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# PREVALENCE AND FACTORS ASSOCIATED WITH SLEEP DISTURBANCE AMONG CHILDREN AND ADOLESCENTS WITH SICKLE CELL DISEASE AT MULAGO NATIONAL REFERRAL HOSPITAL - UGANDA


**BY**

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## DECLARATION

I, **ABDUL KADIR ABDULLAHI AHMED,** declare that all the work in this dissertation is original and has not been submitted for another degree in this or any other university or institution of higher learning.

Signature ..... Date 25/06/2026

This dissertation was submitted with the approval of the following supervisors;

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## DEDICATION

This work is dedicated to my family who have supported me throughout the journey of my education .

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First of all, I thank Allah, and I am grateful for bestowing me his blessing.

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## LIST OF ACRONYMS AND ABBREVIATIONS

| | |
|---|---|
| AASM | The American Academy of Sleep Medicine |
| APA | American Psychiatric Association |
| DIMS | Disturbance of initiating and maintaining sleep |
| SBD | Sleep breathing disturbance |
| DA | Disturbance of arousal |
| SWTD | Sleep-wake transition disturbance |
| DOES | Disturbance of excessive somnolence |
| SHY | Sleep hyperhidrosis |
| SCD | Sickle cell disease |
| IMD | Index of multipe deprivation |
| MNRH | Mulago National Referral Hospital |
| OSA | Obstructive Sleep Apnea |
| SDB | Sleep Disordered Breathing |
| SDSC | Sleep Disturbance Scale for Children |

## OPERATIONAL DEFINITIONS

**Adolescent:** Any person aged 13-17 years.

**Caregiver:** The mother, father, grandmother, or guardian of a child with sickle cell disease who spends the majority of the day with the kid and has lived with them for at least six months is referred to as the carer in this study.

**Child:** A person aged 5-12 years for this study.

**Disturbance of arousal (DOA):** Arousal disturbance the youngster has nightmares or sleepwalks, and the following day, they don't remember them. On the children's sleep disruption scale, the pathological score is equal to or greater than 6.

**Disturbance of excessive somnolence (DOES):** extreme somnolence disturbance The youngster is unable to move upon waking up in the morning, falls asleep unexpectedly in an inappropriate position, wakes up feeling exhausted, or is exceptionally difficult to wake up in the morning. The pathological score on the children's sleep disruption scale is 13 or above.

**Disturbance of the sleep-wake transition (SWTD):** The child frequently twitches or jerks their legs while they are asleep, frequently shifts positions during the night, throws the blankets off the bed, grinds their teeth, talks while they are asleep, and has intense dreamlike sequences while they are not asleep. He exhibits recurring behaviors like jerking or startling certain body parts when you're sleeping, or rocking or hitting your skull. The pathological score on the children's sleep disruption scale is 14 or above.

**Disturbances of initiating and maintaining sleep (DIMS):** Having trouble falling asleep and staying asleep (DIMS) In addition to taking longer to fall asleep, the youngster also grudgingly goes to bed, struggles to fall asleep at night, wakes up more than twice a night, and has anxiety or fear when he can't fall asleep or wakes up during the night. The pathological score on the children's sleep disruption scale is equal to or more than 17.

**Sleep breathing disturbance (SBD):** Breathing problems during sleep the child snores or has trouble breathing at night, gasps for air, and can't breathe while he's asleep. On the children's sleep disruption scale, the pathological score is 7 or above.

**Sleep disturbances:** Disturbances in sleep for at least six months that involve issues with breathing, arousal, excessive somnolence, the sleep-wake transition, hyperhidrosis, and

difficulty falling and staying asleep are all considered sleep disturbances or disorders. The pathological total score on the children's sleep disturbance scale (SDSC) is 51 or above.

**Sleep hyperhidrosis (SHY)**: Hyperhidrosis during sleep the child either perspires heavily at night or as he drifts off to sleep. On the children's sleep disruption scale, the pathological score is 7 or above.

## ABSTRACT

### Background

Children with sickle cell disease are at an increased risk of abnormal sleep disturbance. However, the proportions of such sleep problems are not well documented in this population in Uganda and sub-Saharan Africa. If screened and diagnosed early, sleep disorders can be managed and complications prevented.

### Objective

To determine the prevalence and factors associated with sleep disturbance among children and adolescents with sickle cell disease at the sickle cell clinic of Mulago National Referral Hospital.

### Methods

We enrolled children and adolescents with sickle cell disease at sickle cell clinic of Mulago National Referral Hospital using consecutive sampling. Using semi-structured and interviewer- administered questionnaires and the Sleep Disturbance Scale for Children (SDSC) tool, we captured socio-demographic and clinical characteristics and data on sleep disorders. Simple frequency was used to determine proportion of sleep disturbances for participants with SDSC scores 51 and above. Logistic regression with bivariate and multi variate analysis was done to determine factors associated with sleep disturbances at 5% level of significance.

### Results

Out of the three hundred seventy-two (372) children and adolescents with sickle cell disease sampled, 42 (11.3%) had sleep disturbances. There was a significant association between having a painful episode and sleep disturbance among the study participants with odds ratio of **1.17 (CI 1.059 – 1.298), p = 0.002**

### Conclusion

The findings show that 11.3% of children and adolescents with sickle cell disease at Mulago National Referral Hospital had sleep disturbances. The significant association with painful episodes highlights the importance of targeted interventions to improve sleep quality and overall quality of life in this population.

# CHAPTER ONE: INTRODUCTION

## 1.1 Background

Globally, the number of sickle cell disease births increased by 13.7% between 2000 and 2021 while the total number of people living with sickle cell disease increased by 41.4% during the same period (Piel et al., 2013). Sickle cell disease (SCD) is diagnosed in more than 300,000 newborn children in sub-Saharan Africa annually: with the largest proportion reported in Nigeria, Benin, and Uganda (Piel et al., 2013).

Uganda is one of those countries with high prevalence of SCD (World Health, 2025). According to the World Health Organization (WHO) on SCD, countries like Cameroon, Ghana, Gabon and Nigeria have high prevalence of sickle cell ranging between 20% to 30% yet some parts of Uganda go as high as 45% (World Health, 2025). A study conducted in Uganda between 2014 and 2019 reported prevalence of SCD of up to 9.7% among children aged 0-24 months (APA, 2022).

Sleep disturbances are one of the commonest complications affecting children with SCD (Padmanabhan et al., 2023). In a study conducted to assess sleep-related disorders in children with sickle cell disease, half of children with sickle cell disease were reported to exhibit inability to fall asleep at bedtime and to stay asleep at night and 21% of them experienced long-term insomnia (Hankins et al., 2014). Additionally, around half of the children living with sickle cell disease snored regularly (Hankins et al., 2014). In a recent study conducted in Uganda, a 21.7% prevalence of sleep disturbances among school going children in Uganda was reported (Innocent et al., 2025). Further still, children and adolescents with SCD are at an increased risk of sleep disturbances compared to their counterparts without SCD (Rice et al., 2025). This can be as a result of Vaso-occlusions that cause pain, nocturnal desaturations that result into sleep obstructive apnea, sickle cell disease processes among other causes (Stanfordhealthcare, 2022). Clinical assessment of children and adolescents with SCD and Hemoglobin S-β-thalassemia indicated that more than half of the children examined demonstrated sleep-disordered breathing and over quarter demonstrated upper airway obstruction that could contribute to sleep-disordered breathing and in turn sleep disturbances (Wolfson & Carskadon, 1998).

Sleep disturbances in this population are associated with adverse outcomes, including impaired school performance, reduced quality of life and increased frequency of pain crises (Jin et al., 2021). Moreover studies have documented an increased burden of sleep disturbances in school-

aged children with SCD compared to healthy controls (Daniel, Grant, Kothare, et al., 2010; Downes et al., 2017). Therefore, sleep disruption can impact on cognition which will most likely affect school going children to a larger extent (Jackman et al., 2012).

Interventions aimed at improving sleep demonstrate greater efficacy in children and adolescents, highlighting the potential benefits of early intervention in this population (Bhattacharjee et al., 2010). Given the increased risk of sleep disturbances and cognitive dysfunction in SCD (Hogan et al., 2006), understanding the sleep disturbances of children with SCD is crucial to inform future research and clinical practice in Uganda, and sub-Saharan Africa. Studies characterizing sleep disturbances have been mostly conducted in high-income countries (Butler & Heron, 2008; Daniel, Grant, Chawla, et al., 2010; Downes et al., 2017; Serkan Gunes et al., 2022; Rosen et al., 2014) – yet they harbor less than one-third of the world's children and adolescents living with SCD. A notable gap exists in the literature, with limited published studies investigating sleep disturbances among children and adolescents with SCD in sub-Saharan Africa. This study sought to address this gap by examining the proportions of sleep disturbances and associated factors in children and adolescents with SCD at Mulago National Referral Hospital.

## 1.2 Problem Statement

Three-quarters of children and adolescents living with SCD reside in sub-Saharan Africa, with Uganda, being among the countries with the highest disease burden (World Health, 2025). Children and adolescents with SCD are at a potentiated risk of sleep disturbances which could not only affect day to day lives of this population but also their health and general well-being.

Inadequate sleep among children and adolescents affects brain development, cognition, socio-emotional processes and behavioral functioning (Liu et al., 2024). Considering that most of these children and adolescents are of school-going age, these effects can translate into lesser concentration in class and most likely poor performance at school. Additionally, poor socio-emotional processes and behavior can affect how children interact with each other as well as their response to law and order in society (Ogundele, 2018). All these resultantly affect the general health and well-being of the children as well as those that interact with them in their social circles.

There's a significant gap in literature about sleep disturbance in children and adolescents with SCD in Uganda and sub-Saharan Africa. To date, hardly any studies have investigated the degree of sleep disturbances in children and adolescents with SCD in Uganda. The current

study poised to investigate the proportions of sleep disturbances among children and adolescents with sickle cell disease at Mulago National Referral Hospital in Uganda.

## 1.3 Justification

Identifying whether SCD is associated with sleep disturbances in children and adolescents in the context of sex, age, and socio-economic status, is crucial for enacting appropriate interventions to improve sleep in children and adolescents in Uganda and sub-Saharan Africa at large.

Because of the paucity of literature about sleep disturbance in children and adolescents with SCD in sub-Saharan Africa, our study sought to lay a foundation for targeted into a population of people who are already at risk of poorer health-related quality of life compared to the general population.

The study sought to create awareness among healthcare providers and the community about disturbances in sleep disturbance among children with SCD to enable prompt recognition, diagnosis, and management.

The findings of the study would inform policymakers, and health-related organizations to enact policies and clinical guidelines about the screening, diagnosis, treatment, and prevention of sleep disturbances among this vulnerable population.

The study would generate transferable knowledge to the local, regional, and international community and medical fraternity for use to foster a healthier generation to accomplish health sustainability.

## 1.4 Research Questions

i. What is the prevalence of sleep disturbance among children and adolescents with sickle cell disease at Mulago National Referral Hospital?

ii. What are the factors associated with sleep disturbance among children and adolescents with sickle cell disease at Mulago National Referral Hospital?

## 1.5 Study Objectives

### 1.5.1 General Objective

i. To determine the prevalence and factors associated with sleep disturbance among children and adolescents with sickle cell disease at Mulago National Referral Hospital.

### 1.5.2 Specific Objectives

i. To determine the prevalence of sleep disturbance among children and adolescents with sickle cell disease at Mulago National Referral Hospital.

ii. To determine the factors associated with sleep disturbance among children and adolescents with sickle cell disease at Mulago National Referral Hospital.

## 1.6 Conceptual Framework

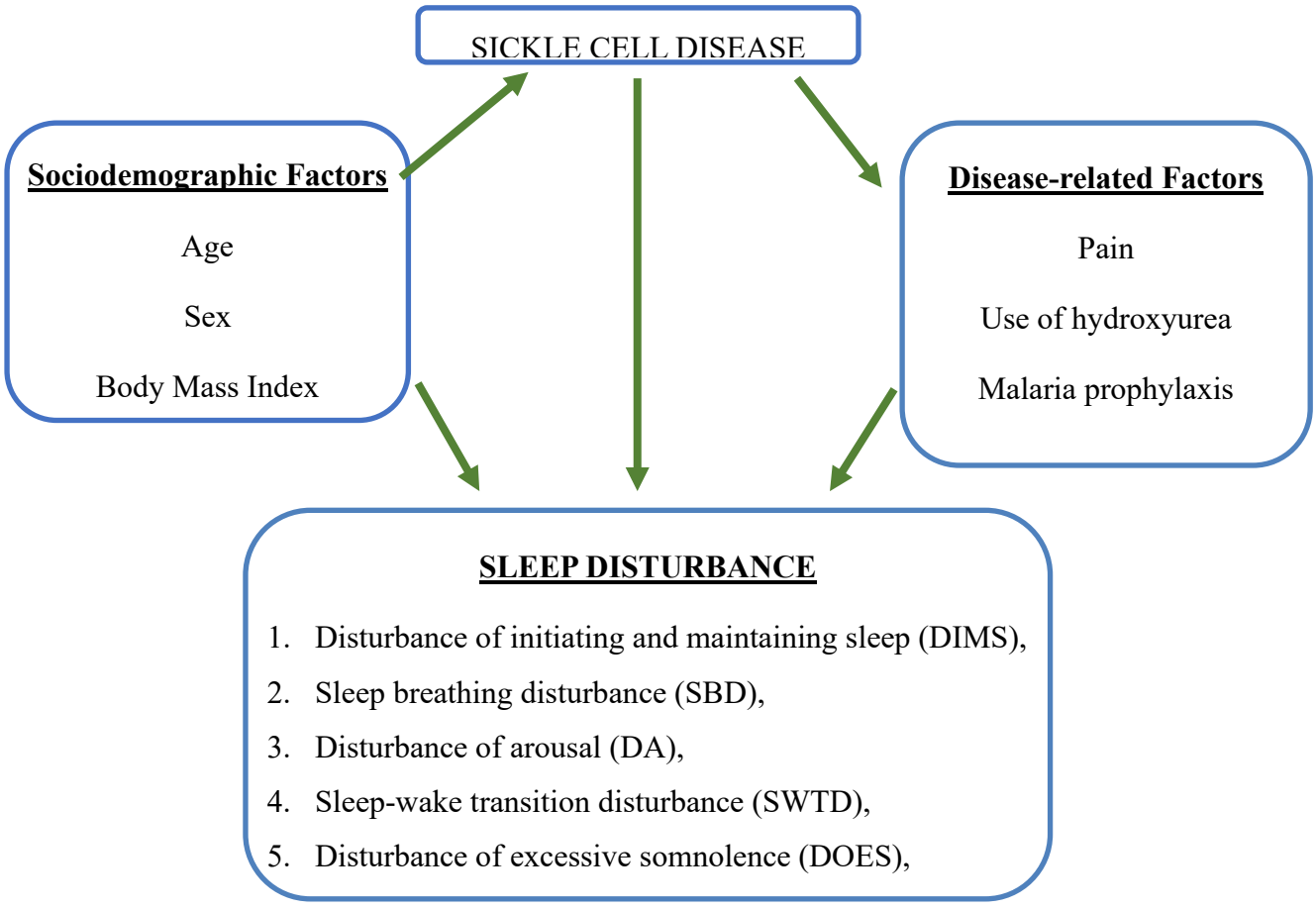


**Figure 1. Conceptual Framework**

### 1.6.1 Narration of the conceptual framework

Children with SCD are at risk of poor sleep disturbance. The disease severity modulated by pain, use of hydroxyurea, and blood transfusions affect the sleep quality and quantity among this population. Sociodemographic factors such as sex, age, and body mass index affect the proportions and nature of such sleep disturbance. Our study looked at prevalence of and factors associated with sleep disturbance among children and adolescent with SCD at Mulago National Referral Hospital using a cross-sectional study design.

# CHAPTER TWO: LITERATURE REVIEW

## 2.1 Introduction

Sickle cell disease is a monogenic blood disorder that has garnered global public health attention (Piel et al., 2013). It's associated with abnormal sickling of red blood cells within blood vasculature and organs at periods of low oxygen tension (Elendu et al., 2023). This hallmark characteristic follows a single-point mutation at the sixth position of the beta-globin gene, leading to a substitution of glutamate for valine (Mangla A, 2026). The resultant beta-globin chain of the adult hemoglobin easily attains a spherical shape in low oxygen tension environments, orchestrating a chain of pathophysiological events that lead to recurrent vaso-occlusive crises, stroke, and end-organ damage among the affected population (Manwani & Frenette, 2013; Rees et al., 2010). The disease preferentially affects people of African and Mediterranean origins (Piel et al., 2010).

More than 300,000 children are born with sickle cell anemia in sub-Saharan Africa annually – the biggest proportion of whom reside in Nigeria, Benin, and Uganda (Piel et al., 2013). Uganda has a 0.7% prevalence of sickle cell disease (Ndeezi et al., 2016) but this is poised to increase by 2050 as more children and adolescents survive and healthcare practices improve across the nation (Piel et al., 2013).

The pathophysiological mechanisms that underlie the covert and overt complications of SCD affect the sleep disturbance of children and adolescents with SCD. This has negative repercussions on their academic and behavioral functioning and their health outcomes across the lifespan (Daniel & Barakat, 2012). Children and adolescents with SCD report high frequencies of disordered sleep patterns due to pain, enuresis, and hypoxemia (Daniel & Barakat, 2012). Studies have reported sleep disorders such as sleep-disordered breathing, daytime sleepiness, sleep anxiety, abnormal sleep durations, nocturnal enuresis, periodic limb movements, and restless leg syndrome (Daniel, Grant, Kothare, et al., 2010; Serkan Gunes et al., 2022; Kölbel et al., 2020; Valrie et al., 2007).

Although more studies (Claire A Abijay et al., 2023; Daniel, Grant, Kothare, et al., 2010; Serkan Gunes et al., 2022; Kölbel et al., 2020; Valrie et al., 2007) have been published or are currently underway regarding characterizing sleep patterns and behaviors in children and adolescents with SCD, such data is still scarce in sub-Saharan Africa, a continental region that harbors more than 75% of the world's population living with SCD (Piel et al., 2013).

## 2.2 Prevalence of Sleep Disturbance in Sickle Cell Disease

In a study conducted to assess sleep-related disorders in children with sickle cell disease, half of children with sickle cell disease were reported to exhibit inability to fall asleep at bedtime and to stay asleep at night and 21% of them experienced long-term insomnia (Hankins et al., 2014). Additionally, around half of the children living with sickle cell disease snored regularly (Hankins et al., 2014).

In another study conducted to assess pediatric obstructive sleep apnea in SCD, it was reported that 43% of children with SCD exhibited obstructive sleep apnea (C. A. Abijay et al., 2023). In one multicenter study conducted to assess sleep disorders in children with sickle cell disease, it was reported that over 80% of children with SCD exhibited signs of obstructive sleep apnea (Al-Otaibi et al., 2017).

In another study conducted to determine sleep disturbance in adults with sickle cell disease, about three quarters of adults living with SCD reported sleep disturbances and 21% even showed signs of depression (Wallen et al., 2014).

In a cross-sectional study in Turkey, by Gunes *et al.* (Serkan Gunes et al., 2022) to investigate the relationship between sleep problems and health-related quality of life in 86 children and adolescents with sickle cell anemia using the CSHQ tool, the authors reported high total sleep problems score (53.22±7.53) compared to the healthy controls (50.68±7.89). They also report that children and adolescents with SCD have more scores on bedtime resistance, sleep onset delay, sleep anxiety, night waking, daytime sleepiness, parasomnia, and sleep disordered breathing.

In Downes *et al.'s* (Downes et al., 2017) study which assessed parent-reported sleep problems in preschool children with SCD and controls in East London, 79% of the children in SCD group reported snoring at least one-to-two nights per week compared to 25% in the control group and 33% in the larger population. Notably, the study had only twenty-two black British children matched with twenty-four controls and 142 unselected typically developing preschoolers.

Kölbel *et al.* (Kölbel et al., 2022) explored the relationship of sleep, cognition, and cortisol in SCD among children and young adults in London. They enrolled forty-five black British participants aged 6-30 years and eighteen controls from the community between 2018 and 2020. They noted that people with SCD took longer to fall asleep and experienced greater wake bouts, mobile minutes, and fragmented sleep compared to controls. Their sleep patterns and behaviors

were assessed using the Index of Multiple Deprivation (IMD) tool and their nocturnal sleep patterns were monitored using MotionWatch8.

### 2.3 Sleep Disturbance in Sickle Cell Disease

Sleep is critical to the normal growth and development of children and adolescents (Serkan Gunes et al., 2022). Altered sleep patterns are associated with cognitive and psychosocial derangements such as disordered attention, memory, behaviors, academic scores, emotional status, and activities of daily living (Gunes et al., 2019; Kölbel et al., 2020). Several pain-related sleep disorders have been characterized and these are crucial among children and adolescents with sickle cell anemia because acute and chronic pain syndromes are frequent hallmarks of the disease across the lifespan (Daniel, Grant, Kothare, et al., 2010; Serkan Gunes et al., 2022; Kölbel et al., 2020; Shapiro et al., 1995; Valrie et al., 2007).

Sleep-disordered breathing is one of the most reported sleep disorders in children and adolescents with SCD (Daniel & Barakat, 2012). Sleep-disordered breathing is defined as disorders of abnormal respiration during the night, either based on ventilation patterns or quantity of ventilation throughout the night (Owens, 2009). Of all the disorders in this category, obstructive sleep apnea is the most common. It occurs due to airflow restriction as the upper airway collapses. This causes hypoxia, hypercapnia, and sleep disruptions (Owens, 2009). Sleep-disordered breathing is associated with pulmonary hypertension, nocturnal enuresis, growth retardation, behavioral and learning difficulties (Marcus, 2001). The gold standard test for diagnosing sleep-disordered breathing is polysomnography (Rundo & Downey, 2019); however, sleep-disordered breathing can be suspected clinically based on parent reports using tools such as the CSHQ score (Owens et al., 2000).

Daniel *et al.* (Daniel, Grant, Kothare, et al., 2010) reported similar findings using the CSHQ tool among children and adolescents with sickle cell anemia in the US. They conducted a cross-sectional study where they compared the sleep patterns of children and adolescents with SCD and their age-matched healthy controls. Children and adolescents with SCD had more night waking, sleep-disordered breathing symptoms, and experienced enuresis than their healthy counterparts.

## 2.4 Factors Associated with Sleep Disturbance in Sickle Cell Anemia

Several factors disrupt sleep in children and adolescents with SCD. They include those related to the disease itself or demographics.

### 2.4.1 Pain

Acute and chronic pain in sickle cell anemia is not uncommon (Wang et al., 2011). It is responsible for most emergency hospital visits and hospitalizations locally and globally. Reviews have consistently deduced pain reduces sleep efficiency, slow-wave sleep, and rapid eye movements (Daniel & Barakat, 2012; Onen et al., 2005). Sleep disruptions can lead to reduced quality of life in children and adolescents whose health-related quality of life domains have been chronically plummeted by sickle cell anemia and its complications (Dampier et al., 2010; Serkan Gunes et al., 2022). A study by Dampier *et al.* (Dampier et al., 2004) noted that nocturnal pain occurred on 12% of the nights among children and adolescents with sickle cell disease. The authors used daily diaries that monitored the occurrence and intensity of pain and sleep parameters including subjective reporting of sleep quality. In Shapiro *et al.'s (Shapiro et al., 1995)* prospective study, children and adolescents reported that sickle cell anemia-related pain affected their sleep quality, rating it poor on 43% of the days with pain compared to 3% of days without pain.

### 2.4.2 Hydroxyurea Use

Studies have shown that hydroxyurea use revitalizes the rheology of red blood cells in sickle cell anemia and thus not only ameliorates the symptoms and complications of sickle cell anemia but also improves the health-related quality of life domains among this population (Ferster et al., 2001; Lobo et al., 2013; McGann et al., 2016; Opoka et al., 2017; Thornburg et al., 2013). However, the relationship between hydroxyurea and sleep disturbances in children and adolescents with sickle cell anemia is not well studied. Existing studies have shown that hydroxyurea may be associated with higher nocturnal and awake oxygen saturations but does not affect the rates of obstructive sleep apnea (Narang et al., 2015; Valrie et al., 2018). Our study will report whether children and adolescents with sickle cell anemia and taking hydroxyurea will have different sleep patterns and behaviors.

### 2.4.3 Socio-Economic Status

Studies have reported that parents of children and adolescents with sickle cell anemia with low socioeconomic status report that their children have more troubles initiating sleep and wake up

more often than their counterparts with high socioeconomic status (Chervin et al., 2006; Crabtree et al., 2005; Daniel, Grant, Chawla, et al., 2010; Montgomery-Downs et al., 2003; Spilsbury et al., 2004). Such children and adolescents also experience more daytime sleepiness, sleep-disordered breathing, and report more daytime tiredness and fatigue.

### 2.4.4 Sex

Generally, male sex in childhood is associated with disordered sleep patterns (Lewien et al., 2021). Several studies globally have also found a higher prevalence of sleeping disorders such as sleep-disordered breathing and parasomnias male than female children (Archbold et al., 2002; Ivanenko & Gururaj, 2009; Lewien et al., 2021; Thiedke, 2001). However, the role of sex predisposition and risk of disordered sleep patterns and behaviors in sickle cell disease is not well studied. Daniel et al. noted that children and adolescents with sickle cell anemia were at higher risk of night waking and sleep-disordered breathing problems regardless of sex and age (Daniel, Grant, Kothare, et al., 2010). Our study will ascertain whether there will be statistically significant differences in sleep patterns between male and female children with sickle cell anemia at Mulago National Referral Hospital.

### 2.4.5 Age

The burden of disordered sleeping patterns varies with age (Lewien et al., 2021). Insomnia has been reported less often among early elementary school-aged children (12%) as compared to late elementary school aged children (22%) (Archbold et al., 2002). Regardless of the health status, Lewien *et al.* found that younger children had a higher prevalence of bedtime resistance, sleep onset delay, sleep-related anxiety, night waking, and parasomnia as compared to the older children (Lewien et al., 2021). Similar patterns of sleep may be observed among children with SCD, but they may be worse due to the compounding effects of the underlying complications associated with SCD (Daniel & Barakat, 2012; Daniel, Grant, Kothare, et al., 2010; Serkan Gunes et al., 2022).

### 2.4.6 Malaria Prophylaxis

Although studies showing a link between malaria prophylaxis and sleep disturbances in SCD are scarce, malaria prophylaxis medicines are associated with a number of side effects like rashes, vomiting and blurred vision(Frimpong et al., 2018). These side effects could result into sleep disturbances among children with SCD who are often given malaria prophylaxis as a control for malaria which is known to triggers vaso-occlusive crises and hospitalization in these children.

# CHAPTER THREE: METHODOLOGY

## 3.1 Study Design

The study utilized a cross-sectional study design.

## 3.2 Study Setting

The study took place in Mulago National Referral Hospital, a national referral hospital located on Mulago Hill in the northern part of Kampala, Uganda's capital. The study participants were obtained from Mulago Sickle Cell Clinic which is the main outpatient clinic for children and adolescents with sickle cell anemia. The sickle cell clinic receives patients from different areas where follow-up of children and adolescents with SCD occurs. The unit receives around 30 to 50 children and adolescents with SCD daily.

## 3.3 Study Population

### 3.3.1 Target Population

All children 6 to 12 years and adolescents 13 to 17 years with SCD reporting at MNRH sickle cell clinic.

### 3.3.2 Accessible Population

All children 6 to 12 years and adolescents 13 to 17 years with SCD reporting at sickle cell clinic of Mulago National Referral Hospital during the study period.

### 3.3.3 Study Population

All children 6 to 12 years and adolescents 13 to 17 years with SCD reporting at the sickle cell clinic of Mulago National Referral Hospital during the study period and met the eligibility criteria.

## 3.4 Eligibility Criteria

### 3.4.1 Inclusion Criteria

- Age between 6 and 17 years of age.
- Confirmed diagnosis of sickle cell disease.
- Given assent and a consent from the caregiver

### 3.4.2 Exclusion Criteria

- Any child or adolescent without a caregiver.
- Any child/adolescent who has lived with the caregiver for less than 6 months.
- Very sick children and adolescents who may require admission.
- Any participant and/or caregiver who doesn't understand English and/or Luganda.

## 3.5 Study Sample Size

For objective one used a sample size formula by Kish Leslie (Kish, 1965), at a 95% confidence interval and error within 5%;

$$N = \frac{Z^2_{\alpha/2} \times p(1-p)}{d^2}$$

$$\mathrm{N}= \frac{Z^2_{\alpha/2} * p(1-p)}{d^2}$$

Where N = Sample size estimate of participants.

$Z_{\alpha/2}$ = Standard Z value at 95% confidence interval, corresponding to 1.96

p = prevalence of sleep disturbance (32%).

d = the sampling error, in this case, set at 5%

Using the study by Munyumu et. al., the prevalence of sleep disturbance in children was 32% (Munyumu et al., 2018),

calculated sample size, N = $\frac{(1.96\ x\ 1.96)\ x\ 0.32(1-0.32)}{0.05\ x\ 0.05}$ = 334.4 participants.

To maintain the power of the study above 80%, we will account for non-responders at 10%, the new sample size will 334.4/0.9 to give 372 participants.

For factors associated, we shall use a Fleiss two proportions formula (Fleiss, 2011).

$$n = \frac{[Z_{\alpha/2}\sqrt{p(1-p)\left(1/q_1 + 1/q_2\right)} + Z_{\beta}\sqrt{p_1(1-p_1)^{1/q_1} + p_2(1-p_2)^{1/q_2}}]^2}{(p_1 - p_2)^2}$$

Where;

n is the population per group

Zα/2 is the standard normal value corresponding to the level of significance (e.g., for a confidence level of 95%, α is 0.05 and the critical value is 1.96),

Zβ is the standard normal value corresponding to the power of the study (e.g., for a power of 80%, β is 0.2 and the critical value is 0.84),

Considering a factor from another study by Patery et al. (2021), the factor associated with sleep disorders among children and adolescents is presence of Epilepsy.

q1=proportion of those with Epilepsy in the study 0.68

q2=proportion of those without Epilepsy in the study 0.32

r= Unexposed/ Exposed =1

p1=proportion of those with sleep disorders and are epileptic 0.94

p2=proportion of those with sleep disorders but non epileptic0.67

p= p1q1 + p2q2

Based on the above formula, the calculated sample size is 80 participants.

We therefore considered the bigger sample size of 372 participants.

### 3.6 Sampling Procedure

Consecutive sampling was used where every participant meeting the study inclusion criteria was selected until the desired sample size is achieved.

### 3.7 Study Variables

#### 3.7.1 Dependent Variables

The dependent variable for this study was sleep disturbance among children and adolescents with SCD and it was assessed using the Sleep Disturbance Scale for Children (SDSC).

The total SDSC score was calculated by summing the scores from all six domains. Participants with a total SDSC score of 51 or higher were classified as having sleep disturbance, while those with a score below 51 were classified as having no sleep disturbance.

#### 3.7.2 Independent Variables

- Demographics – Age and sex.
- Disease characteristics – history of vaso-occlusive crises, stroke, blood transfusion, in the last six months.
- Drugs – hydroxyurea use, malaria prophylaxis, and penicillin prophylaxis.

### 3.8 Study Procedures

#### 3.8.1 Study Flow chart

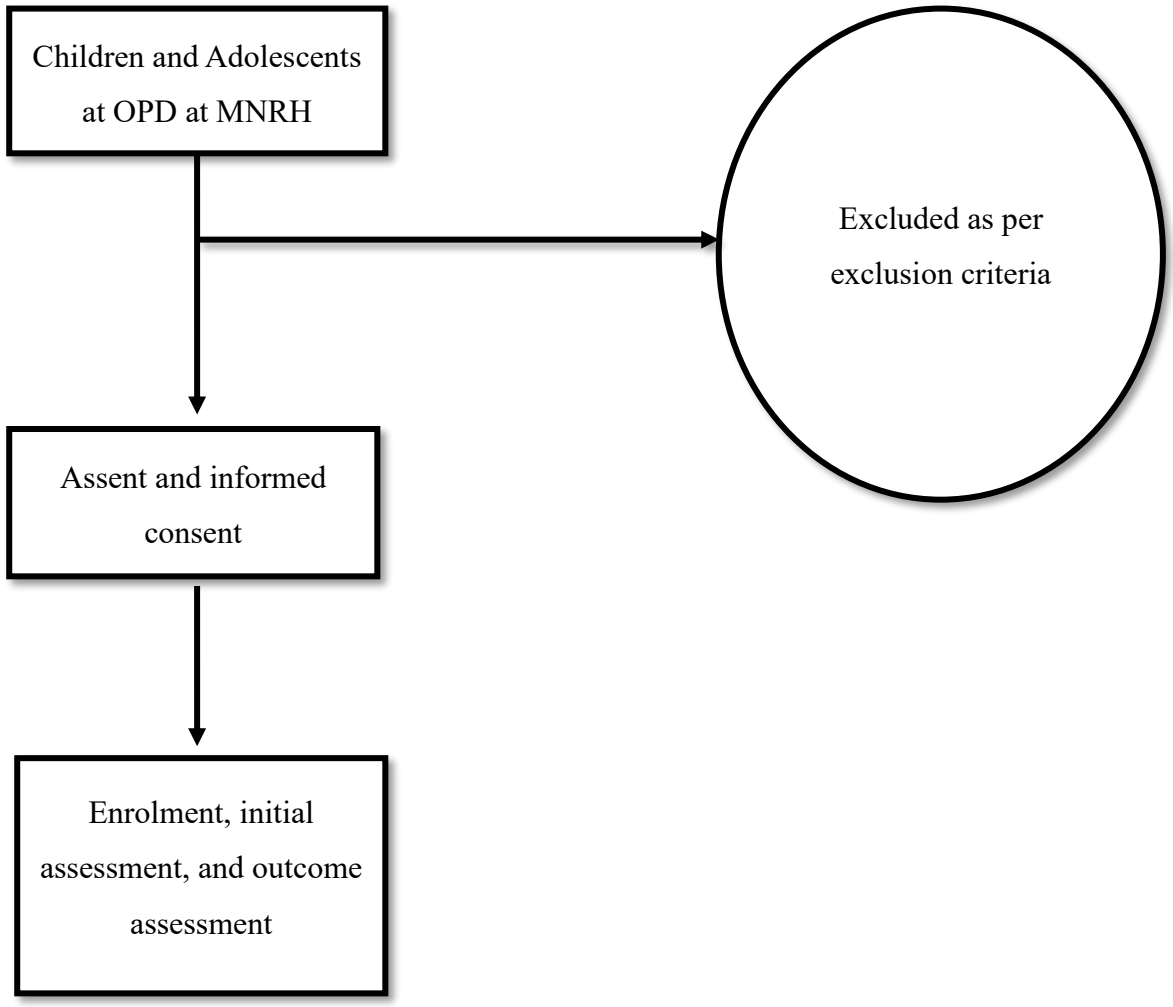


**Figure 2. Study flowchart**

#### 3.8.2 Study Participant Enrolment

A consecutive sampling technique was used to obtain the study participants. Each participant's anthropometric measurements were taken. With the assistance of research assistants, patients were recruited from Monday to Friday of each week for three months. The research assistants were stationed at the sickle cell clinic to identify and recruit the study participants that met the eligibility criteria. The study participants and their caregivers were fully informed about the study; aims, objectives, benefits and risks including satisfactory responses to any arising questions from the target population. Children and adolescents who met the eligibility criteria were voluntarily asked to give written assent, while their care givers gave a written informed consent.

Caregivers provided responses to the questionnaires as the children or adolescents did not know the responses to some questions on the study tool as these questions demand responses about the status of sleep which may not be known to the children or adolescents themselves.

### 3.8.3 Data Collection

Data was collected by the principal investigator with the help of two research assistants. The participants were recruited from the outpatient clinics in June and July 2025. Eligible candidates were taken through the informed consent/ascent procedure and those accepted to participate were given consent and ascent forms to sign (or put a thumbprint, for those who cannot write). The principal investigator or his assistant then administered the questionnaire to the caregivers of the children or adolescents with SCD, ensuring that all questions are clear to them before receiving the response. The interviewer ensured that all parts of the questionnaire are filled.

### 3.8.4 Data Collection Tool

Participant data on sociodemographic and clinical characteristics was captured, using a questionnaire designed by the principal investigator.

Data on the outcome was collected by trained research assistants using sleep disturbance scale for children (SDSC) tool. This is a 26-item instrument developed for evaluating sleep among children aged 3–18 years. The SDSC comprises six domains: disturbance of initiating and maintaining sleep (DIMS), sleep breathing disturbance (SBD), disturbance of arousal (DA), sleep-wake transition disturbance (SWTD), disturbance of excessive somnolence (DOES), and sleep hyperhidrosis (SHY) (Oliviero Bruni et al., 1996). Each item was scored on a five-point Likert scale ranging from 1 (never) to 5 (always), with total scores ranging from 26 to 130.

The SDSC investigates the occurrence of sleep disturbance among children and adolescents over a period of 6 months. However, it has not been validated in Uganda much as it has been used across a number of studies with findings similar to other settings (Innocent et al., 2025; Munyumu et al., 2018). The sleep disturbance score are described below

**Sleep disturbance scores**

| | DIMS | SBD | DA | SWTD | DOES | SHY | Total Score |
|---|---|---|---|---|---|---|---|
| Range score | 7-23 | 3-15 | 3-8 | 6-19 | 5-20 | 2-10 | 28-82 |
| Cut off | ≥ 17 | ≥ 7 | ≥ 6 | ≥ 14 | ≥ 13 | ≥ 7 | ≥ 51 |

### 3.9 Data Management

The study PI reviewed the collected data to clean it and ensure that it's consistent and accurate. The data collection forms were kept in locked cabinets to ensure data safety. Raw data was entered in Epi-Data version 3.1 and was exported to STATA version 15.0 for analysis.

### 3.10 Data Analysis

At univariate analysis, continuous variables were summarized using descriptive statistics such as means, standard deviations, median and interquartile range (IQR) while categorical variables were summarized using frequencies and percentages and displayed in tables or graphs.

The outcomes were presence of any sleep disturbances as described on the SDSC questionnaire. These were dichotomized to indicator variables denoting having or having no sleep disturbance basing on SDSC score. Participants with a total SDSC score of ≥ 51 had sleep disturbance and those with a total SDSC score <51 having no sleep disturbance. The outcomes were code 1 if had sleep disturbance and 0 if having no sleep disturbance. The prevalence of sleep disturbance was obtained by dividing the number participants who have sleep disturbance by the total number of participants in the study.

Bivariate analysis was conducted to assess the association between each independent variable and sleep disturbance. For all categorical variables, Fisher's exact test was used because in some cell, counts were less than five, while Pearson's Chi-square test was used for gender because the cell counts were adequate. For continuous variables, the independent samples t-test was used to compare means between participants with and without sleep disturbance. Variables with a p-value <0.20 at bivariate analysis and variables considered biologically plausible based on literature were included in the multivariable logistic regression model.

A multivariate logistic regression model was used to obtain the adjusted odds ratio. Backward elimination using an inclusion criteria $P < 0.2$ was used to build a model of best fit. Goodness

of fit test was conducted at 5 % level of significance. Interaction and confounding were assessed. Factors that had a p value of <0.05 in the final model were considered significant.

### 3.11 Quality Assurance

The data collection questionnaire tool was pre-tested on 10 participants to ensure the questions are clear and accurate. The PI trained and supervised the research assistants to ensure consistent, accurate data collection. The PI reviewed the raw data, cleaned it, and double-checked it with that entered in Epi Data to ensure completeness and accuracy.

### 3.12 Ethical Considerations

Approval was sought from the Department of Psychiatry and the School of Medicine Research Ethics Committee (SOMREC-2023-632). Administrative clearance was sought and granted from the Mulago National Referral Hospital Administration and Research Ethics Committee under reference MHREC 2954 to conduct the study. Informed consent was sought from each caregiver before their participation. To ensure confidentiality, anonymous identifiers were assigned to each consent form. These were later used in data collection forms. The study tools were kept under lock and key only accessible to the research team to ensure no confidentiality breach occurs.

### 3.13 Referral pathways

Children who were found with sleep disturbances were referred to a pediatric neurologist at Mulago National Referral Hospital to get medical attention for their sleep disorders.

### 3.14 Dissemination of Results

Dissertation books will be written and handed to Makerere University's Department of Psychiatry; Sir Albert Cook Library, School of Graduate Studies, and Mulago Sickle Cell Clinic. Manuscripts will be written and published in peer-reviewed journals. The study results will also be presented at both local and international conferences.

# CHAPTER FOUR: RESULTS

## 4.1 Sociodemographic Characteristics of the Participants

All the 372 participants recruited in the study participated, giving a response rate of 100%. The mean age of the participants was 11.7 (SD = 3.4) years and the mean BMI was 16.6 (± 3.0) kg/m$^2$. More than half of the participants were female,194 (52.2%) and majority of the participants had attained primary school, 265 (71.2%). Majority of the participants were from the central region of the country, 339 (91.2%) followed by the East, 24 (6.5%) and the West, 9 (2.4%). These characteristics are further summarized in Table 1 below.

**Table 1: Sociodemographic Characteristics of the Participants**

| Variable | Frequency, n (%) |
|---|---|
| Age (mean ± SD) | 11.7 (3.4) |
| Gender (Female) | 194 (52.2) |
| Male | 178 (47.8) |
| BMI (mean ± SD) | 16.6 (3.0) |
| Education Level (None) | 8 (2.1) |
| Nursery | 20 (5.4) |
| Primary | 265 (71.2) |
| Secondary | 79 (21.2) |
| Region of origin (Western) | 9 (2.4) |
| Central | 339 (91.1) |
| Eastern | 24 6.5) |

## 4.2 Clinical Characteristics of the Participants

Majority of the study participants 364 (91.1%) used Hydroxyurea. Majority 361, (97.0%) were on malaria prophylaxis, while penicillin use was reported in only 6 participants (1.6%). In the six months preceding the study, only 2 participants (0.5%) had suffered a stroke. The mean number of blood transfusions during this period was 0.4 (± 0.9), and the average number of painful crises was 2.2 (± 2.8). These findings are summarized in Table 2 below. The subsequent section presents the prevalence and patterns of sleep disturbances among the study participants.

**Table 2: Clinical Characteristics of the Participants**

| Variable | Frequency, n (%) |
|---|---|
| Hydroxyurea use (Yes) | 364 (97.9) |
| Malaria prophylaxis (Yes) | 361 (97.0) |
| Penicillin use (No) | 366 (98.4) |
| Stroke (No) | 370 (99.5) |
| Blood transfusion (mean ± SD) | 0.4 (0.9) |
| Painful episodes (mean ± SD) | (2.8) |

### 4.3 Sleep Disturbance Patterns

All six sleep disturbances were prevalent in this study population. SBD was the most prevalent sleep disturbance, n = 58 (15.6%) with a mean sleep disturbance scale for children (SDSC) score of 4.6 (± 2.0) and a range of 3 – 15 followed by disturbance of excessive somnolence (DOES) with 56 (15.0%) participants having the condition and an average SDSC score of 9.3 (± 3.2) and a range of 5 – 20. disturbance of arousal (DA) occurred in 38 (10.2%) participants with a mean SDSC score of 4.1 (± 1.1) and a range of 3-8 while disturbance of initiating and maintaining sleep (DIMS)was prevalent in 29 (7.8%) of the participants with a mean SDSC score of 12.5 (± 2.8) and a range of 7-23. The least prevalent sleep disturbance was sleep hyperhidrosis (SHY) which occurred in only 26 (7.0%) of the participants with an average SDSC score of 3.4 (± 2.1) and a range of (2-10).

The overall prevalence of sleep disturbance in this study sample was 11.3% (n = 42) with a mean SDSC score of 42.3 (± 8.2) and a range of 28-82.

Although the prevalence of some individual sleep disturbance domains was higher than the prevalence of overall sleep disturbance, this finding is expected because classification of overall sleep disturbance was based on the total SDSC score (≥51), whereas domain-specific disturbances were identified using separate cut-off scores for each SDSC subscale. Consequently, participants could meet the threshold for one or more individual sleep disturbance domains without attaining the total SDSC score required to be classified as having

overall sleep disturbance. Therefore, the prevalence of individual sleep disturbances should not be interpreted as additive and may exceed the prevalence of overall sleep disturbance.

These statistics are summarized in table 3 below with the cut off scores for each sleep disturbance.

**Table 3: Sleep disturbance scores among study participant**

| | DIMS | SBD | DA | SWTD | DOES | SHY | Total Score |
|---|---|---|---|---|---|---|---|
| Range score | 7-23 | 3-15 | 3-8 | 6-19 | 5-20 | 2-10 | 28-82 |
| Mean (SD) | 12.5 (2.8) | 4.6 (2.0) | 4.1 (1.1) | 8.4 (2.1) | 9.3 (3.2) | 3.4(2.1) | 42.3 (8.2) |
| Cut off | ≥ 17 | ≥ 7 | ≥ 6 | ≥ 14 | ≥ 13 | ≥ 7 | ≥ 51 |
| Normal sleep n (%) | 343 (92.2) | 314 (84.4) | 334 (89.8) | 364 (97.8) | 316 (85.0) | 346 (93.0) | 330 (88.7) |
| Sleep disturbance n (%) | 29 (7.8) | 58 (15.6) | 38 (10.2) | 8 (2.2) | 56 (15.0) | 26 (7.0) | 42 11.3) |

## 4.4 Factors associated with Sleep Disturbances among children and adolescents with Sickle cell disease

At bivariate, gender ($p = 0.179$, $\chi^2 = 1.805$), education level ($p = 0.009$), hydroxyurea use ($p = 0.050$), malaria prophylaxis ($p = 0.116$), age ($p = 0.025$), body mass index ($p = 0.180$), and number of painful episodes ($p < 0.0001$) were all significant ($p < 0.2$) and were taken to the multivariate model. The results of the bivariate analysis are shown in table 4 below.

**Table 4: Results of bivariate analysis among children and adolescents with Sickle cell anemia**

| Variable | | Sleep Disturbance ( n ) | | Chi-square value | p-value |
|---|---|---|---|---|---|
| | | Yes(n=42) | No n=330) | | |
| Gender | Male | 16(38.1) | 162(49.1) | 1.805 | 0.179[a]* |
| | Female | 26(61.9) | 168(50.9) | | |
| Education level | None | 3(7.1) | 5(1.5) | | |
| | Nursery | 3(7.1) | 17(5.2) | | |
| | Primary | 22(52.4) | 243(73.6) | | 0.009* |
| | Secondary | 14(33.3) | 65(19.7) | | |
| Residence | Western | 0(0.0) | 9(2.7) | | |
| | Central | 38(90.5) | 301(91.2) | | 0.506 |
| | Eastern | 4(9.5) | 20(6.1) | | |
| Hydroxyurea | Yes | 39(92.9) | 325(98.5) | | 0.050* |
| | No | 3(7.1) | 5(1.5) | | |
| Malaria prophylaxis | Yes | 39(92.9) | 322(97.6) | | 0.116* |
| | No | 3(7.1) | 8(2.4) | | |
| Penicillin | Yes | 0(0.0) | 6(1.8) | | 1.000 |
| | No | 42(100) | 324(98.2) | | |
| Stroke | Yes | 0(0.0) | 2(0.6) | | 1.000 |
| | No | 42(100) | 328(99.4) | | |
| | **Mean** | **SD** | **95% CI** | **t-value** | **p-value** |
| Age (Yes) | 12.8 | 3.6 | 11.707 – 13.960 | -2.248 | 0.025* |
| (No) | 11.6 | 3.3 | 11.241 – 11.960 | | |
| BMI (Yes) | 17.2 | 3.4 | 16.171 – 18.278 | -1.344 | 0.180* |
| (No) | 16.6 | 3.0 | 16.243 – 16.883 | | |
| Painful episodes (Yes) | 3.9 | 3.9 | 2.710 – 5.147 | -4.330 | <0.0001* |
| (No) | 2.0 | 2.5 | 1.722 – 2.272 | | |
| Transfusions (Yes) | 0.5 | 0.9 | 0.199 – 0.754 | -0.811 | 0.418 |
| (No) | 0.4 | 0.9 | 0.255 – 0.450 | | |

Table 4. Results of bivariate analysis. Categorical variables analysed using Fischer's exact and Chi square tests, [a] results of chi square test. Continuous variables analysed with student t-test statistic. * p value < 0.2 taken to the multivariate model.

Multi-variate analysis was done using logistic regression on all factors that had a p-value < 0.2 at bivariate analysis while controlling for age. Only one factor was significantly associated with sleep disturbance among the study participants. Having a painful episode was statistically significant with odds ratio of **1.17 (CI 1.059 – 1.298), p-value = 0.002** which shows a 17% increase in the likelihood to have sleep disturbance with every unit increase in the number of painful episodes experienced over a 6-month period.

Attending nursery level of education had higher odds of having sleep disturbance (OR = 1.04) however, this was not statistically significant (p = 0.975). Female gender had higher odds (OR = 1.30) of having sleep disturbance but this was not statistically significant (p = o.485). Use of hydroxyurea, and malaria prophylaxis all showed lower odds of having sleep disturbance over a 6-month period (OR = 0.38, 0.66, p = 0.424, 0.718 respectively), but these were not statistically significant. These findings are summarized in table 4 below.

**Table 5: Multivariate analysis for factors associated with sleep disturbance**

| **Variable** | | **Odds ratio** | **z-value** | **95% CI** | **p-value** |
|---|---|---|---|---|---|
| Age | | 1.06 | 0.72 | 0.903 – 1.245 | 0.475 |
| Gender | Male | 1 | | | |
| | Female | 1.30 | 0.70 | 0.625 – 2.692 | 0.485 |
| Education level | None | 1 | | | |
| | Nursery | 1.04 | 0.03 | 0.085 – 12.811 | 0.975 |
| | Primary | 0.30 | -1.30 | 0.475 – 1.855 | 0.194 |
| | Secondary | 0.53 | -0.72 | 0.094 – 2.995 | 0.472 |
| Hydroxyurea use | No | 1 | | | |
| | Yes | 0.38 | -0.80 | 0.037 – 4.025 | 0.424 |
| Malaria prophylaxis | No | 1 | | | |
| | Yes | 0.66 | -0.36 | 0.070 – 6.256 | 0.718 |
| BMI | | 0.97 | -0.38 | 0.852 – 1.113 | 0.704 |
| **Painful episodes** | | **1.17** | **3.07** | **1.059 – 1.298** | **0.002*** |

# CHAPTER FIVE: DISCUSSION OF RESULTS

## 5.1 Discussion

This study aimed to determine the prevalence of and factors associated with sleep disturbance among children and adolescents with sickle cell disease attending Mulago National Referral Hospital. The findings revealed that 11.3% of participants had sleep disturbance based on the Sleep Disturbance Scale for Children (SDSC) total score cut-off of ≥51.

The prevalence of sleep disturbance observed in this study (11.3%) was lower than that reported in previous studies among children with sickle cell disease. For example, (S. Gunes et al., 2022) found that children and adolescents with sickle cell disease had significantly higher overall sleep problem scores, including bedtime resistance, sleep onset delay, night waking, and daytime sleepiness, compared with healthy controls. Similarly, (Hankins et al., 2014) reported a high prevalence of sleep-related symptoms among children with sickle cell disease, including unrefreshing sleep (54%), short-term insomnia (41%), sleep-maintenance insomnia (30%), chronic sleep-onset insomnia (21%), and habitual snoring (54%). The lower prevalence observed in the current study may be explained by differences in the definition and measurement of sleep disturbance. While the present study used the validated Sleep Disturbance Scale for Children (SDSC) total score cut-off of ≥51 to identify clinically significant overall sleep disturbance (O. Bruni et al., 1996), previous studies frequently assessed individual sleep symptoms or specific sleep disorders rather than a composite measure of overall sleep disturbance. Consequently, participants with isolated sleep problems may have been classified as having sleep disturbances in earlier studies but not in the current study. Differences in disease severity, treatment practices, healthcare access, and sociocultural settings may have further contributed to the observed variation in prevalence estimates.

Although the prevalence of overall sleep disturbance was relatively low, individual sleep disturbance domains were common, particularly sleep breathing disorders (15.6%) and disorders of excessive somnolence (15.0%). This suggests that while many participants experienced specific sleep-related problems, fewer met the threshold for clinically significant overall sleep disturbance as defined by the SDSC.

Painful episodes were the only factor independently associated with sleep disturbance in the multivariable analysis. Each additional painful episode experienced during the preceding six months increased the odds of sleep disturbance by 17%. This finding is biologically plausible because painful vaso-occlusive crises can directly interrupt sleep through discomfort, nocturnal

awakenings, and difficulty maintaining sleep (Lewandowski et al., 2011). Recurrent pain may also activate physiological stress pathways, leading to increased secretion of cortisol and other stress hormones that adversely affect sleep architecture (Daniel, Grant, Kothare, et al., 2010). Furthermore, chronic pain has been shown to reduce sleep efficiency, decrease slow-wave sleep, causes rapid eye movements and increase sleep fragmentation, thereby contributing to sleep disturbance (Young et al., 2025). The relationship between pain and sleep is likely bidirectional, whereby poor sleep may also increase pain sensitivity and contribute to subsequent painful crises.

The finding that demographic and treatment-related factors such as age, gender, hydroxyurea use, malaria prophylaxis, and body mass index were not independently associated with sleep disturbance suggests that disease-related factors, particularly recurrent pain, may play a more important role in determining sleep health among children and adolescents with sickle cell disease. Further longitudinal studies are needed to explore additional clinical and psychosocial factors that may influence sleep disturbance in this population.

### 5.2 Limitations:

A major limitation in the current study was possibility of recall bias in the responses; since the study relied on memory of the study participants. To minimize this, the principal investigator and research assistants conducted sessions of brief participant education and use of prompts. Additionally, the cross-sectional nature of the current study made it not possible to establish causal relationships between the variables.

Additionally, considering that the parents had to give information regarding sleep patterns of their children, they may underestimate sleep disturbances in their child due to the lack of proper awareness of some sleep disturbance symptoms. This was mitigated by encouraging parents and or caregivers to be objective and report exactly what they have observed.

Psychological factors known to influence sleep, such as depression, anxiety, emotional distress, cognition and quality of life, were not assessed. Children and adolescents with sickle cell disease are at increased risk of psychological comorbidities, which may independently contribute to sleep disturbances. The absence of these variables may have resulted in residual confounding and limits the ability of this study to fully explain all factors associated with sleep disturbance.

# CHAPTER SIX: CONCLUSIONS AND RECOMMENDATIONS

## 6.1 Conclusions

The study revealed 11.3% prevalence of sleep disturbance among children and adolescents with sickle cell disease at Mulago National Referral Hospital. The study further revealed a significant association between having a painful episode and sleep disturbance among the study participants.

## 6.2 Recommendations

In regards with the findings of the present study, some of the recommendations include;

Incorporate sleep assessment tools into routine Sickle Cell Disease clinic visits to identify children and adolescents at risk of sleep disturbances early.

Introduce customized pain management plans for individuals, including those that are pharmacologic and non-pharmacologic approaches to improve sleep quality.

Integrate counselling programs and psychological support to patients and caregivers on healthy sleep habits.

Establish referral mechanisms for children with sleep disorders and to ENT services for those with suspected sleep-disordered breathing.

Conduct longitudinal studies to better understand causal relationships between the variables.

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# APPENDICES

## APPENDIX I: INFORMED CONSENT FORM

**Title of the proposed study:**

PREVALENCE AND FACTORS ASSOCIATED WITH SLEEP DISTURBANCE AMONG CHILDREN AND ADOLESCENTS WITH SICKLE CELL DISEASE AT MULAGO NATIONAL REFERRAL HOSPITAL.

**Investigators:**

Dr Abdulkadir Abdullahi Ahmed, Department of Psychiatry Makerere University College of Health Science. Tel. No. 0700870924. Email address: ahmedabdulkadir2025@gmail.com

**Background and rationale for the study:**

Sleep disturbancess involve problems with the quality, timing, and amount of sleep, which result in daytime distress and impairment in functioning. Nearly 25% of all children experience some form of sleep disturbance during their development. Globally, the burden of sleep disturbances has been reported to be close to 80% in some countries. If screened and diagnosed early, sleep disturbances can be managed and prevent the complications. The study will involve 372 children and adolescents with sickle cell disease, as well as their caregivers reporting at paediatric OPD of hospitals of Mulago National Referral Hospital during the study period and meet the eligibility criteria. The children and adolescents who provide informed assent and their caregivers who will provide informed consents, will be selected consecutively and the Sleep Disturbance Scale for Children administered to collect data on the sleep disturbance. The data collected will be analysed to determine the magnitude of sleep disturbance and the characteristics that increase the risk sleep disturbance. The results from the study will be used by clinicians to provide timely screening and referrals of children and adolescents who are at a higher risk of having sleep disturbance.

**A description of sponsors of the research project and the organizational affiliation of the researchers:**

The above research is self-sponsored by Dr Abdulkadir Ahmed and is affiliated to Makerere University.

**Purpose:**

The purpose of the study is to determine the magnitude of sleep disturbance and the factors that predict the occurrence among children and adolescents at Mulago National Referral Hospital. This study will provide an evidence base for clinicians to provide timely screening and referrals of children with sickle cell anaemia who are at a higher risk of having altered sleep patterns and behaviour.

**The estimated duration the research participant will take to in the research project:**

The entire study shall take place for three months. Consenting for the study and filling the questionnaire will take between 20-30 minutes of your time.

**Procedures:**

If you voluntarily choose to participate in the study, you will be asked to sign an informed consent form. The principal investigator and/or a trained research assistant will brief you on the study. He/she will then ask you to answer some simple research questions using our questionnaire which will take about 20 minutes. You may withdrawal from participation at any time without consequences. If you decline to join the study, it will not affect your access to medical care in any way.

**Who will participate in the study:**

A total of 372 children and adolescents with sickle cell and their caregivers reporting at sickle cell clinic of Mulago National Referral Hospital during the study period and meet the eligibility criteria.

**Risks/Discomforts:**

There are no risks expected during this study.

**Benefits:**

There are no direct benefits to you, but the information gathered will help us to improve the chances of detecting and managing sleeping disorders in other children attending Mulago National Referral Hospital.

**Confidentiality:**

All your responses will be kept confidential under lock and key and will only be accessible to the principal investigator. Your identity will not be revealed but information collected will be

seen by those involved in this study. The School of Medicine Research Ethics Committee of Makerere College of Health Sciences (Mak-SOMREC) and the Uganda National Council for Science and Technology (UNCST) may have access to your private information as part of their duty to protect your rights.

**Alternatives:**

Participation in this study is voluntary and you can choose to continue with your routine clinic visit other than participating in the study.

**Cost:**

There are no cost implications to the participant.

**Compensation for participation in the study:**

Each child or adolescent will receive 10,000 Uganda shillings for your time.

**Reimbursement:**

Participants will not receive transport reimbursement since they will be met at the sickle cell outpatient clinic.

**Questions about the study:**

Dr Abdulkadir Abdullahi Ahmed, Department of Psychiatry Makerere University College of Health Science. Tel. No. +256 700 870 924.

Email address: ahmedabudlkadir2025@gmail.com.

**Questions about participants rights:**

If you have questions about your rights as a research participant, you can have your concerns addressed to the chairman school of medicine research and ethics committee, Prof. Ponsiano Ocama Mobile: +256 772-421-190

**Statement of voluntariness:**

Participation in this study is purely voluntary and one joins at his/her own free will. Participants have a right to withdraw from the study at any time without penalty.

**Dissemination of results:**

Participants will get feedback on the findings of the study and any new information that affects the study or data that has clinical relevance to participants (including incidental findings) will be made available to participants and/or their health care providers.

**Ethical approval:**

This study has been approved by the Makerere School of Medicine Research Ethics Committee (Mak-SOMREC) which is accredited by the Uganda National Council of Science and Technology (UNCST).

**Consent:**

**STATEMENT OF CONSENT**

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

Name of caregiver … ……

Signature of caregiver for minors ……. Date …….....

Name of witness ……

Signature of witness ……..…… Date ……

Name of interviewer/person obtaining informed consent …….

Signature of interviewer/person obtaining informed consent ……

Date……...

## APPENDIX II: TRANSLATED CONSENT FORM

**Omutwe gw'omusomo:**

**OBUUNJI N'ENSONGA EZEEKUUSA KU BIZIBU BY'OKWEEBAKA MU BAANA KO N'ABAVUBUKA ABALINA SICKLE CELL MU DDWALIRO LY'EGGWANGA MULAGO.**

**Abanoonyereza:**

Omusawo: Abdulkadir Abdullahi Ahmed, Master mu by'obusawo mu by'emitwe ku ssetendekero wa Makerere kolegi ya sayansi w'eby'obulamu

Simu: 0700870924, omukutu: ahmedabdulkadir2025@gmail.com

**Ennyanjula n'enkola y'omusomo:**

Ebizibu mu kweebaka mulimu, omutindo, biseera ki ne ebbanga ly'otwaala nga weebase nga binno bivaamu obutaba na mirembe mu budde obw'emisana n'obutaba na busobozi kukola byooteekeddwa okukola. Kumpi ebituundu 25% ku baana bonna bafuna ebuzibu mu kweebaka bwebaba bakula. Mu nsi yonna ebuzibu bw'okweebaka bwogerwaako okuba nga bukunukkirizza ebituundutuundu kinaana ku buli kikumi (80%) mu nsi ezimu. Bwebuba bukebeddwa era nebulabibwa mangu, busobola okujjanjabwa era netutaasa ebizibu byaabwo. Omusomo gujja kubeeramu abaana ko n'abavubuka 372 n'abajjanjabi babwe abajja mu kiseera ky'omusomo ku OPD mu ddwalliro ly'eggwanga elijjulirwaamu e Mulago era nga batuukilila n'ebyeetaagisa okubeera mu musomo. Abaana n'abavubuka ko n'abajjanjabi abanaatuwa okukkiriza kwabwe bajja kubuuzibwa ne Sleep Disturbance Scale for Children (SDSC) era bajja kukeberebwa ku mbeera z'okweebaka era bwiino akuŋŋaanyizibwe ku buzibu bwaabwe mu kweebaka. Bwiino onno ajja kweekeneenyezebwa okusobola okulaba obuungi bwe ebizibu mu kweebaka na biki ebyoongera ku bulabe bw'ekizibu kinno. Ebinaava mu musomo gunno bijja kukozesebwa abasawo okusobola okulaba mu budde ko n'okujjulizza abaana n'abavubuka abali mu bulabe obwa wagggulu obw'okufuna obuzibu mu kweebaka.

**Okunyonyola ku basasulira omusomo ko n'enkwaatagana y'ebitongole bya abanoonyereza:**

Omusomo ogwo waggulu ngweesasulila era gukwaatagana ne ssetendekero wa Makerere.

**Omulamwa:**

Omulamwa gw'omusomo kwe kulaba obuungi bwe ebizibu mu kweebaka n'ensoonga ez'ekuusa ku kubutegeera amaangu mu baana ko n'abavubuka mu ddwaliro ly'eggwanga elijjulirwaamu e Mulago.

Ekiseera mu kugerageranya omweetabi ky'anamala mu musomo gw'okunoonyereza:

Omusomo gwonna gujja kutwaala emyeezi esatu. Okukkirizaakwo okweetaba mu musomo ko n'okuddamu ebibuuzo kujja kutwaala wakati w'eddakiika abiri ku asatu (20-30) ku budde bwo.

**Enkola:**

Singa osalawo okweetaba mu musomo nga weyagalidde, ojja kusabibwa okussa omukono ku kiwaandiiko ky'okukkirizza. Omunoonyereza omukulu oba omuyaambi w'okunoonyerezza omutendeke bajja kukutegeeza ebikwaata ku musomo. Era ajja kukusaba okuddamu ku bibuuzo ebyangu nga bikwaata ku kunoonyereza nga bakozesa olupapula. Osobola okuva mu kweetaba kunno obudde bwonna nga tobonerezeddwa. Bwosalawo obuteetaba mu musomo tekijja kutaataaganya mu ngeri yonna ndabilira yo mu by'eddagala.

**Ani aneetaba mu kunoonyerezza:**

Abaana n'abavubuka 372 abalina obulwadde bwa sickle cell n'ababalabirira abajja mu kilinika ya sickle cell mu ddwaliro ly'eggwanga elijjulirwaamu e Mulago nga bazze mu kiseera eky'omusomo era nga batuukirila n'ebyeetaagisa okuyingila mu musomo.

**Obulabe n'okutaataaganyizibwa:**

Tewali bulabe bwonna obusuubilwa mu kiseera ky'omusomo.

**Emiganyulo:**

Tewajja kubaawo miganyulo gilabwaako gyooli naye bwiino anakuŋŋaanyizibwa ajja kutuyamba mu kutereeza ko n'okulaba amaangu ebizibu mu kweebaka mu baana abajja mu kilinika y'enddwadde z'abaana ku OPD mu ddwaliro ly'eggwanga elijjulirwaamu e Mulago

**Okukuuma ebyaama:**

Byonna byonatuddamu bijja kukuumibwa nga bya kyaama era byakuggalirwa mu kasanduke era nga omunonyoereza omukulu yekka yanasobola okubilaba. Ebikukwaatako nga omuntu bijja kukweekebwa Bwiino anakuŋŋaanyizibwa ajja kuba alabibwaako abo bokka abakola ku musomo, Akakiiko ka Makerere School of Medicine Research Ethics Committee (Mak-

SOMREC) ko n'akakiiko ka Uganda aka sayaansi ne tekinologiya (UNCST) bano bebayiinza okutuuka ku bwiino akukwaatako nga sekinoomu, gunno gwe gumu ku milimu gyebakola okusobola okukukuuma ko n'eddembe lyo nga oli mu musomo.

**Eby'okuloondako:**

Okweetaba mu musomo gunno kwa bwa nakyeewa era osobola okusalawo okujja ku nkyaala zo eza bulijjo eza kilinika nebwooba tewetabye mu musomo guno.

**Okusasulila:**

Tewali bikwata ku nsaasaanya ya sente eri oyo eyeetabye.

**Okuliyilirwa kulwentambula olw'okweetaba mu musomo:**

Buli mwaana oba omuvubuka ajja kufunayo omutwaalo gumu ogwa Uganda (10,000) ate ku lw'obudde bwaabwe.

**Okuddizibwaayo:**

Abeetabi tebajja kuddizibwa sente ku lw'entambula yabwe.

**Ebibuuzo ebikwaata ku musomo:**

Singa obeera nebibuuzo ebikwaata mu musomo mwattu tuukirila omusawo: Abdulkadir Abdullahi Ahmed, mu kitongole ky'enddwadde z'emitwe mu ssetendekero wa Makerere kolegi ya sayaansi w'eby'obulamu ku namba ya ssimu 0708571916 omukutu: ahmedabdulkadir2025@gmail.com

**Ebibuuzo ebikwaata ku ddembe lya abeetabi:**

Bwooba olina ebibuuzo ebikwaata ku ddembe lyo nga omweetabi mu kunoonyerezza, binno osobola okubitwaala eri sentebe w'akakiiko akakwaasisa empisa mu kunoonyereza ak'essomero ly'eby'eddagala, Kakeensa. Ponsiano Ocama ku namba ya ssimu: +256 772-421-190

**Olunyilili lw'obwa nakyeewa:**

Okweetaba mu musomo gunno kwa bwa nakyeewa ddala era buli muntu agweetabamu nga yeyagalidde yye kenyini. Abeetabi balina eddembe okuva mu musomo obudde bwoona nga tebabonerezeddwa.

**Okusaasaanya ebizuuliddwa:**

Abeetabi bajja kufuna okumanyisibwa ku bizuuliddwa okuva mu musomo era bajja kutegeezebwa ne ku bwiino yenna omupya nga akosa oba nga wa mugaso mu by'ekisawo ( nga munno mwotwaalidde ebinaaba bizuuliddwa mu butanwa) binno byonna bijja kuba bisobola okutuukibwaako omweetabi oba abo abamukolako mu by'obulamu.

**Okukakasa enkola:**

Omusomo gunno gwakakasibwa akakiiko aka Makerere School of Medicine Research Ethics Committee (Mak-SOMREC) akakakasizibwa akakiiko ka Uganda akakwaasisa empisa mu kunoonyereza (UNCST).

**Olukusa:**

Ekiwandiiko ky'okukkiriza.

..... Ntegedde nti okusalawo kwange okwetaba mu kunoonyereza kuno tekijja kukyusa bujjanjabi bwange obwa bulijjo. Mu nkozesa y'amawulire gano, endagamuntu yange ejja kukwekebwa. Nkimanyi nti nnyinza okuggyayo essaawa yonna. Ntegedde nti nga nssa emikono ku ffoomu eno, sikyewaayo ku ddembe lyange lyonna ery'amateeka wabula lirambika bulaga nti ntegeezeddwa ku kunoonyereza kuno kwe nzikiriziganya kyeyagalire okwetabamu. Kopi ya foomu eno ejja kuweebwa.

Erinnya ly'omuzadde/omukuza w'abaana abatanneetuuka …….....

Omukono gw'omuzadde/omukuza w'abaana abatanneetuuka .....

Olunaku olw'omweezi ……...

Erinnya ly'Omujulizi .....

Omukono gw'omujulizi ..... olunaku .....

Erinnya ly'oyo abuuza/omuntu okufuna okukkiriza okutegeerekese .....

Omukono gw'oyo abuuza/omuntu okufuna okukkiriza okutegeerekese ..... olunaku.....

## APPENDIX III: ASSENT FORM

**Title of the proposed study:**

PREVALENCE AND FACTORS ASSOCIATED WITH SLEEP DISTURBANCE AMONG CHILDREN AND ADOLESCENTS WITH SICKLE CELL DISEASE AT MULAGO NATIONAL REFERRAL HOSPITAL.

**Investigators:**

Dr Abdulkadir Abdullahi Ahmed, Department of Psychiatry Makerere University College of Health Science. Tel. No. 0700870924. Email address: ahmedabdulkadir2025@gmail.com

**Background and rationale for the study:**

Sleep disturbancess involve problems with the quality, timing, and amount of sleep, which result in daytime distress and impairment in functioning. Nearly 25% of all children experience some form of sleep disturbance during their development. Globally, the burden of sleep disturbances has been reported to be close to 80% in some countries. If screened and diagnosed early, sleep disturbances can be managed and prevent the complications. The study will involve 372 children and adolescents with sickle cell disease, as well as their caregivers reporting at paediatric OPD of hospitals of Mulago National Referral Hospital during the study period and meet the eligibility criteria. The children and adolescents who provide informed assent and their caregivers who will provide informed consents, will be selected consecutively and the Sleep Disturbance Scale for Children administered to collect data on the sleep disturbance. The data collected will be analysed to determine the magnitude of sleep disturbance and the characteristics that increase the risk sleep disturbance. The results from the study will be used by clinicians to provide timely screening and referrals of children and adolescents who are at a higher risk of having sleep disturbance.

**A description of sponsors of the research project and the organizational affiliation of the researchers:**

The above research is self-sponsored by Dr Abdulkadir Ahmed and is affiliated to Makerere University.

**Purpose:**

The purpose of the study is to determine the magnitude of sleep disturbance and the factors that predict the occurrence among children and adolescents at Mulago National Referral Hospital.

This study will provide an evidence base for clinicians to provide timely screening and referrals of children with sickle cell anaemia who are at a higher risk of having altered sleep patterns and behaviour.

**The estimated duration the research participant will take to in the research project:**

The entire study shall take place for three months. Consenting for the study and filling the questionnaire will take between 20-30 minutes of your time.

**Procedures:**

If you voluntarily choose to participate in the study, you will be asked to sign an informed consent form. The principal investigator and/or a trained research assistant will brief you on the study. He/she will then ask you to answer some simple research questions using our questionnaire which will take about 20 minutes. You may withdrawal from participation at any time without consequences. If you decline to join the study, it will not affect your access to medical care in any way.

**Who will participate in the study:**

A total of 372 children and adolescents with sickle cell and their caregivers reporting at sickle cell clinic of Mulago National Referral Hospital during the study period and meet the eligibility criteria.

**Risks/Discomforts:**

There are minimal risks expected during this study.

**Benefits:**

There are no direct benefits to you, but the information gathered will help us to improve the chances of detecting and managing sleeping disorders in other children attending Mulago National Referral Hospital.

**Confidentiality:**

All your responses will be kept confidential under lock and key and will only be accessible to the principal investigator. Your identity will not be revealed but information collected will be seen by those involved in this study. The School of Medicine Research Ethics Committee of Makerere College of Health Sciences (Mak-SOMREC) and the Uganda National Council for

Science and Technology (UNCST) may have access to your private information as part of their duty to protect your rights.

**Alternatives:**

Participation in this study is voluntary and you can choose to continue with your routine clinic visit other than participating in the study.

**Cost:**

There are no cost implications to the participant.

**Compensation for participation in the study:**

Each child or adolescent will receive 10,000 Uganda shillings in compensation for your time.

**Reimbursement:**

Participants will not receive transport reimbursement since they will be met at the sickle cell unit.

**Questions about the study:**

Dr Abdulkadir Abdullahi Ahmed, Department of Psychiatry Makerere University College of Health Science. Tel. No. +256 700 870 924.

Email address: ahmedabudlkadir2025@gmail.com.

**Questions about participants rights:**

If you have questions about your rights as a research participant, you can have your concerns addressed to the chairman school of medicine research and ethics committee, Prof. Ponsiano Ocama Mobile: +256 772-421-190

**Statement of voluntariness:**

Participation in this study is purely voluntary and one joins at his/her own free will. Participants have a right to withdraw from the study at any time without penalty.

**Dissemination of results:**

Participants will get feedback on the findings of the study and any new information that affects the study or data that has clinical relevance to participants (including incidental findings) will be made available to participants and/or their health care providers.

**Ethical approval:**

This study has been approved by the Makerere School of Medicine Research Ethics Committee (Mak-SOMREC) which is accredited by the Uganda National Council of Science and Technology (UNCST).

**Consent:**

**STATEMENT OF ASSENT**

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

Name of child/adolescent ……

Signature/ thumbprint ……. Date ……....

Name of witness ……

Signature of witness ……..…… Date ……

Name of interviewer/person obtaining informed consent …….

Signature of interviewer/person obtaining informed consent ……

Date……...

## APPENDIX IV: TRANSLATED ASSENT FORM

**Omutwe gw'omusomo:**

**OBUUNJI N'ENSONGA EZEEKUUSA KU BIZIBU BY'OKWEEBAKA MU BAANA KO N'ABAVUBUKA ABALINA SICKLE CELL MU DDWALIRO LY'EGGWANGA MULAGO.**

**Abanoonyereza:**

Omusawo: Abdulkadir Abdullahi Ahmed, Master mu by'obusawo mu by'emitwe ku ssetendekero wa Makerere kolegi ya sayansi w'eby'obulamu

Simu: 0700870924, omukutu: ahmedabdulkadir2025@gmail.com

**Ennyanjula n'enkola y'omusomo:**

Ebizibu mu kweebaka mulimu, omutindo, biseera ki ne ebbanga ly'otwaala nga weebase nga binno bivaamu obutaba na mirembe mu budde obw'emisana n'obutaba na busobozi kukola byooteekeddwa okukola. Kumpi ebituundu 25% ku baana bonna bafuna ebuzibu mu kweebaka bwebaba bakula. Mu nsi yonna ebuzibu bw'okweebaka bwogerwaako okuba nga bukunukkirizza ebituundutuundu kinaana ku buli kikumi (80%) mu nsi ezimu. Bwebuba bukebeddwa era nebulabibwa mangu, busobola okujjanjabwa era netutaasa ebizibu byaabwo. Omusomo gujja kubeeramu abaana ko n'abavubuka 372 n'abajjanjabi babwe abajja mu kiseera ky'omusomo ku OPD mu ddwalliro ly'eggwanga elijjulirwaamu e Mulago era nga batuukilila n'ebyeetaagisa okubeera mu musomo. Abaana n'abavubuka ko n'abajjanjabi abanaatuwa okukkiriza kwabwe bajja kubuuzibwa ne Sleep Disturbance Scale for Children (SDSC) era bajja kukeberebwa ku mbeera z'okweebaka era bwiino akuŋŋaanyizibwe ku buzibu bwaabwe mu kweebaka. Bwiino onno ajja kweekeneenyezebwa okusobola okulaba obuungi bwe ebizibu mu kweebaka na biki ebyoongera ku bulabe bw'ekizibu kinno. Ebinaava mu musomo gunno bijja kukozesebwa abasawo okusobola okulaba mu budde ko n'okujjulizza abaana n'abavubuka abali mu bulabe obwa wagggulu obw'okufuna obuzibu mu kweebaka.

**Okunyonyola ku basasulira omusomo ko n'enkwaatagana y'ebitongole bya abanoonyereza:**

Omusomo ogwo waggulu ngweesasulila era gukwaatagana ne ssetendekero wa Makerere.

**Omulamwa:**

Omulamwa gw'omusomo kwe kulaba obuungi bwe ebizibu mu kweebaka n'ensoonga ez'ekuusa ku kubutegeera amaangu mu baana ko n'abavubuka mu ddwaliro ly'eggwanga elijjulirwaamu e Mulago.

Ekiseera mu kugerageranya omweetabi ky'anamala mu musomo gw'okunoonyereza:

Omusomo gwonna gujja kutwaala emyeezi esatu. Okukkirizaakwo okweetaba mu musomo ko n'okuddamu ebibuuzo kujja kutwaala wakati w'eddakiika abiri ku asatu (20-30) ku budde bwo.

**Enkola:**

Singa osalawo okweetaba mu musomo nga weyagalidde, ojja kusabibwa okussa omukono ku kiwaandiiko ky'okukkirizza. Omunoonyereza omukulu oba omuyaambi w'okunoonyerezza omutendeke bajja kukutegeeza ebikwaata ku musomo. Era ajja kukusaba okuddamu ku bibuuzo ebyangu nga bikwaata ku kunoonyereza nga bakozesa olupapula. Osobola okuva mu kweetaba kunno obudde bwonna nga tobonerezeddwa. Bwosalawo obuteetaba mu musomo tekijja kutaataaganya mu ngeri yonna ndabilira yo mu by'eddagala.

**Ani aneetaba mu kunoonyerezza:**

Abaana n'abavubuka 372 abalina obulwadde bwa sickle cell n'ababalabirira abajja mu kilinika ya sickle cell mu ddwaliro ly'eggwanga elijjulirwaamu e Mulago nga bazze mu kiseera eky'omusomo era nga batuukirila n'ebyeetaagisa okuyingila mu musomo.

**Obulabe n'okutaataaganyizibwa:**

Tewali bulabe bwonna obusuubilwa mu kiseera ky'omusomo.

**Emiganyulo:**

Tewajja kubaawo miganyulo gilabwaako gyooli naye bwiino anakuŋŋaanyizibwa ajja kutuyamba mu kutereeza ko n'okulaba amaangu ebizibu mu kweebaka mu baana abajja mu kilinika y'enddwadde z'abaana ku OPD mu ddwaliro ly'eggwanga elijjulirwaamu e Mulago

**Okukuuma ebyaama:**

Byonna byonatuddamu bijja kukuumibwa nga bya kyaama era byakuggalirwa mu kasanduke era nga omunonyoereza omukulu yekka yanasobola okubilaba. Ebikukwaatako nga omuntu bijja kukweekebwa Bwiino anakuŋŋaanyizibwa ajja kuba alabibwaako abo bokka abakola ku musomo, Akakiiko ka Makerere School of Medicine Research Ethics Committee (Mak-

SOMREC) ko n'akakiiko ka Uganda aka sayaansi ne tekinologiya (UNCST) bano bebayiinza okutuuka ku bwiino akukwaatako nga sekinoomu, gunno gwe gumu ku milimu gyebakola okusobola okukukuuma ko n'eddembe lyo nga oli mu musomo.

**Eby'okuloondako:**

Okweetaba mu musomo gunno kwa bwa nakyeewa era osobola okusalawo okujja ku nkyaala zo eza bulijjo eza kilinika nebwooba tewetabye mu musomo guno.

**Okusasulila:**

Tewali bikwata ku nsaasaanya ya sente eri oyo eyeetabye.

**Okuliyilirwa kulwentambula olw'okweetaba mu musomo:**

Buli mwaana oba omuvubuka ajja kufunayo omutwaalo gumu ogwa Uganda (10,000) ate ku lw'obudde bwaabwe.

**Okuddizibwaayo:**

Abeetabi tebajja kuddizibwa sente ku lw'entambula yabwe.

**Ebibuuzo ebikwaata ku musomo:**

Singa obeera nebibuuzo ebikwaata mu musomo mwattu tuukirila omusawo: Abdulkadir Abdullahi Ahmed, mu kitongole ky'enddwadde z'emitwe mu ssetendekero wa Makerere kolegi ya sayaansi w'eby'obulamu ku namba ya ssimu 0708571916 omukutu: ahmedabdulkadir2025@gmail.com

**Ebibuuzo ebikwaata ku ddembe lya abeetabi:**

Bwooba olina ebibuuzo ebikwaata ku ddembe lyo nga omweetabi mu kunoonyerezza, binno osobola okubitwaala eri sentebe w'akakiiko akakwaasisa empisa mu kunoonyereza ak'essomero ly'eby'eddagala, Kakeensa. Ponsiano Ocama ku namba ya ssimu: +256 772-421-190

**Olunyilili lw'obwa nakyeewa:**

Okweetaba mu musomo gunno kwa bwa nakyeewa ddala era buli muntu agweetabamu nga yeyagalidde yye kenyini. Abeetabi balina eddembe okuva mu musomo obudde bwoona nga tebabonerezeddwa.

**Okusaasaanya ebizuuliddwa:**

Abeetabi bajja kufuna okumanyisibwa ku bizuuliddwa okuva mu musomo era bajja kutegeezebwa ne ku bwiino yenna omupya nga akosa oba nga wa mugaso mu by'ekisawo ( nga munno mwotwaalidde ebinaaba bizuuliddwa mu butanwa) binno byonna bijja kuba bisobola okutuukibwaako omweetabi oba abo abamukolako mu by'obulamu.

**Okukakasa enkola:**

Omusomo gunno gwakakasibwa akakiiko aka Makerere School of Medicine Research Ethics Committee (Mak-SOMREC) akakakasizibwa akakiiko ka Uganda akakwaasisa empisa mu kunoonyereza (UNCST).

**Olukusa:**

Ekiwandiiko ky'okukkiriza.

..... Ntegedde nti okusalawo kwange okwetaba mu kunoonyereza kuno tekijja kukyusa bujjanjabi bwange obwa bulijjo. Mu nkozesa y'amawulire gano, endagamuntu yange ejja kukwekebwa. Nkimanyi nti nnyinza okuggyayo essaawa yonna. Ntegedde nti nga nssa emikono ku ffoomu eno, sikyewaayo ku ddembe lyange lyonna ery'amateeka wabula lirambika bulaga nti ntegeezeddwa ku kunoonyereza kuno kwe nzikiriziganya kyeyagalire okwetabamu. Kopi ya foomu eno ejja kuweebwa.

Erinnya ly'omwana …….....

Omukono gw'omwana..... Olunaku olw'omweezi ……...

Erinnya ly'Omujulizi .....

Omukono gw'omujulizi ..... Olunaku olw'omwezi.....

Erinnya ly'oyo abuuza/omuntu okufuna okukkiriza okutegeerekese .....

Omukono gw'oyo abuuza/omuntu okufuna okukkiriza okutegeerekese ..... olunaku.....

## APPENDIX V: DATA COLLECTION TOOL

**Date of Interview: …….……. Initials of Participant: …….**

**Study ID: …….**

**SECTION A: SOCIODEMOGRAPHIC FACTORS**

| Variable | Question | Categories |
|---|---|---|
| **Age** | How old is the child? | |
| **Sex** | | ☐Male<br>☐Female |
| **Height of the child** | Height in meters | |
| **Weight of the child** | Weight in Kgs | |
| **Body Mass Index** | | |
| **Residence address** | | |
| **Education** | What level of education are you currently attending? | ☐ None<br>☐ Nursery<br>☐Primary<br>☐Secondary |

**SECTION B: CLINICAL CHARACTERISTICS**

1. Does your child take hydroxyurea? ☐Yes ☐No
2. Does your child take folic acid? ☐Yes ☐No
3. Does your child take malaria prophylaxis? ☐Yes ☐No
4. Does your child take penicillin prophylaxis? ☐Yes ☐No
5. How many blood transfusions has your child had in the last six months?.....
6. How many painful episodes has your child had in the past six months?.....

7. Has your child had a stroke in the last six months? ☐Yes ☐No

**SECTION C: SLEEP DISTURBANCE SCALE FOR CHILDREN**

***INSTRUCTIONS****: This questionnaire will allow us to have a better understanding of the sleep-wake rhythm of your child and of any problems in his/her sleep behavior. Try to answer every question; in answering, consider each question as pertaining to the* ***past 6 months*** *of the child's life. Please answer the questions by circling or striking the number 1 to 5.*

| | | | | | |
|---|---|---|---|---|---|
| How many hours of sleep does your child get on most nights? | 1 *9-11 hours* | 2 *8-9 hours* | 3 *7-8 hours* | 4 *5-7 hours* | 5 *less than 5 hours* |
| How long after going to bed does your child usually fall asleep? | 1 *less than 15'* | 2 *15-30'* | 3 *30-45'* | 4 *45-60'* | 5 *more than 60'* |

| | | | | | |
|---|---|---|---|---|---|
| 5 **Always (daily)** | | | | | |
| 4 **Often (3 or 5 times per week)** | | | | | |
| 3 **Sometimes (once or twice per week)** | | | | | |
| 2 **Occasionally (once or twice per month or less)** | | | | | |
| 1 **Never** | | | | | |
| The child goes to bed reluctantly | 1 | 2 | 3 | 4 | 5 |
| The child has difficulty getting to sleep at night | 1 | 2 | 3 | 4 | 5 |
| The child feels anxious or afraid when falling asleep | 1 | 2 | 3 | 4 | 5 |

| | | | | | |
|---|---|---|---|---|---|
| The child startles or jerks parts of the body while falling asleep | 1 | 2 | 3 | 4 | 5 |
| The child shows repetitive actions such as rocking or head banging while falling asleep | 1 | 2 | 3 | 4 | 5 |
| The child experiences vivid dream-like scenes while falling asleep | 1 | 2 | 3 | 4 | 5 |
| The child sweats excessively while falling asleep | 1 | 2 | 3 | 4 | 5 |
| ). The child wakes up more than twice per night | 1 | 2 | 3 | 4 | 5 |
| . After waking up in the night, the child has difficulty to fall asleep again | 1 | 2 | 3 | 4 | 5 |
| . The child has frequent twitching or jerking of legs while asleep or often changes position during the night or kicks the covers off the bed. | 1 | 2 | 3 | 4 | 5 |
| . The child has difficulty in breathing during the night | 1 | 2 | 3 | 4 | 5 |
| . The child gasps for breath or is unable to breathe during sleep | 1 | 2 | 3 | 4 | 5 |
| . The child snores | 1 | 2 | 3 | 4 | 5 |
| . The child sweats excessively during the night | 1 | 2 | 3 | 4 | 5 |
| . You have observed the child sleepwalking | 1 | 2 | 3 | 4 | 5 |
| . You have observed the child talking in his/her sleep | 1 | 2 | 3 | 4 | 5 |
| . The child grinds teeth during sleep | 1 | 2 | 3 | 4 | 5 |

| | | | | | |
|---|---|---|---|---|---|
| ). The child wakes from sleep screaming or confused so that you cannot seem to get through to him/her, but has no memory of these events the next morning | 1 | 2 | 3 | 4 | 5 |
| . The child has nightmares which he/she doesn't remember the next day | 1 | 2 | 3 | 4 | 5 |
| . The child is unusually difficult to wake up in the morning | 1 | 2 | 3 | 4 | 5 |
| . The child awakes in the morning feeling tired | 1 | 2 | 3 | 4 | 5 |
| . The child feels unable to move when waking up in the morning | 1 | 2 | 3 | 4 | 5 |
| . The child experiences daytime somnolence | 1 | 2 | 3 | 4 | 5 |
| . The child falls asleep suddenly in inappropriate situations | 1 | 2 | 3 | 4 | 5 |
| Disorders of initiating and maintaining sleep (sum the score of the items 1,2,3,4,5,10,11) | | | | | |
| Sleep Breathing Disorders (sum the score of the items 13,14,15) | | | | | |
| Disorders of arousal (sum the score of the items 17,20,21) | | | | | |
| Sleep-Wake Transition Disorders (sum the score of the items 6,7,8,12,18,19) | | | | | |
| Disorders of excessive somnolence (sum the score of the items 22,23,24,25,26) | | | | | |
| Sleep Hyperhydrosis (sum the score of the items 9,16) | | | | | |
| Total score (sum 6 factors' scores) | | | | | |

*After summing the scores for the different scales report the values in the scoring sheet in order to obtain a sleep profile*

Appendix B. SDSC Scoring Sheet

Name: _____ Age: _____

| T score | DIMS | SBD | DA | SWTD | DOES | SHY | TOTAL | T score |
|---|---|---|---|---|---|---|---|---|
| 100+ | **26+** | **11+** | **8+** | **21+** | **20+** | | **74+** | 100+ |
| 99 | **25** | | | **20** | | | **73** | 99 |
| 98 | | | | | | | **72** | 98 |
| 97 | | | | | | | **71** | 97 |
| 95 | **24** | | | **19** | **19** | | **70** | 95 |
| 94 | | | **7** | | | | **69** | 94 |
| 93 | **23** | **10** | | **18** | **18** | **10** | **68** | 93 |
| 90 | | | | | | | **66** | 90 |
| 89 | **22** | | | | | | **65** | 89 |
| 88 | | | | | **17** | | **64** | 88 |
| 86 | **21** | **9** | | **17** | | **9** | **63** | 86 |
| 85 | | | | | **16** | | **62** | 85 |

| | | | | | | | | |
|---|---|---|---|---|---|---|---|---|
| 84 | | | | **16** | | | **61** | 84 |
| 82 | **20** | | **6** | | | | **60** | 82 |
| 81 | | | | | **15** | | **59** | 81 |
| 80 | | | | | | **8** | **58** | 80 |
| 79 | **19** | **8** | | **15** | | | **57** | 79 |
| 77 | | | | | **14** | | **56** | 77 |
| 76 | **18** | | | | | | **55** | 76 |
| 75 | | | | **14** | | **7** | **54** | 75 |
| 73 | **17** | | | | **13** | | **53** | 73 |
| 72 | | **7** | | | | | **52** | 72 |
| 70 | **16** | | **5** | **13** | | | **51** | 70 |
| 69 | | | | | **12** | **6** | **50** | 69 |
| 68 | | | | | | | **49** | 68 |
| 67 | | | | | | | **48** | 67 |
| 66 | **15** | | | **12** | | | **47** | 66 |
| 64 | **14** | **6** | | | **11** | **5** | **46** | 64 |

| | | | | | | | | |
|---|---|---|---|---|---|---|---|---|
| 63 | | | | | | | **45** | 63 |
| 62 | | | | **11** | **10** | | **44** | 62 |
| 60 | **13** | | | | | | **43** | 60 |
| 59 | | | | | | | **42** | 59 |
| 58 | **12** | **5** | **4** | **10** | **9** | **4** | **41** | 58 |
| 56 | | | | | | | **40** | 56 |
| 55 | | | | | | | **39** | 55 |
| 54 | **11** | | | **9** | | | **38** | 54 |
| 53 | | | | | **8** | | **37** | 53 |
| 51 | | **4** | | | | **3** | **36** | 51 |
| 50 | **10** | | | **8** | **7** | | **35** | 50 |
| 49 | | | | | | | **34** | 49 |
| 47 | **9** | | **3** | | | | **33** | 47 |
| 46 | | | | | **6** | | **32** | 46 |
| 45 | **8** | **3** | | **7** | | **2** | **31** | 45 |
| 42 | | | | | **5** | | **29** | 42 |

| | | | | | | | | |
|---|---|---|---|---|---|---|---|---|
| 41 | **7** | | | **6** | | | **28** | 41 |
| 40 | | | | | | | **27** | 40 |
| 38 | | **2** | | | **4** | **1** | **26** | 38 |

## APPENDIX VI: TRANSLATED DATA COLLECTION TOOL

Olunaku lw'omusomo: ……. Amanya mu bufunze: ……

Namba ID: ……

**Ekitundu A: Ensonga z'embeera z'abantu**

| **Variable** | **Ekibuuzo** | **Ekiddibwamu** |
|---|---|---|
| **Emyaka** | Omwana alina emyaka emeka? | |
| **Sex** | | ☐Mulenzi<br>☐Muwala |
| **Obuwanvu bw'omwana** | Obuwanvu mu mita | |
| **Obuzito bw'omwana** | Obuzito mu kilo | |
| **Body Mass Index** | | |
| **Endagiriro y'obutuuze** | | |
| **Okusoma** | level ki ey'obuyigirize gy'oliko mu kiseera kino? | ☐ Tewali<br>☐ Musingi<br>☐Pulayimale<br>☐Siniya |

**Ekitundu B: Embeera z'ebyobulamu**

1. Omwana wo amira Hydroxyurea? ☐Ye ☐Nedda
2. Omwana wo amira folic acid? ☐Ye ☐Nedda
3. Omwana wo amira omusujja gw'ensiri? ☐Ye ☐Nedda
4. Omwana wo amira eddagala lya penicillin prophylaxis? ☐Ye ☐Nedda

5. Okuteekebwamu omusaayi kumeka omwana wo mu myezi omukaaga egiyise?.....
6. Ebitundu bimeka ebiruma omwana wo bye yalina mu myezi mukaaga egiyise?.....
7. Omwana wo alina obulwadde bwa stroke mu myezi omukaaga egiyise? ☐Ye ☐Nedda

**Ekitundu C: Onuzibu bw'okwebaka kw'abaana**

***Ebiragiro:*** *Ekibuuzo kino kijja kutusobozesa okutegeera obulungi ennyimba z'omwana wo n'ebizibu byonna mu nneeyisa ye ey'okwebaka. Gezaako okuddamu buli kibuuzo; Mu kuddamu, buli kibuuzo kitwale ng'ekikwata ku myezi 6 egiyise egy'obulamu bw'omwana. Nsaba oddemu ebibuuzo nga weetooloola oba okukuba ennamba 1 okutuuka ku 5.*

| | | | | | |
|---|---|---|---|---|---|
| 1. Omwana wo afuna otulo otumala essaawa mmeka? | 1 *Sawa 9-11* | 2 *Sawa 8-9* | 3 *Sawa 7-8* | 4 *Sawa 5-7* | 5 *Wansi w'esawa 5* |
| Omwana wo amala bbanga ki nga tanebaka oluvvanyuma lwokugenda mubulili? | 1 *Wansi w'edakia 15'* | 2 *15-30'* | 3 *30-45'* | 4 *45-60'* | 5 *Waggulu w'edakika 60'* |

| | | | | | |
|---|---|---|---|---|---|
| 5 **Bulijjo (buli lunaku)** | | | | | |
| 4 **Ebiseera ebisinga (emirundi 3 oba 5 buli wiiki)** | | | | | |
| 3 **Oluusi (omulundi gumu oba ebiri buli wiiki)** | | | | | |
| 2 **Oluusi n'oluusi (omulundi gumu oba ebiri buli mwezi oba wansi)** | | | | | |
| 1 **Tekibangawo** | | | | | |
| Omwana agenda okwebaka nga tayagala | 1 | 2 | 3 | 4 | 5 |

| | | | | | |
|---|---|---|---|---|---|
| Omwana alina obuzibu okwebaka ekiro | 1 | 2 | 3 | 4 | 5 |
| Omwana awulira nga mweraliikirivu oba nga atya nga yeebaka | 1 | 2 | 3 | 4 | 5 |
| Omwana awuniikiriza oba asika ebitundu by'omubiri ng'agwa mu tulo | 1 | 2 | 3 | 4 | 5 |
| Omwana alaga ebikolwa ebiddiŋŋana ng'okukankana oba okukuba omutwe ng'ate yeebaka | 1 | 2 | 3 | 4 | 5 |
| Omwana afuna ebifaananyi ebirabika obulungi ebiringa ekirooto nga yeebaka | 1 | 2 | 3 | 4 | 5 |
| Omwana atuuyana nnyo nga yeebaka | 1 | 2 | 3 | 4 | 5 |
| ). Omwana azuukuka emirundi egisukka mu ebiri buli kiro | 1 | 2 | 3 | 4 | 5 |
| . Oluvannyuma lw'okuzuukuka ekiro, omwana afuna obuzibu okuddamu okwebaka | 1 | 2 | 3 | 4 | 5 |
| . Omwana yebaka nga asamba amagulu oba yekyusa nnyo mukiro nga yebase | 1 | 2 | 3 | 4 | 5 |
| . Omwana alina obuzibu mu kussa ekiro | 1 | 2 | 3 | 4 | 5 |
| . Omwana asika omukka oba tasobola kussa nga yeebaka | 1 | 2 | 3 | 4 | 5 |
| . Omwana afuluuta | 1 | 2 | 3 | 4 | 5 |
| . Omwana atuuyana ekisusse mu kiro | 1 | 2 | 3 | 4 | 5 |
| . Olabye omwana ng'atambula nga yebase | 1 | 2 | 3 | 4 | 5 |

| | | | | | |
|---|---|---|---|---|---|
| 3. Olabye omwana ng'ayogera mu tulo ye | 1 | 2 | 3 | 4 | 5 |
| 9. Omwana agaya amannyo nga yeebase | 1 | 2 | 3 | 4 | 5 |
| 0. Omwana azuukuka okuva mu tulo ng'akuba enduulu oba ng'asobeddwa osobole okulabika ng'oyita mu ye/ye, naye nga talina kijjukizo kya bintu bino enkeera ku makya | 1 | 2 | 3 | 4 | 5 |
| . Omwana alina ebirooto ebibi by'atajjukira enkeera | 1 | 2 | 3 | 4 | 5 |
| 2. Omwana muzibu mu ngeri etaali ya bulijjo okuzuukuka ku makya | 1 | 2 | 3 | 4 | 5 |
| . Omwana azuukuka ku makya ng'awulira ng'akooye | 1 | 2 | 3 | 4 | 5 |
| 4. Omwana awulira nga tasobola kutambula ng'azuukuka ku makya | 1 | 2 | 3 | 4 | 5 |
| 5. Omwana afuna emisana somnolence | 1 | 2 | 3 | 4 | 5 |
| 6. Omwana yeebaka mu bwangu mu mbeera ezitasaana | 1 | 2 | 3 | 4 | 5 |
| Obuzibu bw'okutandika n'okukuuma otulo (Omugatte gwa 1,2,3,4,5,10,11) | | | | | |
| Obuzibu mu kussa mu tulo (Omugatte gwa 13,14,15) | | | | | |
| Obuzibu bw'okuzukuka (Omugatte gwa 17,20,21) | | | | | |
| Obuzibu bw'okwebaka n'okuzuukuka (Omugatte gwa 6,7,8,12,18,19) | | | | | |
| Obuzibu bw'okusukkulumya ku bulwadde bwa somnolence (Omugatte gwa 22,23,24,25,26) | | | | | |

| | |
|---|---|
| Obuzibu bw'okutuyana ennyo (Omugatte gwa 9,16) | |
| Omugatte (sum 6 factors' scores) | |

*After summing the scores for the different scales report the values in the scoring sheet in order to obtain a sleep profile*

Appendix B. SDSC Scoring Sheet

Name: _____ Age: _____

| T score | DIMS | SBD | DA | SWTD | DOES | SHY | TOTAL | T score |
|---|---|---|---|---|---|---|---|---|
| 100+ | **26+** | **11+** | **8+** | **21+** | **20+** | | **74+** | 100+ |
| 99 | **25** | | | **20** | | | **73** | 99 |
| 98 | | | | | | | **72** | 98 |
| 97 | | | | | | | **71** | 97 |
| 95 | **24** | | | **19** | **19** | | **70** | 95 |
| 94 | | | **7** | | | | **69** | 94 |
| 93 | **23** | **10** | | **18** | **18** | **10** | **68** | 93 |
| 90 | | | | | | | **66** | 90 |
| 89 | **22** | | | | | | **65** | 89 |

| | | | | | | | | |
|---|---|---|---|---|---|---|---|---|
| 88 | | | | | **17** | | **64** | 88 |
| 86 | **21** | **9** | | **17** | | **9** | **63** | 86 |
| 85 | | | | | **16** | | **62** | 85 |
| 84 | | | | **16** | | | **61** | 84 |
| 82 | **20** | | **6** | | | | **60** | 82 |
| 81 | | | | | **15** | | **59** | 81 |
| 80 | | | | | | **8** | **58** | 80 |
| 79 | **19** | **8** | | **15** | | | **57** | 79 |
| 77 | | | | | **14** | | **56** | 77 |
| 76 | **18** | | | | | | **55** | 76 |
| 75 | | | | **14** | | **7** | **54** | 75 |
| 73 | **17** | | | | **13** | | **53** | 73 |
| 72 | | **7** | | | | | **52** | 72 |
| 70 | **16** | | **5** | **13** | | | **51** | 70 |
| 69 | | | | | **12** | **6** | **50** | 69 |
| 68 | | | | | | | **49** | 68 |
| 67 | | | | | | | **48** | 67 |

| | | | | | | | | |
|---|---|---|---|---|---|---|---|---|
| 66 | **15** | | | **12** | | | **47** | 66 |
| 64 | **14** | **6** | | | **11** | **5** | **46** | 64 |
| 63 | | | | | | | **45** | 63 |
| 62 | | | | **11** | **10** | | **44** | 62 |
| 60 | **13** | | | | | | **43** | 60 |
| 59 | | | | | | | **42** | 59 |
| 58 | **12** | **5** | **4** | **10** | **9** | **4** | **41** | 58 |
| 56 | | | | | | | **40** | 56 |
| 55 | | | | | | | **39** | 55 |
| 54 | **11** | | | **9** | | | **38** | 54 |
| 53 | | | | | **8** | | **37** | 53 |
| 51 | | **4** | | | | **3** | **36** | 51 |
| 50 | **10** | | | **8** | **7** | | **35** | 50 |
| 49 | | | | | | | **34** | 49 |
| 47 | **9** | | **3** | | | | **33** | 47 |
| 46 | | | | | **6** | | **32** | 46 |
| 45 | **8** | **3** | | **7** | | **2** | **31** | 45 |

| | | | | | | | | |
|---|---|---|---|---|---|---|---|---|
| 42 | | | | | **5** | | **29** | 42 |
| 41 | **7** | | | **6** | | | **28** | 41 |
| 40 | | | | | | | **27** | 40 |
| 38 | | **2** | | | **4** | **1** | **26** | 38 |

# APPENDIX VII: ADMINISTRATIVE CLEARANCE

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

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

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

23rd June 2025.

**Dr. Abdulkadir Abdullahi Ahmed**
Principal Investigator
Department of Psychiatry
Makerere University

Dear Dr. Abdulkadir,

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

The Management of Mulago National Referral Hospital is pleased to inform you that you have been offered clearance to conduct the study titled **MHREC 2954: "Prevalence and Factors associated with sleep disturbance among children and Adolescents at the sickle cell clinic of Mulago National Referral Hospital."**

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

- That you will follow the research ethical processes
- Agreed to comply with all institutional policies and regulations of Mulago National Referral Hospital
- Agreed to provide end of study report and acknowledge Mulago hospital in all publications

Administrative clearance is valid for one (1) year effective from 23rd June 2025 to 22nd June 2026

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

DR. SEKABIRA JOHN
**AG.EXECUTIVE DIRECTOR**
**MULAGO NATIONAL REFERRAL HOSPITAL.**

**Copied to;**
1. **Incharge – Sickle cell clinic**

## APPENDIX VIII: REC LETTER

MAKERERE UNIVERSITY
P.O. Box 7072 Kampala, Uganda
E-mail: research9@gmail.com
Phone: 256 414 533541
Fax: 256 414 541036/0414 532204
COLLEGE OF HEALTH SCIENCES
SCHOOL OF MEDICINE
RESEARCH ETHICS COMMITTEE

**05/06/2025**

To: Abdulkadir Ahmed

Makere university
0708556891

**Type:** Initial Review

**Re: Mak-SOMREC-2023-632: PREVALENCE AND FACTORS ASSOCIATED WITH SLEEP DISTURBANCE AMONG CHILDREN AND ADOLESCENTS AT SICKLE CELL CLINIC MULAGO NATIONAL REFERRAL HOSPITAL.**

I am pleased to inform you that at the **180** convened meeting on **27/06/2023**, the MAK School of Medicine REC (Mak-SOMREC) meeting voted to approve the above referenced application.
Approval of the research is for the period of **05/06/2025** to **05/06/2026.**

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

1. All co-investigators must be kept informed of the status of the research.
2. Changes, amendments, and addenda to the protocol or the consent form must be submitted to the REC for re-review and approval **prior** to the activation of the changes.
3. Reports of unanticipated problems involving risks to participants or any new information which could change the risk benefit: ratio must be submitted to the REC.
4. Only approved consent forms are to be used in the enrollment of participants. All consent forms signed by participants and/or witnesses should be retained on file. The REC may conduct audits of all study records, and consent documentation may be part of such audits.
5. Continuing review application must be submitted to the REC **eight weeks** prior to the expiration date of **05/06/2026** in order to continue the study beyond the approved period. Failure to submit a continuing review application in a timely fashion may result in suspension or termination of the study.
6. The REC application number assigned to the research should be cited in any correspondence with the REC of record.
7. You are required to register the research protocol with the Uganda National Council for Science and Technology (UNCST) for final clearance to undertake the study in Uganda.

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

| No. | Document Title | Language | Version Number | Version Date |
|---|---|---|---|---|
| 1 | assent | Luganda | pdf | 2025-05-31 |
| 2 | assent | English | pdf | 2025-05-31 |
| 3 | consent form | Luganda | pdf | 2025-05-31 |
| 4 | consent form | English | pdf | 2025-05-31 |
| 5 | Data collection tools | Luganda | pdf | 2025-05-31 |
| 6 | Data collection tools | English | pdf | 2025-05-31 |
| 7 | Protocol | English | pdf | 2025-05-31 |
| 8 | study budget | English | pdf | 2025-04-28 |
| 9 | study time line | English | pdf | 2025-04-28 |
| 10 | COVID-19 & EBOLA risk management plan | English | PDF | 2023-05-10 |

Yours Sincerely


Prof. Ponsiano Ocama
For: MAK School of Medicine REC (Mak-SOMREC)