinical depression. In the univariate and multivariable analysis, various factors including age, gender, education level, health insurance, use of hydroxyurea, hospital admission and blood transfusion showed no significant association with depression, $p>0.05$. Those who experienced painful episodes in the previous 12 months had a significantly higher odds of depression compared to those who had no painful episodes, with a crude OR of 2.56 (95% CI: 1.25 - 5.23, $p = 0.01$). After adjusting for other variables in the multivariate analysis, those who experienced painful episodes still exhibited higher odds of depression (adjusted OR = 2.49, 95% CI: 1.17 - 5.29, $p = 0.01$).

4.2 Qualitative study respondent characteristics.

A total of 6 adolescents were recruited from those with moderate to severe depression and interviews were conducted until data saturation was achieved. Those with 10-14 years accounted for 33.3% while 15-19 years adolescents were 66.6% of the total population. There was an equal distribution of the male and female participants and majority 83.4% had moderate depression.

Table 5: Qualitative study respondent characteristics.

Adolescents interviewed	**n=6(%)**
Age in years	
10-14	2 (33.3)
15-19	4 (66.6)
Gender	
Male	3 (50)
Female	3 (50)
Depression status	
Moderate depression	5 (83.4)
Severe depression	1 (16.6)

Table 6: Summary of themes and subthemes studied.

THEMES	SUBTHEMES
Health related stigma	• Isolation • Loneliness
Acceptance	
Coping mechanisms	• Adaptive coping mechanism • Maladaptive coping
Social support system	• family social support • Community social support

4.3 Health related stigma

4.3.1 Isolation

Participants demonstrated a sense of isolation which often arose when individuals were excluded from tasks that others assumed they could not perform due to their illness. This exclusion was particularly prevalent in school settings and occasionally at home. Such experiences led to strong negative emotions and feelings of inadequacy from the constraints imposed by their illnesses including the inability to do participate in strenuous sports and chores, which in turn hinder their full participation.

> *"They engage in activities without informing me, presuming that perhaps I am incapable of participating." (Interviewee no 4)*

Interestingly, a minority denied experiencing isolation. This could be explained by how their community perceives their illness and so they neither feel different nor excluded. It may also be because sickle cell anemia is quite a common disease in this setting, with no obvious phenotypic features, so they don't feel like outcasts or highlighted in the community.

> *"Where I live, sickle cell is considered just like any other disease, so I don't feel isolated." (Interviewee no 3)*

4.3.2 Loneliness

Loneliness stemming from a lack of connection with others has been closely associated with symptoms of depression. In interviews with adolescents, those who responded expressed individual feelings of loneliness. Some described this experience as being accompanied by unhappiness, worthlessness, and invisibility, often exacerbated by societal judgment.

> "*Currently, I experience a sense of worthlessness and unhappiness, which contrasts with how I felt initially. The reason behind this emotional shift lies in the impact of my illness or problem…" (Interviewee no1)*

As a result of experiencing loneliness, significant impact is seen on their emotional well-being. Some reported resultant feelings of being different from others and sometimes absent from their environment, leading to a sense of disconnection and preferably staying in isolated environments

> *"I'm not comfortable being around people, I see myself so different from others... I'm just on my own; I don't have a permanent friend." (Interviewee no 5)*

4.4 Acceptance

The majority of adolescents interviewed haven't fully embraced the reality that they will live with sickle cell anemia throughout their lives. One interviewee expressed occasional discomfort due to the condition. She continually questions her existence, wondering why she was born with this illness, and imagines an alternate life without it.

> *"Yes, sometimes it bothers me a lot, for example, I keep asking myself questions like, "Why was I born this way? 'What would life be like if I were someone else?" (Interviewee no 4)*

Some adolescents struggle to understand what they are experiencing and have yet to fully come to terms with living with their illness for the duration of their lives. They explore various possibilities, contemplating whether a cure exists or when they might cease taking medications and achieve full recovery. Despite struggling to comprehend why recurrent painful episodes persist even after treatment, they demonstrate resilience in their efforts to accept this reality.

> *"I always fail to understand why, even after being discharged from the hospital you find that the pain returns" (Interviewee no1)*

Attitudes toward accepting an illness varied, and this could be influenced by factors such as the knowledge on the disease or severity of the disease. During interviews, two adolescents expressed acceptance of their condition and had adapted to living with sickle cell anemia. Interviewee No. 3 specifically acknowledged her awareness that she would experience periodic painful episodes, which she attributes to the inherent nature of her illness.

> *"I comprehend that any pain I experience due to sickle cell, whether in my legs, back, or head, is directly linked to the condition. So as a result, it doesn't significantly trouble me." (Interviewee no 3)*

4.5 Coping mechanisms

4.5.1 Maladaptive coping mechanism

Adolescents were interviewed to explore their experiences of depressive symptoms and various types of coping mechanisms they have in place when faced with these symptoms. Some adolescents had maladaptive coping strategies following their initial experiences of depressive symptoms. Some adolescents demonstrated anger outbursts and tears while others experienced sadness and low self-esteem. Approximately one-third had developed suicidal thoughts and even attempted self-harm to escape their emotional suffering.

> *"I wanted to overdose myself. I just find myself in the state of wanting to die then later it seems to disappear…"I took a knife and wanted to cut myself. Another day, I took a pen and wanted to pierce myself…. I take sharp things, the ones that are dangerous, and I try to kill myself"... (Interviewee no 5)*

4.5.2 Adaptive coping mechanisms

Majority of adolescents had developed some effective coping mechanisms which were helpful to them based on individual experiences and based on the level of depressive symptoms that they encountered. Some of the repeatedly mentioned coping mechanisms included chatting with friends, watching television or listening to music, staying alone in quiet environment, and meditation. Other coping mechanisms mentioned included ignoring offending statements, engaging in sports, and avoiding triggering environments.

> "*I always feel hurt; I would just go home, sit and meditate" (Interviewee no 1)*
>
> *"If I feel sad, there is a TV in our house; I will turn on the TV, I will watch. Or if I don't feel like watching TV, then I will go chat with my friends. If not, then I am a tailor; I will take clothes and start sewing." (Interviewee no 3)*

4.6 Social support system

4.6.1 Family social support

Experiences of adolescents with depressions and their social support systems were explored. Most of them had reliable social support networks when dealing with depressive symptoms. These networks included parents, friends, and teachers at school. Among the six adolescents interviewed, four mentioned their families, primarily parents, as their primary social support system. Despite overall care, parents served as a source of encouragement.

> *"I get a lot of comfort from my mother ...I can boldly say that my mother is my pillar of support." (Interviewee no 1)*

4.6.2 Community social support

Community social support came from friends and sometimes teachers in school. One adolescent mentioned a friend who was supportive because they both shared the experience of living with a chronic illness. Certain individuals expressed a lack of trust in their friends, fearing potential betrayal and the exposure of their secrets. Some friends even engaged in teasing and bullying behavior. Notably, one adolescent shared that when feeling distressed due to teasing, they confide in their parents or a teacher at school. Only two of the interviewed adolescents had no effective support system

> *"I can't stay with one person. You find that today you have this friend, and tomorrow she has another friend. I think she will be sharing your information with other people" (Interviewee no 5)*

5.0 DISCUSSION

This study determined the prevalence and associated factors of depression; and to explore lived experiences among adolescents with SCA and depression. The overall prevalence of depression was 53.7%, however most of them had mild symptoms and only 15% were found to have clinical depression (moderate and severe depression)

This was similar to studies done in various continents which also demonstrated higher prevalence of depression among adolescents with SCA. Results revealed that 46% of adolescents with SCA had depression in America (2011), 48% of adolescents attending sickle cell clinics also had depression in Saudi Arabia (2018) and in Congo (2015) 86% of adolescents were found to have depression. (16,21,22) Variations of prevalence estimates across different studies and between different countries could be attributed to different diagnostic tools (PHQ-9, BDI, and DSM-V), different adopted classifications, and study methods used.

Mild depression was more common compared to moderate and severe depression this could mean that most adolescents suffer mild symptoms of depression which resolve however few progress to moderate and severe symptoms. This was similarly observed and reported by Aljumah et al (2016) in Saudi Arabia were the prevalence of mild, moderate and severe depression were 23.2%, 20.6%, and 6.8% respectfully; and another study by Sahril et al in Malaysia (2019) where prevalence of mild, moderate, and severe depression was found to be 16.6%, 12.8%, and 3.8% respectively.(19) However, Lukoo et al (2015) reported mild, moderate and severe depression with prevalence of 14.3%, 77.1%, 8.6% respectively.(16,23) Depression severity has implications when it comes to choice of treatment and prognosis.

Socio-demographic factors like age, sex, level of education and health insurance, had no significant association with depression in this study. Contrary, studies by Alhamoud et al (2018) in Saudi Arabia and Mallicka et al (2021) in India reported that gender, low level of education and low socio-economic status were significantly associated with depression. (17),(20) Furthermore Asnani et al (2010), revealed that higher level of education was associated with higher odds of depression. The difference observed could be attributed to different cultural backgrounds and environmental settings of participants.(21)

Owing to SCA disease severity, participants in this study had mild to moderate disease severity, this may be attributed to the fact that participants were outpatients attending clinic and had no severe symptoms requiring admission. Mild to moderate disease severity had no significant association with depression. These findings were comparatively similar to a study done in Nigeria where disease severity in children and adolescents with SCA had no significant association with depression. A similar tool for assessing disease severity was used in this study.(13)

Painful episodes in the previous 12 month had 2.4 higher odds of depression with CI (1.17-5.29). Similarly, a study by Asnani et al (2010), in Jamaica, showed that participants with frequent painful crises had 2.5 times higher odds of developing depression with a p-value of 0.003. The study also reported that patient-related factors like leg ulcers, frequent visits to the hospital, were significantly associated with higher odds of depression. (21)

From this study, the experiences of adolescents were explored using a qualitative approach. The majority of adolescents with SCA reported health related stigma. They reported to feel isolated and lonely as they were excluded in tasks due to disease limitations. Employing strategies to alleviate loneliness and social isolation could improve the mental health of adolescents with SCA who have depression.

In our study, loneliness and isolation were the most common depressive symptoms among adolescents with SCA. This is similar to a study done in the Denmark by Christiansen et al in 2021, which demonstrated that feelings of loneliness and social isolation were strongly associated with mental illness and depressive symptoms among adolescents and young adults.(22)

Results also reveal that majority of adolescents have not fully accepted the fact that they may have to live with SCA for the rest of their lives. This was similar to findings from Christiansen where adolescents were struggling to understand the pain they go through due to their illness.(22) Attitudes toward accepting an illness could be influenced by factors such as the knowledge on the disease or severity of the disease. Acceptance of living with an illness has a protective role in improving mental health outcomes for people living with a chronic illness like SCA.(25)

Furthermore, this study revealed that adolescents try to cope with challenges of living with the disease through meditation and distractions such as watching television and music and chatting with friends. Some adolescents were found to develop maladaptive coping strategies like trying to attempt suicide, stop taking their medications and self-harm.

Comparably, a descriptive qualitative study done in Jamaica by Forrester also reported that prayer and spiritual activities were among the major coping mechanism in dealing with the illness and other diversion activities like watching TV, surfing the net, and talking to others were also found to be helpful.(23) Good coping behaviors can reduce the chances of developing depression and anxiety disorders in adolescents.

Adolescents with SCA who have developed depressive symptoms experience various challenges in their day-to-day lives. Challenges arising from the society included bullying and name calling among others halting them from developing sincere and comforting relationships. Social support provided by individuals within a close social network significantly improves the overall sense of well-being and aids in coping with chronic illnesses. Family and community support for adolescents were from parents, friends and teachers. However, some reported mistrust from friends, bullying and name-calling.

Similarly Forrester et al, showed experiences among adolescents with SCA, reported that strong family, school, and peer support made them feel accepted in their community despite their illness. (23) Having a good social support system could be beneficial to these adolescents who are not only battling this lifelong illness but also going through puberty and hormonal changes that could make them vulnerable to feelings of hopelessness and depression.

6.0 STRENGTHS, STUDY LIMITATIONS, CONCLUSION AND RECOMMENDATIONS

6.1 Strengths

Conducting a mixed method study design gave us better understanding of the burden of depression and life experiences among adolescents with SCA in our setting.

The sample was representative; including adolescents attending, tertiary and secondary level health facilities.

6.2 Study Limitations and mitigation

Strategic response bias from interviewees, where respondents could give answers to impress the interviewer. This was mitigated by avoiding leading questions during interviews and encouraging honest, complete responses.

Recall bias from interviewees, where participants had to remember some symptoms in the previous 12 months or 2 weeks and the frequency of their occurrence. They could easily miscalculate (under or over estimate) reported events. This was mitigated by shortening recall duration periods.

6.3 Conclusion

Depression is common among adolescents with SCA in our setting with prevalence of 54%; where by mild, moderate and severe symptoms were found to be 38.7 %, 14.7% and 0.3% respectively. Painful episodes experienced by these adolescents were significantly associated with depression.

Our study has uncovered emotional complexities faced by depressed adolescents living with SCA in Tanzania. Loneliness and isolation were commonly experienced. Social support, coping mechanisms, and acceptance played pivotal roles in their well-being. Understanding these experiences can inform targeted interventions and support systems for this vulnerable population.

6.3 Recommendations

This study has highlighted the need for screening adolescents with SCA for depression. Hence, we recommend that mental health assessment and screening for depression should be performed by all clinicians attending adolescents with SCA as part of comprehensive sickle cell care.

Integration of expert mental health services in sickle cell clinics with the availability of a psychologist or counselor. The Tanzania sickle cell guideline mentions that proper education and psychosocial counseling should be offered and a clinical psychologist should be involved when there are concerns about psychological or cognitive well-being and if they face particular difficulties in coping with illness. Those patients who display signs of self-harm or suicidal attempts should be immediately referred to a psychiatrist for care.

Regular screening, prevention and adequate management of chronic pain or frequent painful crisis is very crucial in patients with SCA.

Development of targeted interventions focusing on good coping strategies, acceptance of living with SCA and strengthening social support systems for this vulnerable population.

REFFERENCES

1. WHO Fact Sheet.pdf [Internet]. [cited 2022 Dec 30]. Available from: https://www.who.int/news-room/fact-sheets/detail/adolescent-mental-health

2. Medicaidmentalhealth.org. DSM-5 Criteria : Major Depressive Disorder Treatment of Major Depressive Disorder. DSM-5 Criteria Major Depress Disord. 2018;24–32.

3. Rathod S, Pinninti N, Irfan M, Gorczynski P, Rathod P, Gega L, et al. Mental Health Service Provision in Low- and Middle-Income Countries. Heal Serv Insights. 2017;10.

4. Mangla A, Ehsan M, Agarwal N, et al. Sickle Cell Anemia. [Updated 2022 May 14]. In: StatPearls [Internet]. Treasure Island (FL): StatPearls Publishing; 2022 Jan-. Available from: https://www.ncbi.nlm.nih.gov/books/NBK482164/. 2022;482164.

5. Makani J, Tluway F, Makubi A, Soka D, Nkya S, Sangeda R, et al. A ten year review of the sickle cell program in Muhimbili National Hospital, Tanzania. BMC Hematol. 2018;18(1):1–13.

6. Benton TD, Boyd R, Ifeagwu J, Feldtmose E, Smith-Whitley K. Psychiatric diagnosis in adolescents with sickle cell disease: A preliminary report. Curr Psychiatry Rep. 2011;13(2):111–5.

7. Moody KL, Mercer K, Glass M. An Integrative Review of the Prevalence of Depression among Pediatric Patients with Sickle Cell Disease. Soc Work Public Health [Internet]. 2019;34(4):343–52. Available from: https://doi.org/10.1080/19371918.2019.1606754

8. Katon W, Lin EHB, Kroenke K. The association of depression and anxiety with medical symptom burden in patients with chronic medical illness. Gen Hosp Psychiatry. 2007;29(2):147–55.

9. https://www.statista.com/statistics/1266428/adolescent-population-in-tanzania/ , Accessed on 03 June, 2023. 06:47am. 2023;1266428.

10. Mullen S. Major depressive disorder in children and adolescents. Ment Heal Clin. 2018;8(6):275–83.

11. Rashighi M, Harris JE. 乳鼠心肌提取 HHS Public Access. Physiol Behav. 2017;176(3):139–48.

12. Lukoo RN, Ngiyulu RM, Mananga GL, Gini-Ehungu JL, Ekulu PM, Tshibassu PM, et al. Depression in children suffering from sickle cell anemia. J Pediatr Hematol Oncol. 2015;37(1):20–4.

13. Ezenwosu O, Chukwu B, Ezenwosu I, Uwaezuoke N, Eke C, Udorah M, et al. Clinical depression in children and adolescents with sickle cell anaemia: influencing factors in a resource-limited setting. BMC Pediatr [Internet]. 2021;21(1):1–8. Available from: https://doi.org/10.1186/s12887-021-03015-1

14. Oudin Doglioni D, Chabasseur V, Barbot F, Galactéros F, Gay MC. Depression in adults with sickle cell disease: a systematic review of the methodological issues in assessing prevalence of depression. BMC Psychol [Internet]. 2021;9(1):1–14. Available from: https://doi.org/10.1186/s40359-021-00543-4

15. L K. An Integrative Review of Sickle Cell and Depression. Int Arch Nurs Heal Care. 2015;1(1):1–7.

16. Jerrell JM, Tripathi A, McIntyre RS. Prevalence and treatment of depression in children and adolescents with sickle cell disease: A retrospective cohort study. Prim Care Companion J Clin Psychiatry. 2011;13(2):21977359.

17. Alhomoud A, Gosadi IM, Wahbi HA. Depression among sickle cell anemia patients in the eastern province of Saudi Arabia. Saudi J Med Med Sci. 2018;(6):8–12.

18. Aljumah Z, Ibrahim Ali S, Al-Saleem M, Almogarab K, Alghadeer F, AlEssa F. Depression in Sickle-Cell Disease patients in the Eastern Province. Int J Healthc Sci [Internet]. 2015;3(February 2016):300–2. Available from: www.researchpublish.com

19. Sahril NB, Yaacob NM, Ahmad NA, Abdullah S, Mahadir Naidu B, Aris T. Depression Severity and its Associated Factors among School-Going Adolescents in Malaysia. J Depress Anxiety. 2019;08(04):1–8.

20. Mallicka SC Das, Sahoe P, Priyadarshini P, Manasa R. Prevalence of Severe Depression among Adolescents in Rural Area of Odisha, India. Indian J Community Med. 2021;46(3):438–441.

21. Asnani MR, Fraser R, Lewis NA, Reid ME. Depression and loneliness in Jamaicans with sickle cell disease. BMC Psychiatry. 2010;10(1997).

22. Christiansen J, Qualter P, Friis K, Pedersen SS, Lund R, Andersen CM, et al. Associations of loneliness and social isolation with physical and mental health among adolescents and young adults. Perspect Public Health. 2021;141(4):226–36.

23. Forrester AB, Barton-Gooden A, Pitter C, Lindo JLM. The lived experiences of adolescents with sickle cell disease in Kingston, Jamaica. Int J Qual Stud Health Well-being. 2015;10:1–9.

24. Gilbody S, Richards D, Brealey S, Hewitt C. Screening for depression in medical settings with the Patient Health Questionnaire (PHQ): A diagnostic meta-analysis. J Gen Intern Med. 2007;22(11):1596–602.

25. Casier A, Goubert L, Gebhardt WA, Baets F De, Aken S Van, Matthys D, et al. Acceptance, well-being and goals in adolescents with chronic illness: a daily process analysis. Psychol Health [Internet]. 2013 Nov;28(11):1337–51. Available from: http://www.tandfonline.com/doi/abs/10.1080/08870446.2013.809083

APPENDICES

Appendix 1: Questionnaire

MUHIMBILI UNIVERSITY OF HEALTH AND ALLIED SCIENCES

SCHOOL OF MEDICINE

QUESTIONNAIRE FOR STUDY "**DEPRESSION AMONG ADOLESCENTS WITH SICKLE CELL ANEMIA IN DAR-ES-SALAAM, TANZANIA: PREVALENCE, ASSOCIATED FACTORS, AND LIVED EXPERIENCES.**

.

PART 1;

1. ID number ....……
2. Age ……
3. Sex/gender 1. ME 2 KE
4. Sickle cell clinic 1. MNH 2. Temeke 3. Mwananyamala 4. Amana
5. Address 1.Dar es salaam 2. Upcountry
6. Education level 1. None 2. Primary 3. Secondary
7. Child health insurance 1. Present 2. absent

PART 2: SICKLE CELL ANEMIA SEVERITY

Items in the previous 12 months	0 none	1 once	2 Twice or thrice	3 More than three times
No. of painful episodes				
No. of hospital admissions				
No. of blood transfusions				

Items in the present state	0 <5 CM	1 5-10 CM	2 >10 CM
Splenic enlargement			
Liver enlargement			
Items in lifetime complications	0 none	1 present	
Stroke			
Osteomyelitis			
Arthritis			
Chronic leg ulcers			
Sickle cell nephropathy			
Acute chest syndrome			
Priapism			
Gall stones			
Use of hydroxyurea	0 none	1 present	

PART 3: PHQ-9 TOOL

Over the last 2 weeks, how often have you been bothered by any of the following problems? *(Use "✓" to indicate your answer)*	Not at all	Several days	More than half the days	Nearly every day
1. Little interest or pleasure in doing things	0	1	2	3
2. Feeling down, depressed, or hopeless	0	1	2	3
3. Trouble falling or staying asleep, or sleeping too much	0	1	2	3
4. Feeling tired or having little energy	0	1	2	3
5. Poor appetite or overeating	0	1	2	3
6. Feeling bad about yourself — or that you are a failure or have let yourself or your family down	0	1	2	3
7. Trouble concentrating on things, such as reading the newspaper or watching television	0	1	2	3
8. Moving or speaking so slowly that other people could have noticed? Or the opposite — being so fidgety or restless that you have been moving around a lot more than usual	0	1	2	3
9. Thoughts that you would be better off dead or of hurting yourself in some way	0	1	2	3

____ + _____ + _____ + _____

=Total Score: _____

If you checked off any problems, how difficult have these problems made it for you to do your work, take care of things at home, or get along with other people?

Not difficult at all …	Somewhat difficult …	Very difficult …	Extremely difficult …

Appendix 2: Dodoso

MUHIMBILI UNIVERSITY OF HEALTH AND ALLIED SCIENCES

CHUO CHA UTATIBU

DODOSO LA UTAFITI "SONONA KWA VIJANA RIKA WENYE SIKOSELI WANAOHUDHURIA KLINIKI ZA SIKOSELI, DAR ES SALAAM; UPANA, VISABABISHI NA UZOEFU WA KUISHI NA UGONJWA**."**

SEHEMU YA 1;

1. ID namba ……
2. Umri ……
3. Jinsia 1. ME 2 KE
4. Kituo cha kliniki 1. MNH 2. Temeke 3. Mwananyamala 4. Amana
5. Mahali anapoishi 1. Dar es salaam 2. Mikoa mingine
6. Kiwango cha elimu 1. Hajasoma 2. Praimari 3. sekondari
7. Bima ya afya 1. Ndio 2. Hapana

SEHEMU YA 2; KIPIMO CHA KIWANGO CHA SIKOSELI

VILIVYOTOKEA NDANI YA MIEZI 12 ILIYOPITA	0 Hakuna	1 Mara moja	2 Mara mbili au tatu	3 Zaidi ya mara tatu
Maumivu makali				
Kulazwa hospitali				
Kuongezewa damu				

DALILI ZA SASA	0 <5 CM	1 5-10 CM	2 >10 CM
Kuvimba bandama			
Kuvimba ini			
MADHARA YATOKANAYO NA SIKOSELI	0 hakuna	1 yapo	
Kiharusi (tatizo la mishipa ya fahamu)			
Maambukizi ya bacteria kwenye mifupa			
Ugonjwa wa baridi yabisi (jointi kuvimba na kuuma)			
Vidonda vya muda mrefu kwenye miguu			
Tatizo la figo			
Homa kali ya mapafu			
Uume kusimama bila hiari			
Mawe ya nyongo			
Matumizi ya hydroxyurea	0 Hapana		1 ndio

SEHEMU YA 3; KIPIMO CHA KIWANGO CHA SONONA

Katika wiki mbili zilizopita, ni mara ngapi umesumbuliwa na matatizo tajwa yafuatayo	Hakuna kabisa	Siku kadhaa	Zaidi ya nusu ya siku zote	Karibu kila siku
1. Kuwa na mwelekeo mdogo na kukosa raha	1	2	3	4
2. Kujisikia huwezi kuchangamka, kuwa na huzuni au kukosa tumaini	1	2	3	4

3. Tatizo la kupata usingizi, au kuendelea kulala baada ya kuupata au kulala kupita Kiasi	1	2	3	4
4. Kujisikia kuchoka na kuwa na nguvu kidogo	1	2	3	4
5. Kupungua hamu ya kula chakula au kula kupita kiasi	1	2	3	4
6. Kujisikia vibaya au kujisikia kama umeshindwa au umejishusha au kuishushia(thamani) familia yako	1	2	3	4
7. Tatizo la kutuliza akili kwenye vitu kama kusoma magazeti au kuangalia luninga	1	2	3	4
8. Kusogea au kuzungumza polepole sana hata ingeweza kuonekana kwa watu wengine ama kuwa na mashaka/ wasiwasi au kufadhaika Kiasi hata ukitembea, unatembea kuliko kawaida	1	2	3	4
9. Fikira kwamba heri kufa au kuwaza kujiumiza	1	2	3	4
JUMUISHO LA KILA SAFU ZA JEDWALI				
JUMUISHO LA JEDWALI (PHQ-9)				
Kama kumekuwa na tatizo lolote hapo juu, je ni kwa kiasi gani hili tatizo limeacha usiweze kufanya kazi, kushughulikia maswala ya nyumbani au katika mahusiano yako na watu wengine?	1	Sio vigumu hata kidogo		
	2	Vigumu kidogo		
	3	Vigumu sana		
	4	Vigumu kupitiliza		

Appendix 3: **- Interview guide**

MUHIMBILI UNIVERSITY OF HEALTH AND ALLIED SCIENCES

SCHOOL OF MEDICINE

INTERVIEW QUIDE FOR STUDY: **DEPRESSION AMONG ADOLESCENTS WITH SICKLE CELL ANEMIA IN DAR-ES-SALAAM, TANZANIA: PREVALENCE, ASSOCIATED FACTORS, AND LIVED EXPERIENCES.**

.

Interview guide.

1. Are you having feeling of loneliness and/or isolation?
2. Acceptance
    a) Are you struggling to understand suffering/ pain due to SCA?
    b) Have you accepted living with SCA?
3. What coping mechanism do you use to deal with depressive symptoms?
4. Social support
    a) Does social support from parents/caregivers help reduce depressive symptoms?
    b) Do you have any social support system e.g. caregivers, parents, peers?
    c) What are the social challenges you face.

Appendix 4: Muongozo wa mahojiano

MUHIMBILI UNIVERSITY OF HEALTH AND ALLIED SCIENCES

CHUO CHA UTATIBU

UTAFITI: “SONONA KWA VIJANA RIKA WENYE SIKOSELI WANAOHUDHURIA KLINIKI ZA SIKOSELI, DAR ES SALAAM; UPANA, VISABABISHI NA UZOEFU WA KUISHI NA UGONJWA”

Muongozo wa mahojiano

1. Je, unajisikia hali ya upweke na kutengwa?
2. Kujikubali
    a) Je, unapata shida ya kuelewa mateso/maumivu kutokana na ugonjwa wa sikoseli?
    b) Je umekubali hali ya kuishi na udgonjwa wa siko seli?
3. Je, ni namna ya unakabiliana na dalili za huzuni kufuatia mateso/maumivu kutokana na ugonjwa wa sikoseli?
4. Msaada wa kijamii
    a) Je, msaada wa kijamii kutoka kwa wazazi na walezi husaidia kupunguza dalili za huzuni?
    b) Je una msaada wowote wa kijamii kwa sasa?
    c) Unakabiliana na changamoto katika jamii?

Appendix 5: Consent form

MUHIMBILI UNIVERSITY OF HEALTH AND ALLIED SCIENCES

SCHOOL OF MEDICINE

CONSENT FORM FOR STUDY "**DEPRESSION AMONG ADOLESCENTS WITH SICKLE CELL ANEMIA IN DAR-ES-SALAAM, TANZANIA: PREVALENCE, ASSOCIATED FACTORS, AND LIVED EXPERIENCES.**

.

INTRODUCTION. I'm Linda Paul Athman, a medical doctor pursuing a degree in Master of Pediatrics and child health at Muhimbili University of Health and Allied Science. I am conducting research to assess magnitude of depression among adolescents with Sickle cell anemia and lived experiences of adolescents with depression attending sickle cell clinics in Dar-es-salaam, Tanzania. This study will provide understanding on the magnitude and severity of depression on adolescents with SCA and also provide general emphasis on the importance of screening for depression in clinics using available and validated tools. Confidentiality will be maintained, and only study numbers (rather than names) will be used in questionnaires in order to safeguard your privacy. I will appreciate if you agree to participate in this research because your response and views are very important.

Purpose of the Study This study aims at the magnitude of Depression among adolescents with SCA and lived experience among those with depression. If you accept to take part in the study, you will be asked some questions on demographic information, severity of SCA and also symptoms of depression. The information which you will provide will be confidentially handled and protected in such a way that nobody will be able to access your information, but only the general information which will be used purposely for health-related issues.

How to participate: Participants who will be ready to participate will sign an assent and consent form to approve his/her willingness and the parents' willingness if available.

Possible benefits: Your involvement in this study will be helpful in making evaluation and assisting in planning for health care improvement hence reduction of the burden of Depression on adolescents in Tanzania.

Possible Risks: There are no physical risks or discomforts expected to happen to you during and even after participation of this study because the study only involves collecting information only.

Financial benefit: There is no any financial benefit that you will receive or pay by participating in the study.

Confidentiality: Your information will be kept confidentially. Questionnaires will be marked using special number without involving registration number/names. Nobody will be able to access the information you provide from questionnaire. Your information will remain confidential during and after study work.

Voluntary Participation & Rights to Withdraw: Your participation is voluntary and you have the right to withdraw your information during the study. Your decision will be respected, and no any right health services that will be denied of you by denying to participate.

Whom to Contact: In case of any question or query concerning this study, please contact the principal investigator, Linda Paul Athman from Department of Pediatrics and child Health, MUHAS, P.O.BOX 65001, Dar es salaam, mobile number 0769644226. If you have any question about your rights as a participant, you may contact Dr. Bruno Sunguya, Chairperson of the research and Publications Committee, MUHAS. P.O. Box 65001, Dar es Salaam-Tanzania, Tel +25521503026.

Participation agreement I…….... have read the contents of this form and understand and my questions have been adequately answered. I agree to participate in this study.

Signature of participant…… Date…….
Signature of researcher …… Date……

Appendix 6. Fomu ya ridhaa

CHUO KIKUU CHA AFYA NA SAYANSI SHIRIKISHI MUHIMBILI

SHULE YA UTABIBU

FOMU YA RIDHAA KUSHIRIKI KATIKA UTAFITI WA "SONONA KWA VIJANA RIKA WENYE SIKOSELI WANAOHUDHURIA KLINIKI ZA SIKOSELI, DAR ES SALAAM; UPANA, VISABABISHI NA UZOEFU WA KUISHI NA UGONJWA."

Utambulisho: Habari, mimi ni daktari Linda Paul Athman, mwanafunzi wa shahada ya uzamili wa Udaktari wa watoto katika Chuo Kikuu cha Afya na Sayansi ya Muhimbili (MUHAS). Kwa niaba ya Chuo Kikuu cha Afya na Sayansi za Muhimbili (MUHAS), ninafanya utafiti juu ya ukubwa wa ugonjwa la sonona miongoni mwa vijana rika wenye ugonjwa wa sikoseli na uzoefu wa kuishi na ugonjwa wa sonona kati ya vijana rika wanaohudhuria kliniki za sikoseli, Dar es Salaam.

Kusudi la Tafiti: Tafiti hii inalengo la kugundua ukubwa wa tatizo la sonona kwa vijana rika wenye sikoseli na kuelewa uzoefu wao wa kuishi na tatizo hili la. Ikiwa utakubali kua sehemu ya tafiti hii, utaulizwa maswali katika dodoso juu ya taarifa zako binafsi, na maswali kuhusu athari na matatizo yasababishwayo na ugonjwa wa sikoseli na dalili za ugonjwa wa sonona. Taarifa utakazotoa zitatunzwa kwa usiri na zitalindwa na hamna mtu atakayeweza kupata taarifa zako.

Jinsi ya kushiriki: Mhusika atakaekua tayari kushiriki katika tafiti hii atasaini fomu hii ya makubaliano kama ushahidi wa ukubali wake.

Faida: Kushiriki kwako katika tafiti hii itasaidia kufanya maamuzi na kusaidia kupanga namna ya kuongeza uwazi juu ya ugonjwa wa sonona na kukabiliana ipasavyo kuwasaidia vijana rika wenye sikoseli kuondokana na tatizo hili nchini Tanzania

Athari: Hakuna athari yoyote utakayopata kwa kushiriki katika tafiti hii. Unahaki ya kukubali au kukataa kushiriki katika tafiti hii baada ya kuwa umesoma na kuelewa fomu hii. Uchaguzi wa kukataa hautoadhili kwa namna yoyote ile haki yako ya upatikanaji ya huduma za afya. Maamuzi yako yataheshimiwa na kuzingatiwa.

Faida kifedha: Hakuna faida yoyote utakayoipata kifedha kwa kukubali kushiriki katika tafiti hii.

Usiri: Taarifa zote zitakazokusanywa katika utafiti huu zitatunzwa kwa usiri mkubwa. Taarifa hizi hazitawekwa wazi, namba maalumu zitatumika kuhifadhi taarifa hizo ambazo zitawakilisha jina lako. Mtu yeyote hatoweza kupata taarifa zako binafsi utakazotoa katika utafiti huu. Taarifa zote utakazotoa zitahifadhiwa kwa siri.

Utayari Wakushiriki au Kujitoa: Kushiriki kwako ni hiyari na unaweza kujitoa kwenye Usajili wakati wowote. Unaweza kuamua kushiriki katika tafiti hii baada ya kusoma na kuelewa fomu hii. Maamuzi yako yataheshimiwa na haitakunyima haki yako yoyote kwa kujitoa kwako.

Mawasiliano: Ili kuhojiwa au swali lolote kuhusu utafiti huu, tafadhali wasiliana na mtafiti mkuu, Linda Paul Athman, kutoka katika idara ya Watoto, MUHAS, PO BOX 65001. Dar es salaam, nambari ya simu 0769644226. Ikiwa una swali lolote kuhusu haki yako kama mshiriki unaweza kuwasiliana na Dk Bruno Sunguya, Mwenyekiti wa Kamati ya Utafiti na Machapisho, MUHAS. P.O. Box 65001, Dar es Salaam-Tanzania, Simu + 2552150302-6.

Ridhaa kushiriki katika utafiti: Mimi …… Nimeelezwa/ nimesoma yaliyomo katika fomu hii na nimeelewa maana yake. Nakubali kushiriki katika utafiti huu.

Saini ya mshiriki……..…… Tarehe…….....

Saini ya mtafiti …….....
Tarehe……

Appendix 7: Assent form

MUHIMBILI UNIVERSITY OF HEALTH AND ALLIED SCIENCES

SCHOOL OF MEDICINE

ASSENT FORM FOR STUDY: DEPRESSION AMONG ADOLESCENTS WITH SICKLE CELL ANEMIA IN DAR-ES-SALAAM, TANZANIA: PREVALENCE, ASSOCIATED FACTORS, AND LIVED EXPERIENCES.

INTRODUCTION: I'm Linda Paul Athman, a medical doctor pursuing a degree in Master of Pediatrics and child health at Muhimbili University of Health and Allied Science. I am conducting research to assess magnitude of depression among adolescents with Sickle cell anemia and lived experiences of adolescents with depression attending sickle cell clinics in Dar-es-salaam, Tanzania.

Research is a way to learn about people and if you decide you want to be a part of this study, you and/or your caretaker will be asked a few questions. You may be asked some questions on demographic information, severity of SCA and also symptoms of depression. The information which you will provide will be confidentially handled and protected in such a way that nobody will be able to access your information, but only the general information which will be used purposely for health-related issues.

If you don't want to be in this research study, you will continue to receive the treatment and care you need. It is not a compulsion to be in this study you wish to disengage at any point of time, you may do so. If you enroll as a participant, please sign your name

I, ……want to be in this research study

…… …….

Sign your name here Date

Appendix 8: - Fomu ya ridhaa kwa mtoto

CHUO KIKUU CHA AFYA NA SAYANSI SHIRIKISHI MUHIMBILI

SHULE YA UTABIBU

FOMU YA RIDHAA KUSHIRIKI KATIKA UTAFITI WA "SONONA KWA VIJANA RIKA WENYE SIKOSELI WANAOHUDHURIA KLINIKI ZA SIKOSELI, DAR ES SALAAM; UPANA, VISABABISHI NA UZOEFU WA KUISHI NA UGONJWA**."**

Utambulisho Habari, Jina langu ni daktari Linda Paul Athman, mwanafunzi wa shahada ya uzamili ya Udaktari wa watoto katika Chuo Kikuu cha Afya na Sayansi ya Muhimbili. Tunafanya utafiti juu ya ukubwa wa ugonjwa la sonona miongoni mwa vijana rika wenye ugonjwa wa sikoseli na uzoefu wa kuishi na ugonjwa wa sonona kati ya vijana rika wanaohudhuria kliniki za sikoseli, Dar es Salaam.

Utafiti ni njia ya kujifunza juu ya watu na ikiwa unaamua unatakaa kuwa sehemu ya utafiti huuna/au mlezi wako ataulizwa maswali machache

na maswali kuhusu athari na matatizo yasababishwayo na ugonjwa wa sikoseli na dalili za ugonjwa wa sonona. Tutaangalia pia afya yako ya ujumla na kukushauri kuhusu matibabu yako Taarifa utakazotoa zitatunzwa kwa usiri na yatalindwa na hamna mtu atakayeweza kupata taarifa zako.

Kushiriki kwako ni kwa hiari na sio lazima kama hutaki. Ikiwa utaamua kuatokuendelea kushirii baada ya kuanza, ni sawa pia.

Ikiwa utaamua kuwa katika utafiti huu tafadhali Saini jina lako.

Mimi,…….nataka kuwa katika utafiti huu

…… ……

Andika Saini yako hapa Tarehe

Appendix 9: - Ethical Clearance

UNITED REPUBLIC OF TANZANIA

MINISTRY OF EDUCATION, SCIENCE AND TECHNOLOGY

MUHIMBILI UNIVERSITY OF HEALTH AND ALLIED SCIENCES

OFFICE OF THE DIRECTOR – RESEARCH, PUBLICATIONS AND INNOVATION

Ref. No.DA.282/298/01.C/1770 Date: 30/06/2023

MUHAS-REC-06-2023-1770
LINDA PAUL ATHMAN
SCHOOL OF MEDICINE
MUHAS

RE: APPROVAL FOR ETHICAL CLEARANCE FOR A STUDY TITLED; MAGNITUDE, ASSOCIATED FACTORS AND LIVED EXPERIENCES OF DEPRESSION AMONG ADOLESCENTS WITH SICKLE CELL ANEMIA ATTENDING SICKLE CELL CLINICS IN DAR-ES-SALAAM, TANZANIA.

Reference is made to the above heading,
I am pleased to inform you that the Chairperson has on behalf of the University Senate, approved ethical clearance of the above-mentioned study, on recommendations of the Senate Research and Publications Committee meeting accordance with MUHAS research policy and Tanzania regulations governing human and animal subjects research.

APPROVAL DATE: 30/06/2023
EXPIRATION DATE OF APPROVAL: 30/06/2024

STUDY DESCRIPTION:
Purpose:
The purpose of this mixed method study is to determine the magnitude, associated factors and lived experiences of depression among adolescents aged 11 to 17 years with Sickle Cell Anemia attending sickle cell clinics in Dar es salaam from January to June 2023

The approved protocol and procedures for this study is attached and stamped with this letter, and can be found in the link provided:
https://irb.muhas.ac.tz/storage/Certificates/Certificate%20-%2014623.pdf and in the MUHAS archives.

The PI is required to:

1. Submit bi-annual progress reports and final report upon completion of the study.
2. Report to the IRB any unanticipated problem involving risks to subjects or others including adverse events where applicable.
3. Apply for renewal of approval of ethical clearance one (1) month prior its expiration if the study is not completed at the end of this ethical approval. You may not continue with any research activity beyond the expiration date without the approval of the IRB. Failure to receive approval for continuation before the expiration date will result in automatic termination of the approval for this study on the expiration date.
4. Obtain IRB amendment (s) approval for any changes to any aspect of this study before they can be implemented.
5. Data security is ultimately the responsibility of the investigator.
6. Apply for and obtain data transfer agreement (DTA) from NIMR if data will be transferred to a foreign country.
7. Apply for and obtain material transfer agreement (MTA) from NIMR, if research materials (samples) will be shipped to a foreign country.
8. Any researcher, who contravenes or fail to comply with these conditions, shall be guilty of an offence and shall be liable on conviction to a fine as per NIMR Act No. 23 of 1979, PART III section 10 (2)
9. The PI is required to ensure that the findings of the study are disseminated to relevant stake holders.
10. PI is required to be versed with necessary laws and regulatory policies that govern research in Tanzania. Other guidance is available on our website https://ore.muhas.ac.tz/.

Dr. Nahya Salim Masoud,
Chairperson, MUHAS Research and Ethics Committee

Muhimbili University of Health and Allied Sciences
DIRECTOR
Research, Publications & Innovations
Box 65001

Appendix 10: - Permission Letters for data collection

THE UNITED REPUBLIC OF TANZANIA

MINISTRY OF HEALTH

MUHIMBILI NATIONAL HOSPITAL

In reply please quote;

Ref. No.: MNH/CRTCU/Perm/2023/445 **Date: 17th July, 2023**

Head of Department,

- Paediatrics and Child Health Noted, Appolo. 10.08.2023
- Internal Medicine

Muhimbili National Hospital

RE: PERMISSION TO COLLECT DATA AT MNH.

Name of Student	**Linda Paul Athman**
Title	**"Associated Factors and Lived Experiences of Depression Among Adolescents with Sickle Cell Anemia Attending Sickle Cell Clinics in Dar es Salam Tanzania".**
Institution	Muhimbili University of Health and Allied Sciences
Supervisors	Dr. Fatima Mussa (MUHAS)
Co - Supervisor	Dr. Honesa Kipasika (MNH)
Period	17th July, 2023 to 30th January, 2024

Approval has been granted to the above mentioned student to collect data at MNH. ***A final study report should be lodged with Clinical Research, Training and Consultancy Unit.*** *Dissemination of study findings to MNH stakeholders shall be overseen by* **Dr. Honesta Kipasika** *(MNH) Co – supervisor.*

Kindly ensure that the student abide to the ethical principles and other conditions of the research approval.

Sincerely,

P.O. Box 65000 DAR-ES-SALAAM MUHIMBILI NATIONAL HOSPITAL

Dr. Jessie Mbwambo

Head of Clinical Research, Training and Consultancy Unit

c.c DMS

c.c Dr. Honesta Kipasika

c.c **Linda Paul Athman**

UNITED REPUBLIC OF TANZANIA
MINISTRY OF HEALTH

DAR ES SALAAM REGION
ADDRESS: "HEALTH"
PHONE: 022 – 2861903
IN REPLY PLEASE QUOTE
REF. NO. MOHCDGEC/ARRH/R.1/VOL XVI/34

AMANA REGIONAL REFERRAL HOSPITAL
P.O. BOX. 25411
DAR ES SALAAM.

19/10/2023

Principle Investigator,
Department of Paediatrics and Child Health,
MUHAS,
P. O. Box 65001,
DAR ES SALAAM.

Re: PERMISSION FOR DATA COLLECTION

Refer to your letter dated 06th July, 2023 which requested us to allow Dr. Linda Paul Athman to conduct research and collect data in our institution

We are here to acknowledge your request with the following conditions, that she must submit the results of her research after completion of analysis in order the hospital to make use of data's to solve hospital problems.

Regards.

Dr. Rose Ntambuto
For: MEDICAL OFFICER INCHARGE
AMANA REGIONAL REFERRAL HOSPITAL

JAMHURI YA MUUNGANO WA TANZANIA
WIZARA YA AFYA.
HOSPITAL YA RUFAA YA MKOA YA TEMEKE
Baruapepe:temekerh@afya.go.tz,S.L.P 45232 Dar es Salaam,Simu 0222856007

Kumb. Na. TRRH/RSC/9/9/02/41 **Tarehe: 24/10/2023**

Ndg. Linda Paul Athman
Muhimbili University of Health and Allied Sciences
S.L.P 65001,
DAR ES SALAAM.

YAH: OMBI LA KUFANYA UTAFITI KUHUSU "Magnitude, Associated Factors and Lived Experiences of Depression Among Adolescents with Sickle Cell Anemia Attending Sickle Cell Clinics in Dar es Salaam, Tanzania" (RESEARCH)

Tafadhali husika na somo tajwa hapo juu.

Nimepokea barua yako ya tarehe 06 Julai, 2023 kuhusu ombi lako la kufanya Utafiti (Research) katika Taasisi yetu, kuhusu **"Magnitude, Associated Factors and Lived Experiences of Depression Among Adolescents with Sickle Cell Anemia Attending Sickle Cell Clinics in Dar es Salaam, Tanzania".**

Ombi lako limekubaliwa, utatakiwa kulipa ada kiasi cha **Tshs.100,000/=**. Hivyo wasiliana na mhasibu wa mapato wa Hospitali **Ndg. Lusajo Nsajigwa** kwa namba **0717 959495** ili akupatie control Number kwa ajili ya malipo ya ada hii ili uweze kuruhusiwa kufanya utafiti.

Asante kwa ushirikiano.

TEMEKE REGIONAL REFERRAL HOSPITAL
RECEIVED
27 OCT 2023
P. O. Box 45232
DAR ES SALAAM

Dkt. Husna Msangi
Kny; MKURUGENZI
HOSPITALI YA RUFAA YA MKOA YA TEMEKE

Nakala: CSCO

Tafadhali hakikisha taarifa ya utafiti inabaki hospitalini

THE UNITED REPUBLIC OF TANZANIA
MINISTRY OF HEALTH

Telephone Address:

Telephone: 022-2760500

Mwananyamala Regional
Referral Hospital,
P.O.Box 61665
Dar es Salaam.

RE: NO.: MA. 59/240/01/64

DATE: 26st Oct, 2023

Director,
Muhimbili University of Health and Allied Science,
P.O.BOX 65001,
DAR ES SALAAM.

RE: LINDA PAUL ATHMAN, TO CONDUCT HIS RESEARCH IN MWANANYAMALA REGIONAL REFERRAL HOSPITAL

The captioned subject refers

2. May you be informed that your prescribed request for your bonafide student **Linda Paul Athman,** to conduct his Research in our Institution through your letter referred **No. HD/MUH/T.291/2019** dated **06th July, 2023**, ***Tilled " Magnitude, Associated Factors and Lived Experiences of Depression Among Adolescents with Sickle Cell Anemia Attending Sickle Cell Clinic In Dar es Salaam, Tanzania. from 31th October and 31November,2023***". is asserted.

3. The Institution charges **50,000/=**, as a Research fee. The payments are to be made upon reporting.

4. May he report to the Administration and HR department head for further instruction.

KNY: MGANGA MKUU WA
HOSPITALI YA MWANANYAMALA
S.L.P 61665
DAR-ES-SALAAM

Thanks.

Dr. Atugonza Kyalusi Kyaruzi
RESEARCH COORDINATOR
FOR: MEDICAL OFFICER INCHARGE
MWANANYAMALA REGIONAL REFERRAL HOSPITAL

COPY:
Head of Paediatric Department - **MWANANYAMALA REGIONAL REFERRAL HOSPITAL**

Student - **Linda Paul Athman**