



**FACULTY OF HEALTH SCIENCES
DEPARTMENT OF COMMUNITY AND PUBLIC HEALTH**

FINAL YEAR MASTERS' DISSERTATION

**NEURODEVELOPMENT AMONG CHILDREN (6-59 MONTHS)
WITH SICKLECELL DISEASE AT MBALE REGIONAL
REFERRAL HOSPITAL IN EASTERN UGANDA: A CROSS-
SECTIONAL STUDY**

By

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BU/GS22/MPH/18

**This final year masters' dissertation is submitted to the Department of
Community and Public Health in partial fulfilment for the award of
Master of Public Health of Busitema University.**

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DECLARATION

This report is my original work and has not been presented to any other university or institution of higher learning before.

Signature 

Date 31/08/2026

APPROVAL

This dissertation has been submitted for examination with the approval of the following supervisors.

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LIST OF ABBREVIATIONS AND ACRONYMS

CDC	Center for Disease Control
DAZ	Development for Age Z-score
HAZ	Height- for- age Z-score
LMIC	Low-Middle-Income Countries
MDAT	Malawi Development Assessment Tool.
MUAC	Mid Upper Arm Circumference
NDD	Neurodevelopmental delays.
RRH	Regional Referral Hospital
SCD	Sickle Cell Disease
SCI	Silent cerebral infarct
SDG	Sustainable Development Goals
TCD	Transcranial doppler
UDHS	Uganda Demographic Health Survey
VOC	Vaso`-occlusive crisis
WHO	World Health Organization
WHZ	Weight- for- height Z-score

OPERATIONAL DEFINITIONS

Children under five years	For the purposes of this study, this term refers specifically to infants and children aged 6 to 59 months.
Neurodevelopment	Refers to the ongoing growth, organization, and maturation of a child's brain, which dictates how they learn, communicate, behave, and interact with the world. This is measured as a Development for Age Z-score (DAZ score) when measured by the Malawi Development Assessment Tool (MDAT).
Sickle cell disease	A genetic hemoglobinopathy confirmed in this study by hemoglobin electrophoresis results indicating HbSS. Pathophysiologic ally, it is characterized by abnormal hemoglobin that causes red blood cells to become rigid and sickle-shaped, leading to premature hemolysis and vaso-occlusion.

ABSTRACT

Background: Sick Cell Disease (SCD) is the most common genetic blood disorder globally, with approximately 15,000 children born with the condition annually in Uganda. SCD-related central nervous system complications often impair cognitive, social, and physical neurodevelopment. While neurodevelopment delay is documented in preterm (13%) and birth-asphyxiated (66.7%) Ugandan children, there is a paucity of comparative data regarding children with SCD. This study compared neurodevelopmental delay among children under five years with SCD in Eastern Uganda.

Methods: We conducted a cross-sectional study between March 2025 and September 2025 at Mbale Referral Hospital pediatric unit. We included 350 children under five years (117 with sickle cell disease and 233 without sickle cell disease). The primary outcome was neurodevelopmental delay defined as a score of less than -2 development for age Z-score (DAZ) assessed using the Malawi Development Assessment Tool. We performed independent sample *t*-tests to compare development for age z-scores between children with and without sickle cell disease. We used inverse probability of treatment weighting analyses to calculate the effect of sickle cell disease on neurodevelopment.

Results: The median age of the children was 40.9 months (interquartile range 27.8 - 54.3 months). Overall, children with sickle cell disease had 0.89 lower DAZ scores compared to their peers without sickle cell disease. Among the children with sickle cell disease, those not enrolled on hydroxyurea had 0.4 lower DAZ scores in the social and language domains compared to those on hydroxyurea. The average exposure effect was -0.87, 95% CI [-1.19, -0.55] and the average exposure effect among the exposed was -0.62 [-1.01, -0.23].

Conclusion

Children with sickle cell disease had lower developmental scores across all domains (social, gross motor, fine motor and language) compared to those without SCD. These findings highlight the developmental vulnerability associated with sickle cell disease in early childhood. Efforts towards timely screening and management of developmental delays among children are needed to improve their quality of life and long-term development. This may be through integration of neurodevelopmental screening into routine sickle cell disease care.

CHAPTER ONE: INTRODUCTION

1.1 Background to study

Sickle cell disease (SCD) is the most common prevalent inherited blood disorder globally (Knight, King, Strouse, & Tanabe, 2021; Piel, Hay, Gupta, Weatherall, & Williams, 2013), with approximately 300,000 infants born with the condition annually (Kato et al., 2018). The burden is disproportionately concentrated in Africa, which accounts for two-thirds of the 120 million people living with the sickle cell trait and Approximately 1,000 children are born with this disease every day. In Uganda, the overall prevalence of sickle cell disease is 0.8%, and studies suggest that at least 15,000 babies are born with sickle cell disease per year (Ndeezi et al., 2016).

The pathophysiology of SCD involves vaso-occlusive crises that lead to tissue hypoxia. In pediatric populations, this often manifests as complications within the central nervous system, including stroke, silent cerebral infarcts, and neurocognitive deficits (Wang et al., 2001). These complications affect the child's daily life activities both physically and mentally. Research indicates that the window from birth to three years is particularly critical, as children with SCD frequently exhibit significant delays in: Cognitive processing, Language acquisition, and Motor function (Thompson, Gustafson, Bonner, & Ware, 2002). These delays are influenced by a complex interplay of biological and environmental factors (Aygun et al., 2011; Bills, Schatz, Hardy, & Reinman, 2020; Heitzer et al., 2021; Steen et al., 2002; Steen et al., 2003), yet they remain under-addressed in clinical settings within Low- and Middle-Income Countries (LMICs).

Despite having the highest burden of SCD, there is a profound lack of data regarding neurodevelopment in Ugandan children with the disease. While local studies in the Mayuge district have identified NDD prevalence rates ranging from 7.5% (Namazzi et al., 2019) in the general population to 66.7% (Chebet et al., 2023) in children with birth asphyxia, the specific prevalence among the SCD population remains unknown. Currently, Uganda's Health Management Information System (HMIS) does not document these delays, suggesting that neurodevelopmental assessments are not a routine part of sickle cell care. Given that early detection is vital for promoting optimal developmental outcomes (Knight et al., 2021). Therefore, this study compared the neurodevelopment of children with SCD and those without SCD in MRRH Eastern Uganda.

1.2 Statement of the problem

Despite SCD being a leading cause of childhood morbidity in Uganda with 0.2–1% prevalence across regions and accounting for up to 15,000 births annually, the associated "silent" burden of neurodevelopmental delay remains largely unaddressed. The pathophysiology of SCD, characterized by chronic hypoxia and vaso-occlusive crises, places these children at an elevated biological risk for stroke and neurocognitive impairment.

This risk is further compounded by the socio-environmental challenges prevalent in low-resource settings like Eastern Uganda. Currently, there is a critical evidence gap regarding the exact prevalence and nature of NDD among children under five with SCD in this region. While general pediatric NDD rates are documented, the specific "double burden" faced by children with SCD is not captured in the national Health Management Information System (HMIS). Consequently, neurodevelopmental screening is not integrated into routine SCD clinical care. Without data-driven evidence, many children miss the window for early detection and specialized intervention, leading to irreversible developmental deficits and poor long-term quality of life. Therefore, this study compared the neurodevelopment of in children with SCD and those without SCD in MRRH Eastern Uganda.

1.3 Objectives

1.3.1. Main objective

To compare the neurodevelopment between children aged 6 to 59 months with and without SCD at MRRH in Eastern Uganda.

1.3.2 Specific objective

To compare the neurodevelopment between children aged 6 to 59 months with and without SCD at MRRH in Eastern Uganda.

1.4 Research question

What is the difference in the neurodevelopment between children aged 6 to 59 months with and without SCD at MRRH in Eastern Uganda?

1.5 Justification of the study

Findings from this study will contribute to the evidence base and enhance understanding of neurodevelopment among children with SCD. These insights may help inform and improve interventions, as well as guide health messaging for healthcare workers and caregivers of children with SCD. Additionally, the results could influence clinical practice, for example by supporting the integration of routine screening for neurodevelopment into standard sickle cell disease care.

1.6 Hypothesis of the study

Children aged 6 to 59 months with SCD have lower development for age Z-scores compared to those without SCD in Eastern Uganda.

1.7 Conceptual or theoretical framework

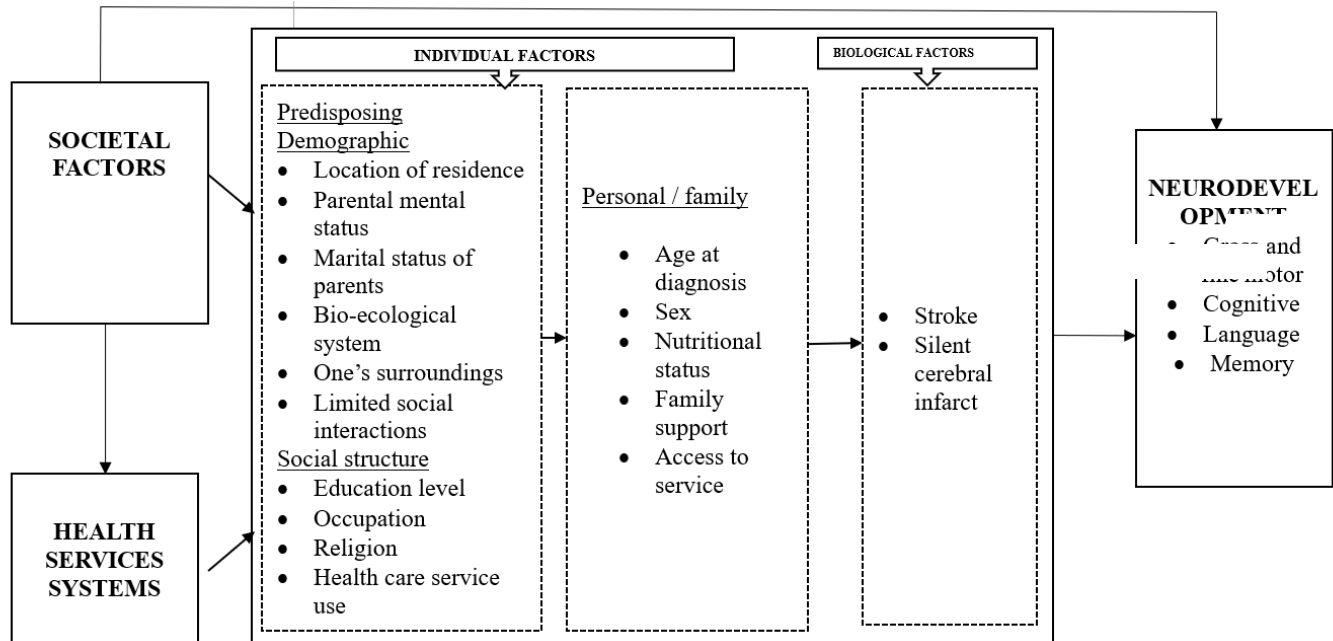


Figure 1 Theoretical framework for factors associated with neurodevelopmental delays in children under five years

The bio-ecological system theory of early child development spells out the biological and environmental factors and has a complex interaction that may result in neurodevelopmental delays. The environmental factors include limited social interactions, poverty, and one's surroundings. Social emotional development of a child is shaped by family relationships and parental practices. As young children, we learn by observing those around us, and through social referencing environment that builds the confidence of the child in the ability to communicate and relate to others, results from a loving and positive relationship, coupled with active stimulation and encouragement. However, these are compromised by the number of children in the family, nutritional deficiencies during infancy and early childhood, maternal factors, including educational and responsiveness, and the three delays in seeking care, such as delay in making, due to ignorance and cultural practices; delay in reaching health facility; and delay in receiving care at the facility, because of system challenges. The framework assumes that distal determinants of social demographic background, environmental factors, nutritional factors, and clinical factors, influence the severity of the sickle cell disease, which in turn influences intermediate determinants that directly influence neurodevelopmental delays.

CHAPTER TWO: LITERATURE REVIEW

2.1 Sickle cell disease

Sickle cell, disease is a genetic condition, inherited when a child receives two genes: one from each parent code, for abnormal hemoglobin (CDC, 2019). SCD remains a big public health problem in the world with about 5% of its population having a trait. Globally, approximately 300,000 new babies are born annually worldwide (Kato et al., 2018) and approximately 225,000 children with SCD are born in sub-Saharan Africa each year. In Uganda, 15,000 to 20,000 affected infants have a disorder that affects the shape of hemoglobin in the red blood cells, leading to the formation of a sickle shape (Ndeezi et al., 2016).

SCD is characterized by modification in the shape of red blood cells from the smooth, donut shape into a crescent or look like a c-shaped farm tool called “sickle”. It is caused by a defect in beta chains where a given amino acid is replaced by another [substitution of valine for glutamic acid] at position six [6] resulting in abnormal hemoglobin. The deformation of red blood cells into a crescent shape makes them hard and sticky, resulting in early hemolysis and sequestration in the small blood vessels. Hence, it is associated with; recurrent vaso-occlusion and hemolysis, that contribute to acute episodes of pain, tissues, ischemia, inflammation, and progressive organ damage (Ware, de Montalembert, Tshilolo, & Abboud, 2017). The sickle shape contributes to co-morbidities throughout the lifetime, including pulmonary hypertension, stroke, organ damage, gall bladder disease and premature (Schnog et al., 2004).

The consequences of SCD are multisystem, with a wide range of acute and chronic complications that afflict patients through their lifetimes and reduce life expectancy quality and productivity of both parents and caregivers (Holdford, Vendetti, Sop, Johnson, & Smith, 2021). The primary symptomatic manifestations of SCD; unpredictable, severe, disabling, often ubiquitous pain, begin in infancy, and becomes more frequent and severe with age. Pain typically occurs in the back, extremities, chest, and abdomen. Chronic SCD pain and progressive organ damage and organ failure, are punctuated by Vaso- occlusive crisis (VOC), which results from blockage of the blood flow in small blood vessels, by malformed red blood vessels, causing tissues ischemia, inflammation, and severe episodes of pain. Inflammation in turn leads to further blockage of red blood cells, and other cellular elements creating a vicious cycle (Field et al., 2019). Not only are there many children with SCD in Africa, but they also have high frequency of stroke risks, such as severe anemia, that contributes to sickle cell cerebral vasculopathy, and associated brain injury (Munube et al., 2016).

2.2 Neurodevelopment in children with sickle cell disease

Neurodevelopmental delay is the term that describes disruptions in skills development of infants and young children (Villagomez et al., 2019). In low- and middle-income countries over 250 million children do not

fulfill their development potential in cognition, communication, behavior and motor skills which results in poor school performance and intergenerational poverty (Grantham-McGregor et al., 2007); however, little is known about the prevalence in children with SCD. Currently babies with SCD are identified early and this has reduced the high mortality rate and many of these children are surviving but could this be associated with high prevalence of neurodevelopmental delays. The early child neurodevelopment involves the organization and function of the central nervous system, that starts early in embryonic life and continues for years after birth. The child's neurodevelopmental skills are similar in pattern and timing for most children (Cermak, 1998). During the first three years of life, early development is marked by enormous gains in gross motor abilities, fine motor coordination, language abilities, and marked improved ability to solve increasing complex problems. The development of each skill influences the development of others. However, the genetic factors, environmental factors, or combination of both affects these skills development.

Many studies have shown neurodevelopment in children. Globally, 8.4% of children under 5 years have neurodevelopment (DeBaun & Kirkham, 2016; Oluwole, Noll, Winger, Akinyanju, & Novelli, 2016; Ware et al., 2017). There is little epidemiological information on neurodevelopment in sub-Saharan Africa. Many studies are conducted in developed world yet the highest prevalence of SCD is in Africa. Systemic analysis for the global burden of disease study 2016, reported that development disability prevalence figures for low-and middle-income countries at 0.4% to 45.2%. In Uganda, a study in Eastern Uganda showed that 12.7% of infants have at least one of the domains of neurodevelopment delays (Namazzi et al., 2019). In another study, neurodevelopment was found to be 7.5% and 20.4% for term and preterm babies, respectively (Namazzi et al., 2020) while babies born as obstructed labor was found to be at 67.5% (Chebet et al., 2023). However, there is limited data on the prevalence of neurodevelopment in children with sickle cell disease. The exact magnitude of neurodevelopment in children 0 to 5 years with SCD is still uncertain.

Neurodevelopmental delays are common in children with SCD 0 to 5 years, studies showed that there was high prevalence of children with fine and / or gross motor delays at 38%, and both cognitive and motor skills at 41.7%. The overall increased prevalence of NDD among children under 5 years with SCD is 45.8% (Knight et al., 2021). In another systematic review study about the neurodevelopmental delay in infants and toddlers with SCD, it was found that the developmental delay ranged from 17.5% to 50% and increased with age (Hoyt et al., 2022). However, these statistics were reached, after reviewing articles that were done in United States of America. This could be different in the Ugandan context. Nevertheless, Uganda's statistics could be in the same range.

2.3 Risk Factors associated with neurodevelopment children under 5 years with SCD

NDD increases with age, as was seen in the studies that followed children with SCD, 6 to 36 months (Thompson et al., 2002). The increase of the NDD could be associated with the decline of fetal hemoglobin and increasing chances of anemia. There is evidence that NDD can be present as early as infancy, and highly prevalent in adulthood, due to brain damage.

Brain damage is mostly caused by stroke and silent cerebral infarct, which affects the development of the child. The prevalence of stroke in children with SCD is 5% to 10%, in absence of primary stroke prevention, with transcranial Doppler (TCD) screening and blood transfusion (Armstrong et al., 1996). Children with SCD have an increased risk of neurological complications, including stroke, silent cerebral infarction (SCI), and cognitive deficits, due to tissue hypoxia, related to Vaso- occlusion (Wang et al., 2001). Up to 37% reported to have silent infarcts by age of 14 years, and 27% by 6 years (DeBaun & Kirkham, 2016). Strokes and silent cerebral infarct contribute to NDD, with lifelong implications (Balkaran et al., 1992). SCI and / or stroke are common complications in children with SCD, and are important risk factors of NDD, with 27% children experienced SCI or stroke before 5 years (Cancio et al., 2015).

Without preventive measures, children with sickle cell disease are 200-fold more susceptible to stroke, compared to general pediatric population (Ohene-Frempong et al., 1998). It is paramount therefore that this is assessed in all children with SCD, however TCD screening is not popular in our facilities, hence we may be having children with NDD. Children with sickle cell anemia are highly susceptible to stroke and other manifestations of pediatric cerebral vasculopathy (Green et al., 2019; Oluwole et al., 2016). NDD is strongly related to prior stroke. Severe anemia in children can affect cerebral oxygen supply, causing prolonged repetitive and hypoxic ischemic events, leading to cerebral damage abnormalities and lesions in the basal ganglia, thalami, white a grey matter (Zonnenberg et al., 2016).

Slowed development is thought to result from a combination of social determinants and biological factors (Bills et al., 2020). Determinants such as good nutrition, environmental stimulation and maternal factors including education level and responsiveness are particularly protective, and studies show that both economic- status and parental educational levels are associated with NDD (Asiimwe, Kananura, Kajjura, & Yeka, 2019). Uganda's demographic data shows that the highest population is poor, and women with no education are 10%, 57% primary level, 25% secondary level, and only 8% tertiary level, and men are at 4%,55%, 29% and 12%, respectively (UDHS, 2022) which could increase the risk of NDD.

Socio-demographic factors are strong drivers of neurocognitive performance than the disease severity or disease modifying treatment (Heitzer et al., 2021). Environmental predictors of developmental delays include parental, family income (Armstrong et al., 2013), and neighborhood resources (Drazen, Abel, Gabir, Farmer,

& King, 2016). Aygun and others also found community characteristics to be independent predictors of cognitive development in young infants (Aygun et al., 2011).

Lower parental education is associated with lower cognitive scores, and higher education with higher language development, memory, and attention in children with SCD. Children from poor families have an 83% higher risk of NDD, compared to those from rich families, those fed on the recommended meal diversity have a 25% lower risk of NDD, and those breastfed exclusively for six months have also lower risk of NDD, compared to those who did not (Chebet et al., 2023). However, this was a study in children born with obstructed labor, which may be different in those with SCD. Nevertheless, wasting and stunting were prevalent among children with SCD (Asiimwe et al., 2019), but this was with children 5 to 12 years, so cannot be based on this research. Poverty, insufficient cognitive stimulation, and malnutrition are significant environmental factors for typical neurodevelopment. Male sex is associated with delays in neurocognitive function and neurodevelopment (Montanaro et al., 2013). Poor neurocognitive development was also found to be dependent on age. The study by Green et al., found that neurodevelopment delays increase with age (Green et al., 2019).

There is scarcity in literature to date, on neurodevelopment outcomes among children under 5 years of age, with SCD. Previous studies have not particularly focused on the much younger children in their first 1,000 days of life, a time of critical brain growth neural circuitry, and development. There are many risk factors that have been identified, but there remain environmental, biological, and social economic risk factors for NDD that have not been evaluated in children with SCD, in Uganda. Many of the studies were done in the developed world, with little known in low resource countries like Uganda. Early detection of NDD in young children with SCD is important, to promote optimal development. The purpose of this study is to provide a comprehensive understanding of the prevalence, severity, and associated risk factors in children with SCD under 5 years of age. From the literature, this will be among the few studies in Uganda to focus on young children with SCD and neurodevelopmental deficits under 5 years.

CHAPTER THREE: METHODOLOGY

3.1 Study design

This was a cross-sectional study among children under five years of age between March 2025 to September 2025.

3.2 Study setting

The study was conducted at the pediatric sickle cell clinic of Mbale Regional Referral Hospital, a public tertiary facility in Eastern Uganda. The hospital serves as a referral center for six major general hospitals and multiple health sub-districts in the Elgon region, with a catchment population of more than four million people. The outpatient sickle cell clinic is staffed by a consultant pediatrician, pediatricians, pediatric residents, clinical officers, and nurses. It operates once a week and provides routine follow-up care, including medication refills and clinical assessments, for children with sickle cell disease who are not in painful crises or sick. The Ministry of Health Uganda has strengthened national sickle cell disease care through the adoption of several key interventions. Hydroxyurea is now recommended as part of routine management under the Uganda clinical guidelines (2023), although uptake and documentation vary across facilities. Transcranial Doppler screening is also recommended for stroke risk assessment, but it was not routinely available at the study sites during the data-collection period. In addition, nationwide newborn screening using the Gazelle platform was launched on 9 February 2026, after completion of this study. These developments provide important context for interpreting the care environment in which our study was conducted. We included MRRH because it runs a SCD clinic and would provide us with the required sample size.

3.3 Study variables

3.3.1 Dependent variable

Neurodevelopment was neurodevelopment assessed using the Malawi Developmental Assessment Tool (MDAT), a validated tool for evaluating child development across four domains, fine motor, gross motor, language and social development in children from birth to six years in low-resource settings. The MDAT, is a validated tool for evaluating child development across four domains, cognition, gross motor, language and social development in children from birth to six years in low-resource settings (Gladstone et al., 2010).

3.3.2 Independent variables

The main exposure was the child's sickle cell disease status. Additional characteristics included child-level factors such as age, sex, nutritional status, history of hospitalization, use of hydroxyurea and history of common childhood illnesses. We also collected sociodemographic and economic characteristics of the primary caregiver, including age, marital status, education level, number of siblings, birth order, household

wealth, and history of birth complications.

3.4 Study population

Children between 6 and 59 months with sickle cell disease, and those in the same age group without sickle cell disease.

3.4.1 Inclusion criteria

Our study participants were children between 6 and 59 months of age with and without sickle cell disease. Children with SCD were recruited from the pediatric sickle cell clinic at MRRH. For the comparison group, we enrolled siblings, close relatives, or neighbors within the same age range (6 and 59 months). The dry spot blood samples for these children were taken off for sickle cell testing to confirm their genotypes and avoid misclassifying their exposure status.

3.4.2 Exclusion criteria

We excluded children between 6 and 59 months with and without SCD who had other chronic illnesses such as congenital heart disease or epilepsy that affect neurodevelopment.

3.5 Sample size

The sample size was calculated using Open-Epi version 3 (<http://www.openepi.com>). For comparison of two independent means, assuming 80% power, a 95% confidence level, and a 2:1 allocation ratio of children without SCD to those with SCD. Using a mean difference of 0.4 in neurodevelopmental delay scores and a common standard deviation of 1.0 from a previous study at Mulago Hospital Sickle Cell Clinic in Kampala (Bangirana et al., 2024), the estimated minimum sample size was 222 children (74 with SCD and 148 without SCD). However, a total of 350 children were enrolled (117 with SCD and 233 without SCD) to improve the precision of the estimates and increase statistical power.

3.6 Sampling technique

We used consecutive sampling to include participants in the study. This is because it was the most feasible way to obtain both our numbers and beat our timeline. However, since we recruited for about 5 months, the participants recruited did not systematically differ from those not recruited.

3.7 Data collection

We identified children between 6 and 59 months of age with sickle cell disease attending the pediatric sickle cell clinic at MRRH. Primary caregivers were approached and invited to a private space where trained research assistants (trained nurses and midwives) obtained written informed consent. After consent, an electronic structured questionnaire in Kobo Toolbox was administered to collect relevant sociodemographic, socio-economic and clinical information from the caregiver. Each child was then assessed for neurodevelopment using the MDAT across four domains: gross motor, fine motor, language (through direct observation), and social development (through caregiver interview). Each item was marked as pass or fail,

and if the child was uncooperative, the response was recorded as “I don’t know.” The four domains were used to compute a score classifying children as having or not having neurodevelopmental delay.

Primary caregivers were also asked whether they had children of similar ages without sickle cell disease in their households or neighborhoods or among their relatives. The primary caregivers provided the study team with telephone contacts of the parents/caregivers to those children without sickle cell disease. These parents/caregivers were contacted by telephone and invited to participate in the study. For each child with sickle cell disease assessed, we invited two children of similar age from their communities as comparison group. Written informed consent was obtained from each of the caregivers before any interviews and neurodevelopmental assessment were conducted. Anthropometric measurements such as weight were measured three times using a digital SECA weighing scale, and length was measured using a length mat. Mid-upper arm circumference (MUAC) was measured using a pediatric MUAC tape at the midpoint between the olecranon and acromion of the left arm using a standard tape.

3.8 Data management

The data was collected in Kobotool box using electronic structured questionnaires. The electronic questionnaire had validation rules and audit trails to ensure completeness and quality of the data collected. The collected data was uploaded in Stata version 18.0 (StataCorp LLC, College Station, Texas, USA) where it was cleaned, merged and analysed. The raw and cleaned data were kept securely in a password-protected computer.

3.9 Data analysis

Data were analysed in Stata software version 18.0 (Stata Corp; College Station, TX, USA). We summarized continuous variables as means (standard deviations) or medians (interquartile ranges) as appropriate. The categorical variables were summarized as frequencies and proportions. We performed independent sample *t*-tests to assess the differences in the overall mean DAZ scores and across domains between children with and without sickle cell disease. Mean differences with corresponding 95% confidence intervals (CIs) were reported. IPTW was used to estimate multiple treatment effects, including the average treatment effect (ATE), hereafter correctly termed the average exposure effects, and the average treatment effect on the treated (ATET), hereafter correctly termed the average exposure effects among the exposed. For the Inverse Probability of Treatment Weighting (IPTW) approach, we included variables that increased the risk of the outcome, even though they did not affect exposure (SCD). These included parental education, wealth index, age of the primary caregiver, relationship of the primary caregiver to the child, marital status, residence, age of the child, child’s sex, nutrition status of the child, dietary diversity, siblings under five years, and immunization status.

To address potential misclassification in the IPTW models, we conducted a sensitivity analysis using inverse probability weighted regression adjustment (IPWRA) and augmented inverse probability of treatment weighting (AIPW). After these analyses, we assessed covariate balance using standardized mean differences, variance ratios, and overlap plots. Since the balance characteristics were consistent across all models, we report only a single set of results to represent all the analyses.

Propensity score distribution

The distribution of the estimated propensity scores for children with and without sickle cell disease (figure 2). The density plots reveal a high degree of overlap between the two groups. Specifically, both groups are represented across the propensity score range of approximately 0.2 to 0.95. This overlap suggests that children with SCD had counterparts with similar baseline characteristics in the non-SCD group, satisfying the positivity assumption required for valid IPTW estimation.

All models (IPTW, AIPW, and IPWRA) were adjusted for parental education, wealth index, caregiver age/relationship, marital status, residence, child age/sex, nutritional status (WHZ), dietary diversity, presence of siblings <5 years, and immunization status.

3.10 Ethical considerations

We obtained ethical approval to conduct the study from the Busitema University Faculty of Health Sciences Research Ethics Committee (BUFHS-REC-2024-217). We also sought administrative clearance from Mbale Regional Referral Hospital to conduct the study at the pediatric unit. Written informed consent was obtained from all caregivers and was obtained before data collection. Children identified with neurodevelopmental delay were linked to a/c within the hospital for further assessment and management.

CHAPTER FOUR: RESULTS AND DISCUSSION

4.1 Results

4.1.1 Characteristics of caregivers to children under five years

We enrolled 350 participants, the median child age was 40.9 months, and interquartile range (27.8-54.3) months. Most of the primary caregivers of children, 71.7% (251/350) were mothers. Most of the primary caregivers, 70.3% (246/350) were aged 18 to 34 years. Seventy-two per cent (253/350) of the participants resided in rural areas, and the distribution across the wealth tertiles was comparable (Table 1).

Table 1. Characteristics of primary caregivers to children under five years with and without SCD in Eastern Uganda

Characteristics	No SCD n (%)	Has SCD n (%)	Total N (%)
	N=233	N=117	N=350
Primary caregiver			
Mother	161 (69.1)	90 (76.9)	251 (71.7)
Father	35 (15.0)	7 (6.0)	42 (12.0)
Other relative	37 (15.9)	20 (17.1)	57 (16.3)
Age of main care giver			
18-34	167 (71.7)	79(67.5)	246(70.3)
35-44	44(18.9)	23(19.7)	67(19.1)
45+ older	22(9.4)	15(12.8)	37(10.6)
Maternal education			
None	9 (3.9)	1 (0.9)	10 (2.9)
Primary	117 (50.2)	54 (46.2)	171 (48.9)
Secondary	84 (36.1)	44 (37.6)	128 (36.6)
Tertiary	23 (9.9)	18 (15.4)	41 (11.7)
Paternal education			
None	12 (5.2)	4 (3.4)	16 (4.6)
Primary	96 (41.2)	34 (29.1)	130 (37.1)
Secondary	82 (35.2)	52 (44.4)	134 (38.3)
Tertiary	36 (15.5)	23 (19.7)	59 (16.9)
Don't know	7 (3.0)	4 (3.4)	11 (3.1)

Residence			
Rural	163 (70.0)	90 (76.9)	253 (72.3)
Urban	70 (30.0)	27 (23.1)	97 (27.7)
Marital status of parent			
Single	14 (6.0)	17 (14.5)	31 (8.9)
Married/cohabiting	211 (90.6)	96 (82.1)	307 (87.7)
Divorced/separated	8 (3.4%)	4 (3.4)	12 (3.4)
Wealth quintile			
Poor	84 (36.1)	36 (30.8)	120 (34.3)
Middle	79 (33.9)	40 (34.2)	119 (34.0)
Rich	70 (30.0)	41 (35.0)	111 (31.7)

4.1.2 Characteristics of children

A third of the children, 33.4% (117/350) had SCD. Fifty seven percent (119/350) of the children were aged 3 to 5 years, and fifty three percent (185/350) were male (Table 2). Among the children with sickle cell disease, 70.9% (83/117) were enrolled on hydroxyurea and almost all of them 98.3% (115/117) were taking folic acid supplements (Table 2).

Table 2. Characteristics of children under five years with and without SCD in Eastern Uganda

Characteristics	No SCD n (%)	Has SCD n (%)	Total N (%)
	N=233	N=117	N=350
Age of child			
Less than 1 year	42 (18.0)	27 (23.1)	69 (19.7)
1 to 3 years	56 (24.0)	26 (22.2)	82 (23.4)
Above 3 years to 5 years	135 (57.9)	64 (54.7)	199 (56.9)
Child born preterm			
No	224 (96.1)	112 (95.7)	336 (96.0)
Yes	9 (3.9)	5 (4.3)	14 (4.0)
Sex of the child			
Male	116 (49.8)	69 (59.0)	185 (52.9)
Female	117 (50.2)	48 (41.0)	165 (47.1)
Weight-for-length/height Z-score			

Wasting	36 (16.6)	20 (17.5)	56 (16.9)
Normal	148 (68.2)	87 (76.3)	235 (71.0)
Overweight	33 (15.2)	7 (6.1)	40 (12.1)
Food diversity in diet			
No	200 (85.8)	110 (94.0)	310 (88.6)
Yes	33 (14.2)	7 (6.0)	40 (11.4)
Fully immunized for age			
No	77(30.0)	37(31.6)	114
Yes	156(70.0)	80(68.4)	236
Ever breast fed			
No	1(0.4)	0	1 (0.3)
Yes	201(86.3)	98(83.8%)	299 (84.2)
Missing	31(13.3)	19(16.2%)	50 (14.3)
Living with a sibling under 5 years			
No	67(28.8)	51(43.6)	118 (33.7)
Yes	166(71.2)	66(56.4)	232 (66.3)

4.1.2 Neurodevelopment among children

Of the 350 children enrolled, only 5 (1.3%) had overall DAZ score of -2 and 3 of these were those with SCD. Children with SCD had 0.89 lower mean DAZ scores compared to children without SCD. Children with SCD had lower mean DAZ scores in all the domains as compared to children without SCD (Table 3). Children on hydroxyurea had 0.4 lower mean DAZ scores for the social and language domains compared to those not on hydroxyurea (table 4).

Table 3. Comparison of DAZ Scores for neurodevelopment between children with and without SCD in Eastern Uganda

Domain	No SCD	Has SCD	Overall	Mean	T test	95% CI
DAZ scores	mean (sd)	mean (sd)	mean (sd)	difference	P-value	
Overall	1.65 (1.84)	0.76 (1.2)	1.35 (1.71)	0.89	<0.001	0.57 - 1.22
Social	1.66 (1.29)	1.37 (0.92)	1.56 (1.19)	0.29	0.015	0.06- 0.53
Gross motor	0.87 (1.34)	0.33 (1.26)	0.69 (1.34)	0.54	0.0003	0.25 -0.83
Fine motor	1.48 (1.80)	0.90 (1.41)	1.28 (1.70)	0.58	0.0012	0.23- 0.92
Language	0.79 (1.70)	0.33 (1.55)	0.64 (1.67)	0.47	0.0107	0.11- 0.83

*Mean difference = (No SCD - SCD), $p < 0.05$

Table 4. Comparison of DAZ scores for neurodevelopment among children with SCD on hydroxyurea versus those not on hydroxyurea in eastern Uganda

Domain DAZ scores	Not on hydroxyurea mean (sd)	On hydroxyurea mean (sd)	Overall mean (sd)	Mean difference	T test P value	95 % CI
Overall	0.75 (1.36)	0.76 (1.14)	0.76 (1.20)	0.01	0.9859	-0.54, 0.53
Social	1.09 (0.98)	1.49 (0.88)	1.37 (0.92)	0.40	0.0438	-0.79, -0.01
Gross motor	0.27 (1.69)	0.36 (1.05)	0.33 (1.26)	0.09	0.7685	-0.72, 0.54
Fine motor	0.96 (1.50)	0.88 (1.38)	0.90 (1.41)	-0.08	0.7705	-0.51, 0.69
Language	0.01 (2.50)	0.45 (0.91)	0.33 (1.55)	0.44	0.3185	-1.34, 0.45

* Mean difference = (On hydroxyurea – Not on hydroxyurea), $p < 0.05$

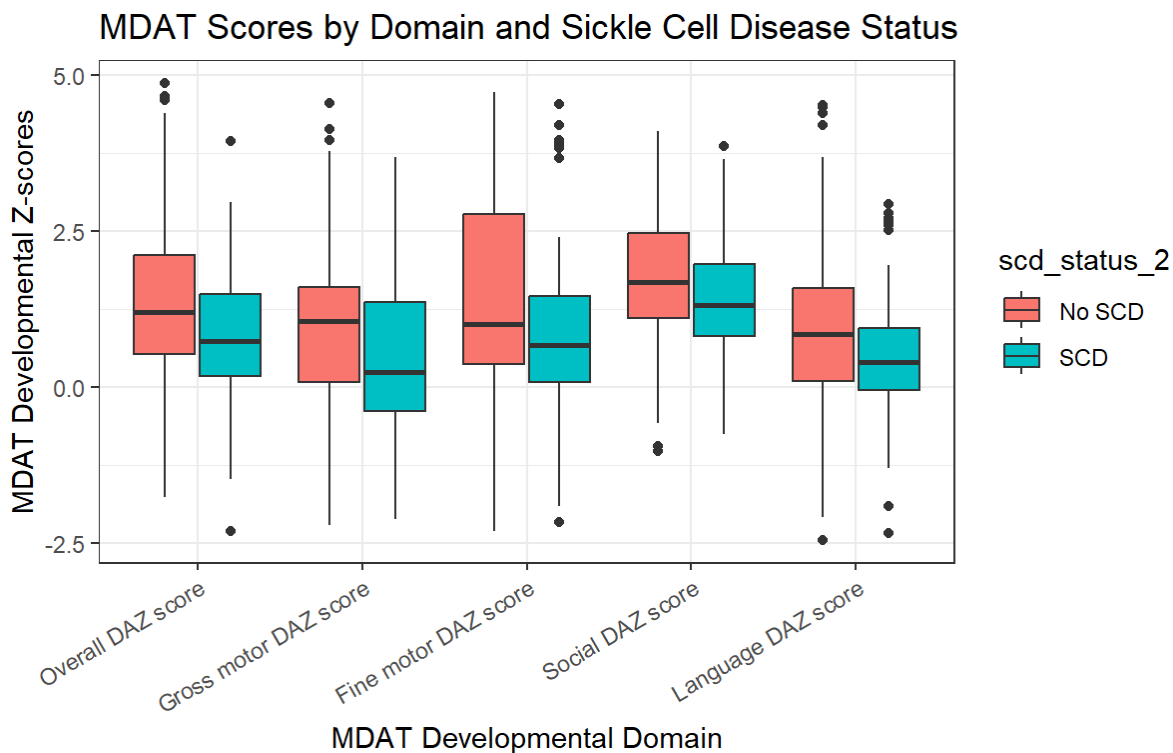


Figure 2: DAZ scores across different domains by SCD status of children in Eastern Uganda

4.1.3 Effect of sickle cell disease on neurodevelopment

The average exposure effect was -0.87, 95% CI [-1.19, -0.55] (Table 4). The average exposure effect

among the exposed was - 0.62 [- 1.01, - 0.23]. There was a covariate overlap across all models.

Table 5: Treatment effects (with 95% confidence intervals) of SCD on neurodevelopment among children under five years in Eastern Uganda

Model	TE	MDAT score model
IPTW	ATE	- 0.87 [- 1.19, -0.55]
IPTW	ATET	- 0.62 [- 1.01, - 0.23]
AIPW	ATE	- 0.86 [- 1.19, -0.54]
IPWRA	ATE	- 0.20 [- 0.45, -0.05]
IPWRA	ATET	- 0.65 [- 1.04, - 0.27]

*TE-Treatment Effect/Exposure Effect

ATE-Average Treatment Effect/Average Exposure Effect

ATET-Average Treatment Effect Among the Treated/ Average Exposure Effect Among the Exposed

IPTW-Inverse Probability of Treatment Weighting

AIPW-Augmented Inverse Probability Weighting

IPWRA-Inverse Probability Weighted Regression Adjustment

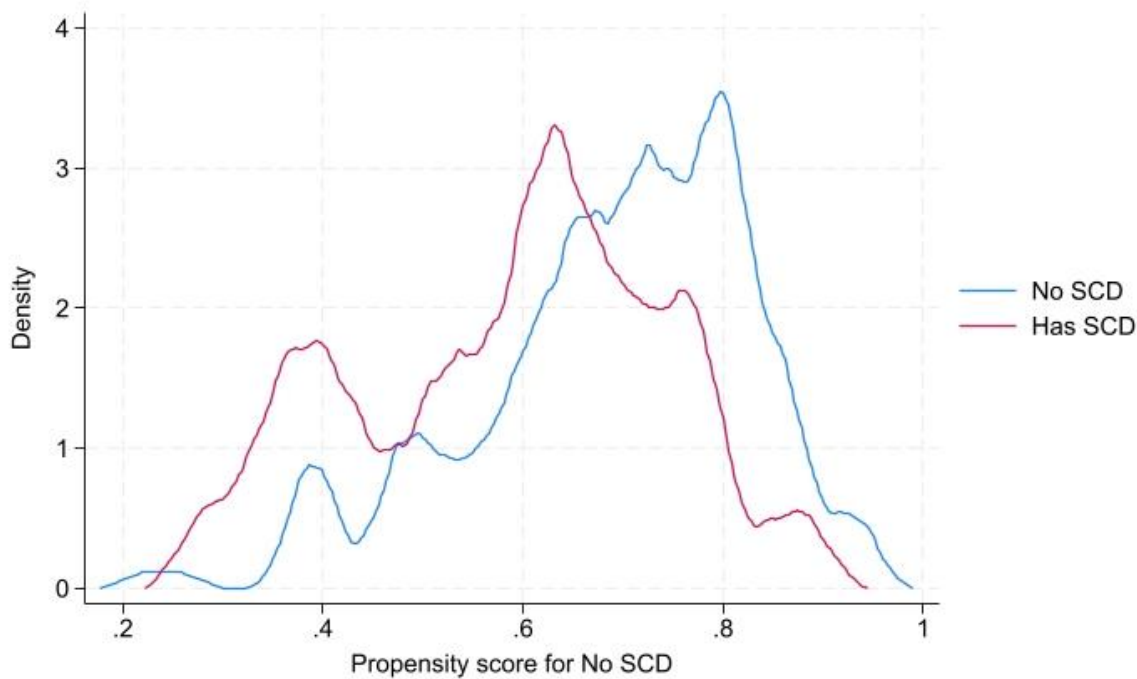


Figure 3. A density plot showing the overlap of propensity scores between children with SCD and without SCD

4.2 Discussion

This study compared the neurodevelopment between children with and without SCD at MRRH in Eastern Uganda. This study observed a difference in neurodevelopment scores between children with SCD and their peers without SCD.

4.2.1 Neurodevelopment between children with and without SCD

The overall mean Development for Age Z-score (DAZ) was 1.65 (SD 1.84), suggesting generally favorable developmental progress. However, children with SCD had 0.89 lower DAZ scores in all domains compared to those without SCD. Our findings are consistent with those from high income settings. For instance, a study from the USA found that a higher percentage of children with SCD scored below the cut off on neurodevelopmental screening than those without SCD (Wang et al., 2021). Another study found that over 50% of children with SCD scored significantly below average on cognition and expressive language subscales (Drazen, Abel, Gabir, Farmer, & King, 2016). A recent systematic review including ten studies found that the rate of developmental delay ranged from 17.5% to 50% (Hoyt et al., 2022). This observed difference in neurodevelopment may be attributed to the fact that children with SCD suffer from chronic anemia, recurrent pain crises, increased risk and burden of infection (Armstrong, 2006), silent cerebral infarcts and other neurological complications unlike the general pediatric population (Lance et al., 2021). SCD impacts multiple organ systems due to chronic hypoxia due to reduced oxygen carrying capacity of the

hemoglobin in the red blood cells. This chronic physiological stress associated with SCD could adversely affect neurodevelopment in early childhood may limit children's capacity to engage in appropriate play, exploration, and learning opportunities. As a result, children with SCD have increased vulnerability to neurodevelopment across all domains. The reduction in DAZ scores among children with SCD is clinically meaningful, as it may translate into delayed attainment of key developmental milestones, difficulties with school readiness, and long-term challenges in social and academic functioning. This difference in developmental delay observed in our study highlights the need for early screening and management of neurodevelopmental deficits among children with sickle cell disease. Integrating routine neurodevelopmental screening in the routine SCD care especially in low resource settings where children are often diagnosed too late when interventions cannot reverse or slow down the progression of neurodevelopmental deficits or sequelae are key. Early stimulation programs, caregiver education, and timely referral to rehabilitation services could help mitigate the developmental risks associated with SCD.

4.2.2 Effect of hydroxyurea on neurodevelopment among children with SCD

Children with SCD who were receiving hydroxyurea had slightly higher DAZ scores, particularly in the social and language domains, than those who were not. This finding is consistent with prior studies, for instance Heitzer *et al.*, found that early use of hydroxyurea limits the detrimental neurocognitive effects of SCD (Heitzer *et al.*, 2021). Use of hydroxyurea reduces the frequency of vaso-occlusive events, infections, acute chest syndrome, blood transfusions, and hospitalizations (Thornburg *et al.*, 2012; Tshilolo *et al.*, 2019). As a result, children have improved general physical health which enhances their social interaction with peers and language development. Other studies suggest that hydroxyurea may reduce chronic hypoxia and cerebral vascular injury (Ware *et al.*, 2016) which are known contributors to neurodevelopmental deficits. In addition, hydroxyurea confers additional neuroprotective, inflammatory growth benefits in children (Fogliazza, Berzieri, Carbone, Ciriaco, & Esposito, 2025). If present, these biological pathways alongside potential indirect psychosocial benefits such as increased participation in peer activities and improved communication offer plausible explanations for the observed differences in social and language domain scores between children receiving and not receiving hydroxyurea in our cohort. However, as hydroxyurea was not randomly assigned in our study. This association should be interpreted with caution, as children on hydroxyurea may differ systematically from those who are not. For example, in disease severity, healthcare access, or caregiver engagement, any of which could independently influence developmental outcomes.

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4.2.3 Study strengths

This study is among the first in Uganda to compare neurodevelopment in children with and without SCD using age-matched community controls, and it has several notable strengths. First, exposure misclassification was minimized by identifying children with SCD from hospital registers and by laboratory screening all controls to confirm their SCD-negative status. Second, recruiting siblings and age-matched neighbors as controls helped ensure comparable

environmental and social contexts. Third, neurodevelopmental delay was assessed by trained research assistants using the MDAT, a validated tool for African settings, which enhanced the reliability of our findings.

4.2.4 Study limitations

Nonetheless, several limitations should be noted. First, blinding of assessors to SCD status was not feasible, given the observable physical characteristics of affected children, which may have introduced observer bias. Second, recruiting SCD cases from a pediatric outpatient clinic may have introduced selection bias, as these participants could disproportionately represent families with better healthcare access or children with more severe disease requiring frequent hospital visits. Similarly, recruiting controls from siblings, relatives, and neighbors rather than through random population sampling may have introduced further selection bias; although inverse probability weighting was used to balance measured covariates between groups, this approach cannot account for unmeasured confounders such as maternal depression or anxiety, and residual bias may remain. Relatedly, healthy siblings included as controls may not represent a fully unaffected comparison group, as children growing up with a sibling with SCD can experience altered parental attention, household resource allocation, and psychosocial stress related to their sibling's illness, potentially influencing the developmental, nutritional, or psychological outcomes assessed. Additionally, some study variables relied on caregiver self-report, which may have introduced recall bias. Hydroxyurea use was documented only as a binary yes/no variable, without capturing duration or intensity of therapy; since hydroxyurea's beneficial effects on hemoglobin and cerebral blood flow are likely dose and duration-dependent, this may have obscured a dose-response relationship and led to an underestimation of its true effect on neurodevelopmental outcomes. Future studies should capture more detailed hydroxyurea exposure data to better characterize this relationship. Finally, although transcranial Doppler (TCD) screening is recommended by the Uganda Clinical Guidelines (2023) for stroke risk stratification, TCD services were not routinely available during the study period, so stroke risk categorization could not be incorporated into our analysis. We acknowledge this as a limitation, given the relevance of cerebrovascular risk to neurodevelopmental outcomes.

CHAPTER FIVE: CONCLUSIONS AND RECOMMENDATIONS

5.1 Conclusions

Children with sickle cell disease had lower developmental scores across all domains (social, gross motor, fine motor and language) compared to those without SCD. These findings highlight the developmental vulnerability associated with sickle cell disease in early childhood. Efforts towards timely screening and management of developmental delays among children are needed to improve their quality of life and long-term development. This may be through integration of neurodevelopmental screening into routine sickle cell disease care. As national SCD care continues to expand access to hydroxyurea, routine TCD screening, and Gazelle-based newborn diagnosis, future studies incorporating these interventions may be important to comprehensively assess neurodevelopmental outcomes among children with SCD in Uganda.

5.2 Recommendations

1. Caregivers

- Caregivers play a central role in supporting the development of children with SCD should be encouraged to engage in regular early stimulation activities at home, ensure consistent clinic attendance, and support adherence to prescribed treatments such as hydroxyurea to facilitate their children's neurodevelopment.
- Caregivers are also well-positioned to notice early signs of developmental delay and should seek timely assessment when concerns arise.
- Strengthening caregiver knowledge and involvement can significantly improve developmental outcomes and overall quality of life for affected children.

2. Clinicians

- Integrate routine developmental monitoring into standard SCD care, using validated tools to identify delays early.
- Clinicians should also provide guidance on early stimulation, nutrition, and follow-up, and ensure timely referral to rehabilitation or early intervention services when delays are detected.
- Consistent initiation and monitoring of hydroxyurea, in line with national guidelines alongside counselling to support adherence for all children with SCD.

3. Policy makers

- Prioritize expanding access to core SCD interventions, including hydroxyurea, TCD

screening, and newborn screening services platforms such as Gazelle.

- Training of health workers in developmental surveillance and early intervention to improve developmental outcomes of the children with SCD.
- Integrating developmental services into national SCD care pathways to facilitate timely screening and management of developmental delays among children with SCD.

4. Researchers

- Examine neurodevelopmental trajectories in children with SCD within the evolving landscape of expanded hydroxyurea access, routine TCD screening, and universal newborn screening.
- Studies exploring the timing, duration, and adherence to hydroxyurea and their impact on developmental outcomes are particularly needed.
- Research into cerebrovascular risk, silent infarcts, and contextual factors such as nutrition and early stimulation will deepen understanding of developmental vulnerability.

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APPENDENCES

APPENDIX I: STUDY WORK PLAN

	2024											
Activity	Sep	Oct	Nov	Dec	Jan	Feb	Mar	Apr	May	Jun	Jul	Aug
Develop and submit Research to the Department of Public and Community Health for approval.												
Develop and submit a Research proposal to the Department of Public and Community Health for approval												
Submit Research Proposal to Higher Degrees Committee for Approval												
Submission of Research proposal to Busitema University Research Ethics Committee for ethical approval												

Data collection and entry												
Data analysis, and presentation of results												
Research Report Writing												
Presentation of Research Report to the Department for Approval												
Present and Defend the Thesis report												
Submission of Final Thesis Report to the University												

APPENDIX II: BUDGET

Item	Quantity	Unit cost	Total cost	Comment
Box files	2	15,000	30,000	For storing study documents
Notebooks	4	10,000	40,000	Documentation
Printing costs		100,000	100,000	For printing necessary study documents
Airtime		100,000	100,000	For coordinating study activities
Internet		100000	100,000	Literature search
Token for study participants	350	20,000	8,680,000	To be reimbursed to study participants for their time
Allowances for research assistants	350	10,000	4,340,000	for reimbursement of transport and lunch for assistants throughout the study period
Ethical Approval costs	2	-	2,000,000	To obtain ethical approval from Uganda National council for science and technology and Busitema University REC
Transport and Lunch for laboratory officers to test the control group	217	10,000	2,170,000	To facilitate testing of age mates, siblings, and playmates of children under 5 years who assumed to be without SCD
Total costs			17,560,000	

APPENDIX III: INFORMED CONSENT

+PROTOCOL TITLE: The neurodevelopment among children under five years with sickle cell disease in Eastern Uganda: A cross sectional study

PRINCIPAL INVESTIGATOR: BERNARD MAUMBE.

1. PURPOSE: Why is this research study being conducted?

Sickle cell disease (SCD) is a genetic condition that causes several complications including neurological complications. Assessments of neurodevelopment coupled with earlier interventions improves quality of life. Our study will inform clinical practice for example in planning for services for children with Neurodevelopment and contribute to the attainment SDG-3 that is ensure a healthy life, and promote wellbeing for all, at all ages and SDG-4 that is ensure lifelong learning. Our study is purely research, and we hope to contribute to the advancement on understanding on the Neurodevelopment among children with SCD. The main objective of the study is to determine the prevalence of neurodevelopmental delay among children under-five years with sickle cell disease in Eastern Uganda.

2. INVESTIGATORS: Who is conducting this research study, and where is it being conducted?

The study will be conducted at the paediatric ward and sickle cell clinic at Mbale Regional Referral Hospital (MRRH) which is a government-funded public tertiary hospital. It is being sponsored by ENRICH Busitema university and the principal investigator is a student of Busitema University. The other investigators are health workers of Mbale Regional Referral Hospital.

3. POPULATION: How are individuals selected for this research study? How many will participate?

The eligibility criteria will be as follows: The children with SCD between 6 months and 59 months attending the clinic at MRRH. Children aged from 6 to 59 months (under 5 year's children) Siblings without SCD, Rest will be other close relatives or neighbors of same age group if sibling does not get in that order. The siblings, close or neighbors included in the study will have undergone a screening test for sickle cell disease and they are negative. All children with history of neurological impairment, prior to the age of four months will be excluded. We will identify the children under-five with sickle cell disease attending sickle cell clinic at Mbale regional referral hospital. A trained research assistant will explain the study protocol to the mothers or caregivers of these children, and after obtaining written informed consent. We will then collect data and perform neurodevelopment assessment, using the Malawi Developmental Assessment Tool (MDAT).

We will also obtain informed consent from mothers/ caregivers attending the same clinic, to bring the children without sickle cell disease, and assess them for neurodevelopment (the invited children will be age mates or playmates of same identity, as those with SCD). We expect to have 350 participants recruited.

4. PERIOD: For how long will this research study take place? How long am I expected to participate in this study?

The study will take three to four months but the total period the potential participant is expected to participate in this study is one to two months.

5. PROCEDURES: What will take place in this study? What do I have to do if I am in this research study?

The sampling technique will be that all eligible children whose parents /caregivers have provided an informed consent will be recruited and a sample is attained. We will collect data using structured questionnaires, have socio-demographics, nutrition history, medical history administered to a mother or

caregiver, physical examination, and the MDAT tool to the children. The structured questionnaire and Malawi development assessment tool (MDAT) is embedded in the Kobo tool on the phone which will take about a maximum of 45 minutes if there is cooperation. Children without sickle cell disease will have to be screened to make sure that they don't have sickle cell disease, tests will be carried out by the laboratory personnel.

6. RISKS: What are the risks of this research study? What could go wrong?

We do not anticipate any risk; however, we may be asking you to share with us some very personal and confidential information and you may feel uncomfortable talking about some of these topics. You don't have to answer any question or take part in the survey if you don't wish to do so, and that also fine. You don't have to give us any reason for not responding to any questions or for refusing for taking part in the interview.

7. BENEFITS: What are the benefits of this research study?

There will be no direct benefit to you, but your participation is likely to help us find neurodevelopment and factors associated with them in children under five years with sickle cell disease. Your contribution will help us inform clinical practice for example in planning for services for children with Neurodevelopment and contribute to the attainment SDG-3 that is ensure a healthy life, and promote wellbeing for all, at all ages andSDG-4 that is ensure lifelong learning. You will also contribute to the advancement on understanding on the Neurodevelopment among children with SCD and form the basis for further research.

8. COSTS: What costs are associated with the research study? Will I receive payments/compensation or incentives?

You will not be provided with any incentives to take part in the research. However, we will provide twenty thousand shillings for your time and travel expense.

9. PARTICIPANT'S RIGHTS: What are my rights as a research participant?

(a). Voluntariness: Do I have to participate in the research study?

You participation is voluntary, and refusal to participate will in no way affect current or future care received. Each participant will receive a summary of results.

(b). Alternatives: If I do not want to take part in this research study, what are the other choices?

Continue with the care as before and the care shall not be interrupted.

(c). Withdrawal: Do I have to continue participating in the research study even when I don't want to?

You don't have to take part in this research if you do not wish to do so and choosing to participant will not affect you in any way. You may stop participating in the survey at any time that you wish.

d). Privacy: How will your privacy be observed?

We will not be sharing any information about you to anyone outside of the research team. The

information that we collect from this research project will be kept private. The information will be entered into kobo tool which has a password so the information can easily be accessible by other persons rather than the researcher. Names shall be used but instead identification numbers.

(e). Confidentiality: How will your data be protected? Who may see, use or share your health information?

We will not be sharing any information about you to anyone outside of the research team. The information that we collect from this research project will be kept private in the kobo tool with password accessibility. All the information will be captured dignitary.

10. CONTACTS: Who do I contact in case of any questions or concerns?

Contact Bernard Maumbe, principal investigator on 0772851265 for any other questions or concerns you may have about this study: OR Contact Dr. Edith Mbabazi, Chairperson, Busitema University Faculty of Health sciences Research Ethics Committee (BUFHSREC) on +256 704 414441 for concerns with participants' rights and other ethical-regulatory issues.

DOCUMENTATION AND AUTHORIZATION OF INFORMED CONSENT

What does my signature or thumbprint on this consent form mean?

- I have read this consent form and was given enough time to consider the decision to participate in this study.
- This research study has been satisfactorily explained to me, including possible risks and benefits.
- All my questions were satisfactorily answered.
- I understand that participation in this research study is voluntary and that I can withdraw at any time.
- I am signing this consent form prior to participation in any research activities.
- I give voluntarily my permission to participation in this research study
- I will be provided a copy of the fully signed consent form for my reference

_____	_____	_____
Name of Participant (PRINT) (DD/MM/YYYY)	Participant's Signature/Thumbprint	Date

_____	_____	_____
Name of Investigator/Associate (PRINT) (DD/MM/YYYY)	Signature of Investigator/Associate	Date

Witness Statement & Signature (If Required)

I confirm that the information in this consent form was accurately explained to, and understood by the participant, parent and/or guardian as required, and that informed consent was voluntarily given.

■ _____	_____

Name of **Witness (PRINT)**
(DD/MM/YYYY)

Signature of **Witness**

Date

APPENDIX IV: DATA COLLECTION TOOLS

General questionnaire: determining neurodevelopment amongst children under-five with sickle cell disease in eastern Uganda.

Section 1: Identification data

QNO	QUESTIONS AND FILTERS	CODING CATEGORY
101	Serial number	
102	Participant's ID number	
103	Date of interview	
104	Start time	
105	End Time	(Put at the end of the tool)
106	Interview Result	Completed Partially completed
107	Name of research Assistant	

Section 2: Socio-Demographic Characteristics

201	Maternal age	1. <19 years 2. 20-30years 3. 31-48 years	
202	Marital status	1. Single 2. Married 3. Separated	
203	Have you ever attended school?	1. Yes 2. No	2 go to 205
204	What is the highest level of education you have attained?	1. Primary 2. Lower secondary (O' Level) 3. Upper secondary (A' Level) 4. Tertiary 5. Other (specify)	
205	What is your main occupation?	1. None/ housewife 2. Businesswoman 3. Salaried/waged worker 4. Other (Specify) Type in text	
206	Religion	1. Born again 2. Catholic 3. Protestant 4. Seventh day Adventist 5. Muslim 6. Others (specify) Type in text	
207	Residence	1. Peri-urban 2. Rural	
	Household		
	HOUSEHOLDS PROPERTY		
208	Does household have		Yes No
	READ OUT EACH	Radio	1 2
		TV	1 2

		Mobile phone (Smart)	1	2
		Mobile Phone (Buttons)	1	2
		Computer	1	2
		Motor vehicle	1	2
		Motorcycle	1	2
		Bicycle	1	2
		Canoe	1	2
		Cattle	1	2
		Sheep	1	2
		Goat	1	2
		Pigs	1	2
		Chicken/Birds	1	2
		Others	1	2
	Does the main house the following Household property			
209	Floor	1. Cement/tiles 2. Mud 3. Other		
210	Walls	1. Bricks 2. Stones 3. Mud and wattle 4. Grass 4. Other		
211	Roof	1. Iron sheets 2. Tiles 3. Grass 4. Canvas /Tarpaulin 5. Others		
212	What kind of toilet facility does the household have	1=Flush toilet 2=VIP toilet 3=Pit latrine covered 4=Pit latrine not coved 5=Others specify		
213	What do you use for cooking	1. Wood 2. Charcoal 3. Kerosine 4. Gas 5. Electricity 6.Others (specify		
	Paternal information			
214	Have you ever attended school?	1. Yes 2. No		2 go to 215
215	What is the highest level of education you have attained?	1. Primary 2. Lower secondary (O' Level) 3. Upper secondary (A' Level) 4. Tertiary 5. Other (specify)		
215	What is your main occupation?	1. None/ peasant farmer 2. Businessman		

		3. Salaried/waged worker 4. Others (Specify) Type in text	
Section 3: Child's information/ characteristics			
301	Sex of child (<i>Interviewer observe and record</i>)	4. Male 5. Female	
302	Are you the household head	4. Yes 5. No	
303	How old is the child? State age in completed year		
304	When was he or she born?	Day Month Year	
305	Was he or she ever been admitted with malaria in the hospital?	1. Yes 2. No	2 go to 307
306	How many times?	1. Once 2. Twice to thrice 3. More than 4 times	
307	Was the child exclusively breast fed for six months?	1. Yes 2. No	
308	Does the child's deity meet food diversity (4 of 7 groups which include: grains, roots and tubers, legumes and nuts, dairy products, flesh foods, eggs, vitamin rich fruits and vegetables, other fruits and vegetables)	1. yes 2. No	
309	How many meals does the child have a day	1. <4 meal 2. >4meals	
310	What is the HIV status of the child	1. Negative 2. Positive	
311	What is the height/ length of the child? Measure		
312	What is the weight of the child? Measure		
313	What is the mid upper arm circumference of the child? Measure		
314	What is the physical growth outcome? Measure	1. Underweight (WAZ <-2) 2. Moderate (WAZ<-2& <-3) 3. Severe malnutrition (WAZ <-3)	

MALAWI DEVELOPMENT ASSESSMENT TOOL (MDAT)

INSTRUCTIONS AT START OF MDAT:

To say to the mother/carer when you begin the MDAT: *Byokoba mama/amulabirira nga otandise MDAT*

This test is to see what your child is doing in terms of their development. We will spend about half an hour with you and your child and during that time. We will do some playing with your child as well as asking you some questions about how your child is playing and what your child is doing at home. You may see us make some marks on a piece of paper. We would not expect your child to do everything we are asking about so do not worry if they only do some of the tasks. This is normal particularly when they are in a strange environment. We will feed back to you about how your child is doing at the end of the session. Khukhebela khuno khuwetselesa siina shesi umwana wowo anyala khukhola nga walekhanisile khubukhulu byowo. Khunenyaa nu mwana wowo lundi khukhurebvekho iwe birebo, umwana wowo enyaa aryena lundi bindu sina byesi umwana alikhukhola ingo unakhubona ifwe nga khuwandikha byebyesikhukhebele khulupapula. *Ifwe sikhusubila umwana wowo khukhola bulisindu shesi khumureba ta nasiryo ukheyembelelela nga umwana wanyalisile khukhola bilala ne bibindi byamukhasa ta. Kane khukhubolele iwe byesi umwana wowo akholile nga khamalile khumureba byekhukhola.*

****Remember that at the end of the assessment you will want to give some feedback to the mother. Please read section on feedback to make sure that all mothers are provided with feedback and advice whatever the child scores on the assessment.**

INSTRUCTIONS FOR INDIVIDUAL ITEMS: SOCIAL

		1. Smiles, but not at a particular person. (amunamuna, ne siili bumundu ta.) Smiles, but not always sure whether it is in response to someone else or not. “How does your baby smile?”
		2. Smiles in response to a person. (amunamaunila umundu) With the child in mum’s arms or on his or her back, see if the baby will smile in responseto the mum’s or your smile and vocalizations. “Will your baby smile in response to you?”
		3. Frolics with mother or caregiver (moves body in response to another person).(antsakha ni maayi wewe oba umulinda / washukha wamulolayo nga wamulomileyo) if the child moves his or her body in response to being played with by mom. “Will your baby move his body in response to being played with?”
		4. Frolics alone, plays around moving body, kicking legs in a happy way.(atsakha yengene, wenyaa ni kumubili kwewe, was amba bikele nga wasanyukhile) Lies on his or her back and plays around with self, moving body and kicking legs happily.Can ask mom. “Will your baby play around with himself by moving his body and kicking his legs happily?”
		5. Recognizes or calms and quiets with caregivers/known family members.(Ategeela oba wassila lundi wewombekha ngali ni baba mulinda oba ni babandu bemungo besiamanyile) Stops crying or quiets when mom or another known family member takes the baby. Askmom if not observed. “Will your baby stop crying or calm when you or another known family member takeshim?”
		6. Will take porridge from a spoon when fed by a caregiver.(Anweela bubuugi khusijiiko nga ali khulisibwa ni babamulinda) Able to eat porridge off a spoon when given by mom/caregiver, but cannot yet hold a spoon. Can eat off mom’s fingers rather than spoon if this is what is usually used by mom. “Is your baby able to eat porridge off a spoon or your fingers?”
		7. Helps to hold a cup while mom gives a drink.: (ayeta khuwambakho sikombe nga maayi ali khumuwa shekhunywa) Cannot yet manage to drink from a cup by self, but will put hand up to cup when momputs the cup to his or her lips. “Does your baby help to hold the cup when you put it to his lips to drink?”
		8. Puts arms up or indicates in some way that they want to be picked up.(asuta kamakhono oba wokesanisa musambo ikindi ari khakana ba musutte) Baby deliberately shows that they want to be picked up by either stretching out arms ortrying to lift self towards mom/caregiver. Ask mom if not observed. “Does your baby put his arms up or indicate in some way that he wants to be picked up?”
		9. Can hold a spoon with porridge but not get to mouth well.(Anyala khuwamaba bubugi khusikiko ne sanyala khunywa bulayi ta) Can hold a spoon in hands when being fed and may try to put the spoon in mouth, butcannot do it very well. Need to be clear that it is a spoon with food on it. “Can your baby hold a spoon with food in it in his hands when being fed? He does notneed to be able to put the spoon in his mouth.”
		10. Drinks from a cup well without spilling. (anywela musikombe bulayi nga satsukha binywa ta) Is able to pick up a cup of water half full and drink from it without spilling any.

	11. Is able to indicate, by pointing, that they want something.: (anyala khulakilila nga okesa ni lulwala ari khakana sisindu) Can show by either pointing or maybe by simple language/noises that they want a particular thing eg. Pointing to the water/cup when they want a drink. “Is your baby able to point to things that he wants?”
	12. Can eat by picking up morsels of food from a plate. (anyala khulya nga abukula bilyo bifwiti khukhwama musawani) Picks up food in little small portions that mom has separated from the main bit of food. Can hold them in his/her hand and put to mouth. Recognizes it is food, not just grasping it when put in hand. “Can your child pick up small bits of food and feed himself using his hand?”
	13. Puts hands out to have them washed. : (arawo kamakhono nga akana bamusabise) Cannot wash hands by self, but understands that he/she needs to have them washed before eating, therefore helps by putting or holding hands out when mom washes them. Not just having them washed in any way, but must understand that they are having them washed. “Will your child put his hands out to have them washed?”
	14. Can hold a spoon and take porridge by self, but spills some. (anyala khuwamba sikijiiko lundi weenywesa bubuugi nga sibutsutsukha ta) Able to feed self with a spoon, but not that well. Spoon sometimes even turns over and spills some, but child enjoys feeding self. “Is your child able to feed himself with a spoon? It’s okay if he spills some.”
	15. Indicates in some way that they need to go for a poo/pee, for example by crying, pulling at pants or saying something. : (alakana musambo indala ari khana khutsa musinko/ khwiweta . shekhubonelakho aliilia, wekhisa asi tsimbale oba waloma sisindu). “Can your child indicate in some way that he needs to go poo or pee?”
	16. Wants to join in with singing games.: (akana naye embile atwela ni babandu nga benyaa) Is not yet able to do the singing games, but likes them and wants to be part of it even in a small way. “Even if your child is unable to do singing games does he enjoy them and want to be a part of them?”
	17. Able to greet either by extending hand or verbally.: (Anyalisa khukhesa nga ayila kumukhono oba waloma tsiliomo) Has learned to put out hand to greet someone or can say a verbal greeting. “Can your child greet people either by giving his hand or saying “hello”?”
	18. Sharing things, including food with others. (khugabanana bibintu ni babandi, nga bilyo) Understands to share things with others, for example if with friends or other family members, will share food that he or she is given. “Will your child share with others (ex) food?”
	19. Does poo or pees by themselves without wetting their pants. : (empisa /apamamweene ne sanyirasa mu mpale yewe ta) Is able to know that they need to pee or pass a stool and do it without wetting or soiling themselves. Never wets self. [PASS = AUTOMATIC PASS FOR #15] “Is your child able to go poo or pee without having accidents (wetting or soiling
	20. Can feed self well using a spoon without spilling. (Anyalisa khulya umwene khusikiko ne sibitsutsukha ta) Can use a spoon well and does not spill or make a mess.

		[PASS = AUTOMATIC PASS FOR #14] “Can your child feed himself using a spoon without spilling?”
		21. Can make own morsels of food and put in mouth. (unayalisa khubukula bilyo bifitifiti uwmwene wara mukhanwa? separate balls of food from main portion and form into a ball to put into mouth. Doesnot need to be making a perfect ball. [PASS = AUTOMATIC PASS FOR #12] “Can your child break off pieces of food and feed them to himself?”
		22. Able to undress by themselves. (Asobola okwetolamu engoye mwene) Can take off any item of clothing by themselves. Need to be able to remove it completely.Can be just one item of clothing. “Can your child take of at least one piece of clothing by himself?”
		23. Wants to go and visit a friend’s house (shows independence).(akana khutsa wo mulilwana ni yingo wo musaale wewe? “Does your child show independence (ex) wants to go and visit a friend’s house?”
		24. Can go to the toilet by themselves anywhere. (Anyala khutsa musinko umwene oba buli anandu? Can go poo or a pee by themselves without help, but anywhere eg. Outside, notnecessarily on the toilet. [PASS = AUTOMATIC PASS FOR #19] “Can your child remove his/her clothes and go poo or pee by himself without help
		25. Can eat food with bits in it or bones. (anyala khulya bye khuluma oba bilimo kamangumba?“Is your child able to eat food with seeds or bones in it?”
		26. Is able to dress self but not completely. (Anyala khukwara umwene ne sili ilala ta.) Is able to put on at least one article of clothing, for example a T-shirt or skirt.“Is your child able to put on at least one piece of clothing by himself?”
		27. Washes hands well by self before/after eating. (umwene asaba mukhono nga antsa khuulya oba nga wamalile khuulya? Is able to wash his or her hands without any help before and after eating. [PASS = AUTOMATIC PASS FOR #13] “Does your child wash his hands without help before and after eating?”
		28. Knows to keep quiet at important meetings or ceremonies.(wamanya khusiila umweene ngali khumikholo kimiboofu / kye kumukaso? “Does your child know to keep quiet at important events or ceremonies?”
		29. Does household chores or helps father or mother in a useful way. (Akholakimilimo kye muntsu oba wayeta papawe oba maayi wewe musambo ye Kumukaso?) eg. Drawing water/hoeing. This can even be just a small amount of help, but not justpretend. Make sure there are tasks that you ask about that boys could do.
		30. Able to dress by themselves completely. : (Anylaa khukhwara bikwaro bulayi umweene) Can put on clothes without help, may have help only if tying shoelaces, buttoning orzipping things which are hard to do. [PASS = AUTOMATIC PASS FOR #26] “Is your child able to dress himself completely without help (expect for tying shoelaces, buttoning or zipping things)?”

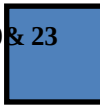
		31. Understands the concept of discipline (Ategela itsambasa yetsisambo) e.g.. Causes and consequences eg. Knowing that bad words may lead to punishment. “Does your child know that certain actions may lead to punishment?”
		32. Plays games with turn taking. (enyaa kiminyawo nga umundu umulala wamalile, ukundi welakho) “Will your child play games with others with turn taking?”
		33. Knows how to be respectful to elders. (wamanya khukhwo keesa lukoosi / isambo indayi isi abo bamufura bukhulu mumunko) Is polite and shows respect when around elders. For example, putting hands together as a sign of respect or kneeling. “Does your child show respect around elders?”
		34. Is able to go to the toilet/pit latrine by self. (anyala khutsa musinko umwene) Is able to go and use the pit latrine by themselves and does not need any help in anyway. [PASS = AUTOMATIC PASS FOR #24] “Is your child able to go to the toilet by himself?”

FINE MOTOR

		1. Follows face/object to midline. (alolelela bibindu nga babikendesela irangisi we tsimoni tsewe) Put the child on his/her back and hold a bright object or place your face above the child's face at about 15 cms. Move the object/face in an arc from one side to the other. See if the child follows the object/face with eyes to the midline.	
		2. Fixes and follows through 180 degrees. (sakamisa khulolelela ni khulondelela bibindu nga watereile) See if the child will follow the face or bright object through a complete arc from left to right e.g. through 180 degrees. [PASS = AUTOMATIC PASS FOR #1]	
		3. Puts hands together in front of eyes or mouth : (ara kamakhono kewe atwela iburangisi wetsimoni oba kumunwa) While the child is lying on his/her back, put the child's hands in front of his/her eyes to look at them and see if he/she keeps them there to look at them. Child also passes if he/she brings hands in front of eyes or mouth spontaneously. Do not cradle the baby in the parent's arms during this. Child automatically passes if s/he recognizes his/her hands.	
		4. Reaches for large thing. (anyalisa khukhwolelela sisindu biboofu) If child is sitting in parent's lap, see if the child will try and grasp an object such as the rattle. Examiner to bring the rattle near the child and observe whether child could reach object. Use bright object that child can see well. "Does your baby reach for toys?"	6
		5. When holding objects, tends to put in mouth. : (nga wawambile bibindi , akhaka khubira mukhanwa) Often when the baby has picked up toys, they like to explore them by putting them in their mouth. Child automatically passes if already playing with toys. "Does your baby bring toys to his mouth when holding them?"	
		6. Grasps hold of large thing. (aamba wakumisa bibindu biboofu) 4 See if the child able to pick up/grasp an object. The examiner gives the child a spoon, rattle or a pen in his hands and sees whether the child can grasp the object in his hands without letting it fall off. [PASS = AUTOMATIC PASS FOR #4] "Will your baby pick-up or grasp toys?"	
		7. Can pick up a larger object from ground. (e.g. spoon or rattle) (anyala khubukula sisindu siboofo khukhwama aasi .(nga sikijiiko oba khansaasi) When sitting on mom's lap or on the floor, likes to try and reach out and pick up objects off the ground or table. Keep objects slightly out of reach, so that they have to reach. [PASS = AUTOMATIC PASS FOR #4 & 6] "Can your baby pick up toys from the ground?"	
		8. Can see a small object such as a piece of maize or a bean.(anyala khubona bibindu bifwiti nga imitso yelikanda oba kamayindi) When the child is sitting on mom's lap, place a small object like a piece of maize or a bean in your hand and show it to the child. See if they notice it by pointing, looking at it, or if they want to touch it or pick it up. They don't have to pick it up – can just look at it.	

		9. Transfers objects from one hand to the other hand. (Ayuusa bibindu wamisa mu mukhono kukuundi wabiira mu kundi) Give the child a block and then try and give them another to the same hand. The child will often pass the first block to the other hand so that he/she can take the second one. “Can your baby transfer a toy from one hand to the other?”
		10. Picks up small things in a RAKING fashion. : (abukula bibndu bifwiti nga atandikhila khusifwiti naabi welakho siboofu) Place a piece of maize or a bead on the table (or a small piece of food) and ask the child to pick it up. Score a YES if child can pick it up by RAKING (using all four fingers). [PASS = AUTOMATIC PASS FOR #7]
		11. Strikes on object with another in imitation with the examiner. (ampaka bibindu wara khungaki khusindu sisindi nga alekasa uyo ulikhumulekela) Take a block in each hand and strike them together while the child is watching. Put a block in each of the child’s hands and ask the child to do the same. Also passes if claps toys or hands together. The examiner can repeat the procedure 2 times.
		12. Finds object under piece of cloth. (ahetsa, wanyola sisindu sisili mukuboo asi) Show child an interesting object (e.g., car or ball) and let him/her play with it. Then put it under a piece of cloth while the child is watching. Ask child to find the toy. Score as YES if child looks for, reaches for OR retrieves object under cloth. Child DOES NOT have to succeed in getting object; the point is that the child knows it is hidden and searches for it.
		13. Picks up maize or bean with thumb and one finger. (Abukula kamayindi oba likanda nga rambisa lulwala luboofu ni lufiti lutwela) Place a piece of maize or a bead on a surface and ask the child to pick it up. Score a YES if child can pick it up with thumb and one of small fingers only. 10 [PASS = AUTOMATIC PASS FOR #10]
		14. Puts 1 or more blocks in and out of cup. (Ara khatafali khatwela butafali bukali musikombe lundi wenyusamo musikope) One by one, put 2 blocks into the cup, explaining what you are doing. Remove each block one by one, also explaining what you are doing. Then put the cup and blocks directly in front of the child and say, “Now you do it. Put the blocks [POINT TO THE BLOCKS] into the cup [POINT TO INSIDE THE CUP]”. “Now you do it. Put the blocks [POINT TO THE BLOCKS] into the cup [POINT TO INSIDE THE CUP]”. Allow about 1 minute. If the child puts at least one block into the cup, say “Great! Now take the block [POINT TO BLOCK IN THE CUP] and put it on the mat.” “Great! Now take the block [POINT TO BLOCK IN THE CUP] and put it on the mat.” Score as a YES if the child puts at least 1 cube in and out of a cup when shown by an examiner.
		15. Pushes a little car along. (Asindikha khamotokha khafwiti) Put the car on the mat in front of the child and say, “See, look at the car.” “See, look at the car.” DO NOT push the car or tell the child to push the car. Score as YES if child pushes the little car along playing with it and showing that he or she knows it should be moving.

		16. Puts blocks into jar with screw on lid in imitation. (abukula kamabale/butafali wabura khakebe awamala warakho sifunikho). One by one, put 4 blocks into the jar, explaining what you are doing. Dump the blocks from the jar. Place the jar and blocks directly in front of the child and say, “Now you do it. Put the blocks [POINT TO THE BLOCKS] into the bottle [POINT TO INSIDE THE BOTTLE]”. “Now you do it. Put the blocks [POINT TO THE BLOCKS] into the bottle [POINT TO INSIDE THE BOTTLE]”. Allow about 1 minute. Score as a YES if the child puts at least one cube in the jar when shown by an examiner.
		17. Dumps blocks out of jar purposefully. (Atsukha kamabale/ butafali bwarura mumukebe musambo yesi umwene akanile) If child does not turn the jar on the side or upside down during administration of item 16, show child how to turn the jar over to dump the blocks out. Then ask the child to do it. “Now you do it. Dump the blocks out of the bottle.” Score as YES if child is able to turn the bottle upside down or sideways to get the blocks out, even if only ONE block is dumped out. DO NOT score yes if child pulls blocks out of the jar with fingers or hands.
		18. Scribbles on paper (straight scribble) (Akhakakho khuwandikha khulupapula – awandikha buterefu) Put a piece of paper in front of the child and put the pen/pencil in the child’s hand. Say, “Go ahead and draw a picture.” “Go ahead and draw a picture.” DO NOT show child what to do. The child must make purposeful marks on the paper, more than just slight marks on the paper, in a back and forth manner. Score NO if child stabs paper with pen/pencil.
		19. Scribbles on paper (circular scribble). (akhakakho khuwandikha khulupapula – nga abotokhelesa/khasako) Put a piece of paper in front of the child and put the pen/pencil in the child’s hand. Say, “Go ahead and draw a picture.” “Go ahead and draw a picture.” DO NOT show child what to do. Child must scribble in a circular way, not just back and forth. [PASS = AUTOMATIC PASS FOR #18]
		20. Builds a tower of 2 blocks. (Apanga butafali bibiri) Get 12 blocks out of the basket. On a solid, flat surface, build a tower of 2 blocks. Give 2 blocks to the child and ask the child to build a tower of blocks just like yours. Blocks must remain stacked for ≤ 3 seconds. “Now you do it. Build a tower with the blocks.”
		21. Puts pegs into board in ≤ 2 minutes. (Engisaka bitsaki mukubawoo khulikho kimyanya mu mumbuka ikhabirisa ndakiika tsibili ta) Take all the pegs out of the pegboard. Show the child how to put 1-2 pegs into the board, explaining what you are doing. Ask the child if s/he understands how to put the pegs in the board. “Do you understand how to put the pegs in the board?” “Do you understand how to put the pegs in the board?” If child does not seem to understand, demonstrate again. Remove all pegs and then ask the child to put them back in as quickly as possible. “Now you put all the pegs in the board as fast as you can.” “Now you put all the pegs in the board as fast as you can.” Score a YES for this item if child places all (8) pegs in board in 2 minutes or less.

	22. Builds tower of 4 blocks. (Apanga butafali bune) See item 20. After building tower with 2 blocks, demonstrate for child how to add blocks to make a tower of 4 blocks. Score YES if tower of 4 blocks remains standing for ≤ 3 sec. <i>“Now you do it. Add 2 blocks to your tower.”</i>	20 & 23 
	23. Builds tower of 6 blocks. (Apanga butafali busesaba) See items 20 & 22. After building tower with 4 blocks, demonstrate how to add blocks to make a tower of 6 blocks. Score YES if tower of 6 blocks remains standing ≤ 3 sec. <i>“Now you do it. Add 2 blocks to your tower.”</i>	20 & 22 
	Puts pegs into board in up to ≤ 30 seconds. (Engisaka bitsaki mukubawoo khulikho kimyanya mu mumbuka ikhabirisa butikitiki kamakhumi kataru ta. 24. See item 21. Score a YES for this item if child places all (8) pegs in board in ≤ 30 seconds .	 21 
	[PASS = AUTOMATIC PASS FOR #21] 25. Unscrews and screws back on lid of jar. (enyusakho sifunikho khukukebe lundi welakho wekalawo sifunikho) Hold the jar in one hand, and the lid in the other. Directly in front of the child, slowly screw the lid on the jar then take the lid off, explaining what you are doing. “See how I screw the lid on and unscrew the lid to take it off?” <i>“See how I screw the lid on and unscrew the lid to take it off?”</i> DEMONSTRATE TWICE. Put the jar and lid in front of the child and say, “Now you do it. Put the lid on and take it off, just as I showed you.” <i>“Now you do it. Put the lid on and take it off, just as I showed you.”</i> Score a YES if child is able to screw lid on (and not just “push” or “pat” lid on) AND unscrew (and not just pull) lid off the jar.	
	26. Threads 6 beads (Ampanga bubuma busesaba khuluwuntsi) Get the string and 8 beads out and put them in front of you. Directly in front of the child, place 2 beads on the string, explaining what you are doing. “See how I am putting the string through the hole in the beads?” <i>“See how I am putting the string through the hole in the beads?”</i> Put the string with 2 beads threaded on it, along with the remaining 6 beads in front of the child and say, “Now you do it. Put all the beads on the string, just as I showed you.” <i>“Now you do it. Put all the beads on the string, just as I showed you.”</i>	
	27. Copies a vertical line (as drawn by the examiner) within about 30 degrees (Akoopa lulayini luleyi (nga umulekeli naronile) mukhambanga mudiguri kamakhumi kataru) Draw a vertical line MOVING TOWARD THE CHILD, while saying, “See, I make a line here.” <i>“See, I make a line here.”</i> Show the child and ask him/her to make a line that looks just like yours. “Now you make a line just like mine.” <i>“Now you make a line just like mine.”</i> Score YES if child's line is within about 30 degrees of from your line.	
	28. Picks longest stick 3 times out of 3 tries (alondamo kimilundu kitaru khasala khafura buleyi mubisala bitaru) Put down 2 sticks of different lengths and say to the child, “Show me which one is longest.” <i>“Show me which one is longest.”</i> DO NOT indicate whether the child was correct. Administer this item 2 more times, switching the location of the longest stick each time. Child must pick the longest stick all 3 times to get a YES for this item.	

		29. Picks heaviest box 3 time out of 3 tries (Abukula kimilundi kitaru khambokisi khafurisa busiroo mutsimbokisi tsitaru) Put the two weights in the child's hands at the same time and ask, "Which one is heavier?" "Which one is heavier?" Do not indicate which response was correct. Administer this item 2 more times, being certain to alternate placing the heavier weight in both the right and left hands. Child must pick the heavier box all 3 times to get a YES for this item.
		30. Can make a bridge with 3 blocks. (anyala wombekha bulalo nga arambisa butafali butaru.) Get 6 blocks out. Make a bridge for the child out of 3 blocks, explaining to the child what you are doing. "See how I make a bridge with the blocks?" "See how I make a bridge with the blocks?" Leave your model in place and put 3 blocks in front of the child. Ask the child to make a bridge that looks just like yours. "Now can you make a bridge with these blocks just like mine?" "Now can you make a bridge with these blocks just like mine?" Score YES if child
		31. Makes a doll out of clay. (abummba ndole mu mulitosi) Can make a doll out of clay by themselves or another complicated toy such as a car. "Can you make a doll or car out of this clay?" "Can you make a doll or car out of this clay?"
		32. Copies a circle (alekasa khu khurona isako) Draw a circle, explaining to the child what you are doing. "See how I am drawing a circle?" "See how I am drawing a circle?" Show the child the circle and ask him/her to make one just like yours. "Now can you draw a circle like mine?" "Now can you draw a circle like mine?" You can allow up to 3 trials for the child to make a circle. Score YES for any nearly complete or complete circle.
		33. Copies a cross (Akopa khurona khasalaba) Draw a vertical line MOVING TOWARD THE CHILD, while saying, "See, I make one line here." "See, I make one line here." Then, draw a horizontal line crossing. "And another line here?" "And another line here?" Ask the child to make a cross just like yours. "Now can you make a cross like mine?" "Now can you make a cross like mine?" Credit is given for anything where the 2 lines intersect. [PASS = AUTOMATIC PASS FOR #27]
		34. Copies a square: (Akopa khurona khambokisi khali ni tsimande tsilekhana) Draw a square, describing what you are doing. "See how I make four lines to make a square?" "See how I make four lines to make a square?" Ask the child to make a square just like yours. "Now can you draw a square like mine?" "Now can you draw a square like mine?" To receive credit, the child's drawing must have four sides and be a similar shape to a square, but does not need to be perfect.

LANGUAGE

		1. Startles or jumps/responds to sounds. (asusa byekhukhwilamo wekesamo kamakono) If child responds or jumps when a loud sound is made. Can be a response in any way e.g. change in activity or expression or eye movement. “Does your child startle (jump or respond in any way) when a loud sound is made?”
		2. Happy vocalizing or making sounds – not crying. (Asanyukhila khurusa kamakono – ne sili khulila ta) Makes sounds other than crying e.g. throaty sounds or sounds such as “uh” or “eh” or “a, a, a” or gurgling sounds. Any vocal sound rather than crying. “Does your baby make sounds other than crying?”
		3. Laughs/chuckles. (Atsakha/ wetingitya) See if the child laughs out loud or whether the mom or guardian says they do. “Does your baby laugh?”
		4. Turns to voice. (Ayukha walolelela isi likono lyamila) In response to the rattle or to mom’s voice, does the child turn his or her head towards the sound? Best to test both sides. “Will your baby turn his head towards your voice?”
		5. Uses single syllables or sounds, for example Ma, Pa, Da, Ba, Ta. (arambisa likono lityela, shekhubonelakho Ma, Pa, Da, Ba, Ta) Listen for these sounds. If you do not hear baby make these sounds, ask mom if child makes at least one syllable-vowel combination as described. “Does your baby make single syllable sounds (ex) Ma, Pa, Da, Ba, Ta?”
		6. Responds to his or her name. (afukila/ akhulolayo nga wamulakile lisisna lyewe) Score a YES if child looks at you when you call his/her name. Be careful to distinguish between a response just to being called in a certain tone of voice and knowing his name. Child does not need to say his or her name.
		7. Uses 2/4 syllable babble such as Dada, Mama, Mimi, Tata, Papa, Yaya, Baba. (Dada, Mama, Mimi, Tata, Papa, Yaya, Baba.) (Arambisa bilomo nga bino Dada, Mama, Mimi, Tata, Papa, Yaya.) Listen to whether the baby is able to make sounds that could be copied and sound almost like words. Needs to be clear or distinct sounds, not just vocalizations. Or ask mom if child makes at least one syllable-vowel combination as described. [PASS = AUTOMATIC PASS FOR #5] “Does your baby make two syllable sounds (ex) MaMa, Dada, Mimi, Tata?”
		8. Understands when being cautioned about danger. For example when parent says “STOP!” to child, s/he stops even briefly. : Ategera nga wamurewure khubusiku. Shekhubonelakho nga umusaali wamulomile ari akamisa , umwana akama mu bwangu). Ask mom if child understands to stop doing something when told “No,” e.g., going too close to the fire, playing in dirty water, etc. Score as YES if child stops activity in response to “no.” “Does your baby stop what he is doing when you say “Stop!” even if just for a
		second?” 9. Indicates by gesture to say “No”. (Okesa bubonero bumanyisa buri “ta”) This requires definite shaking of head or shrugging of shoulders, etc., in showing refusal. Not just turning away from the situation or withdrawing. If not observed, ask mother. “Does your baby make a gesture to indicate “No”?”

		10. Follows simple commands (1 step) (alondelela bilakilo bibyangu (bibikombesa khukhola sisindu sitwela)) Give the CUP to the child and let him/her play with it for about 10 seconds. Then,ask the child to give you the cup. DO NOT GESTURE IN ANY WAY OR HOLD OUT YOUR HAND. Mark as YES if child completes action. Can ask up to 2 times. “Here is a cup.” (Wait 10 seconds) “Please give me the cup.”
		11. Unclear talk/jabber in sentences - pretends to talk. (sakanikha bulayi ta - akhaka khukanikha) : Listen to whether you hear child talk to themselves or while playing with any of the test materials. If unable to witness this,ask mom. Mark YES if child makes sentence-like sounds (even if they are not all real words or sentences). “Does your child pretend to talk in sentences even if he does not use real words?”
		12. Says 2 words, but words other than those used for mother and father. (Alomakho bilomo bibili , bilomo byenjawulo sili byekhuloma biri mama namwe papa ta)Ask mom how many words the child says and write down all words she mentions. These can include names of people as long as they are directed toward the person. Words need to be directed at some particular object. [PASS = AUTOMATIC PASS FOR #7] “What words does your child say?”
		13. Says 2 words together. (Aloma bilomo bibili kumulundu kutyela): Listen to whether the child is putting two words together in a meaningful phrase that indicates something. This does not include the use of 2 words to indicate oneidea, such as “all gone” or “bye bye”. If not heard, ask the parent. [PASS = AUTOMATIC PASS FOR #12] “Does your child put two words together ex) “I want” or “I do”?”
		14. Says 6 words, but words other than those used for mother and father. (Alomakho bilomo bisesaba , bilomo byenjawulo sili byekhuloma biri mama namwe papa ta Ask mom how many words the child says and write down all words she mentions. These can include names of people as long as they are directed toward the person. Score a YES if 6 words or more are heard or mentioned by parent. [PASS = AUTOMATIC PASS FOR #12]
		15. Follows 2 step commands. ” (alondelela bilakilo (bibikombesa khukhola bibindu bibili) Child is able to follow a command where they have to understand and then do a succession of two things. Place the CAR and BALL on the mat/table. Say to the child, “Get the CAR/BALL and put it in the basket”or “Get the CAR/BALL and give it to your mother [OR OTHER PERSON]” Do not indicate how to complete the action by pointing, looking or gesturing. Mark as YES if child completes action. Can ask up to 2 times. “Get the CAR/BALL and put it in the basket” or “Get the CAR/BALL and give it to your mother [OR OTHER PERSON]”
		16. Child can IDENTIFY (point to or give you) 5 objects you name. (Anyala wakhwokesa oba wakhulakana oba wakhuya bibindu birano byesi iwe ubula kamasina) Remove 12 objects from the basket. Say to the child “Give [OR SHOW] me the spoon,” “Pass me [OR POINT TO] the cup,” etc. Score a YES if child can identify at least 5 of the objects. Doesn’t matter which objects are identified. “Give [OR SHOW] me the spoon. Give [OR SHOW] me the cup.” Repeat for a total of 10 objects.

		17. Speaks clearly in sentences. : (akanikha bulayi tsilomo) Child's speech is fully understandable. Score as YES if child can use one or more sentences to describe or explain something. If not heard, ask mother. [PASS = AUTOMATIC PASS FOR #14] “Does your child speak in clear sentences that are fully understandable?”
		8. Points to 2 or more body parts.(okeesa bisitsa bibili oba khubirakho bisitsa bibili byekumubili) Ask the child, “Where is your nose? Where are your eyes? Show me your ears? Where is your mouth?” Score a YES if child knows TWO or more body parts. “Where is your nose? Where are your eyes? Show me your ears? Where is your mouth?”
		19. Child can NAME 5 objects in the basket. (umwana anyala khuboola kamasina kebibindu birano musiipo) Remove 12 objects from the basket. Say to the child “What is this?” as you point to or hand the child the object. Score a YES if the child can name at least FIVE (5) items. It does not matter which objects the child names. [PASS = AUTOMATIC PASS FOR #16] “What is this?” Repeat for a total of 12 objects.
		20. Child can tell you his or her first name. (umwana anyala khuboola lisina lyewe lisokha) Ask the child, “What is your name?” “What is your name?” Score as a YES if child can say their first name. Do NOT administer this item by saying, “Is your name John?” Child must tell you their name.
		21. Knows actions of 3 or more objects. (wamanya kumukaso kw'ebibindu bitaru oba khubirakho) USE cup, pencil, matchbox, and car. Ask “Which one is for drinking/eating?” “Which one is for writing?” “Which one is for lighting fire?” “Which one is for driving?” DO NOT LOOK AT OR GESTURE TOWARD THE OBJECTS WHEN ASKING THEIR FUNCTION. Score as a YES if child can point to 3 or more correctly. “Which one is for drinking/eating?” “Which one is for writing?” “Which one is for lighting fire?” “Which one is for driving?”
		22. Child can IDENTIFY (point to or give you) 10 objects you name.(Anyala wokesa oba walakana bibindu likhumi nga abiloma kamasiina. Remove 12 objects from the basket. Say to the child “Give [OR SHOW] me the spoon,” “Pass me [OR POINT TO] the cup,” etc. Score a YES if child can identify at least 10 of the objects. Doesn't matter which objects are identified. [PASS = AUTOMATIC PASS FOR #16] “Give [OR SHOW] me the spoon,” “Pass me [OR POINT TO] the cup,” etc.
		23. Child can NAME 10 objects in the basket. (umwana khuboolakamasina kebibindi likhumi bili musimpo) Remove 12 objects from the basket. Say to the child “What is this?” “What is this?” as you point to or hand the child the object. Score a YES if the child can name at least TEN (10) items. It does not matter which objects the child names.

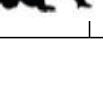
[PASS = AUTOMATIC PASS FOR #19 & #22]

		24. Child is able to categorize things.(umwana wamanya bibindu bifanana ni bikhafanana ta) Ask the child – “Tell me some things that you eat.” “Tell me some things that you eat.” Each food must be distinct (e.g child CANNOT receive credit for saying “fruit” and “mango”). Then say, “Good. Now tell me some animals that you know....” “Good. Now tell me some animals that you know....” Each animal must be distinct. Score YES if child is able to tell you 3 or more different foods OR 3 or more different animals.
		25. Child is able to follow a 3 step command. ” (umwana anyala khulondelela bilakilo bilimo bye khukhola bitaru. For example, “stand up, clap your hands and turn around in a circle” “stand up, clap your hands and turn around in a circle” Score a YES if child is able to understand command and carry out all 3 actions in correct order. Do not demonstrate. [PASS = AUTOMATIC PASS FOR #15]
		26. Is able to tell you the use of 3 or more objects. (Anyala khukhubolelela kumukaso kwe bibindu biratu oba khubirakho) Get out the car, spoon, broom, bottle. Without naming the object, POINT to each item and say, “What do you do with THIS?” or “What is THIS for?” “What do you do with THIS?” or “What is THIS for?” Score YES if child correctly uses action words (verbs) for 3 or more objects. For example, when asked, “What do you do with a spoon?” the child can say “Eat” or “It's for eating.” Answers such as “It's for food,” or “Food,” lack verbs and are not acceptable.
		27. Can do 2 syllable recall. (anyala khukhwilamo bilomo bibili khubino “pa, chi, tu, Go”) Say to the child. “When I say this, copy me....Pa, Chi, Tu, Go”. “When I say this, copy me....Pa, Chi, Tu, Go”. Say to the child, say “pa.” “Say “pa”” Wait for the child to say “pa.” Then say to the child “say pa, chi”, “say pa, chi.” Wait for the child to say “pa, chi.” Then say to the child “say pa, chi, tu”, “say pa, chi, tu.” Wait for the child to say “pa, chi, tu.” Then say to the child “say pa, chi, tu, go”, “say pa, chi, tu, go”. See how far the child can get i.e. How many they can do. Answer YES to this if they can at least do the first TWO eg. Pa and Pa, Chi.
		28. Child knows 2 of 3 comprehension questions. (umwana amanya birebo bibili khu birebo bitaru) Ask the child, “What do you do when you are hungry?” “What do you do when you are tired?” “What do you do when you are cold?” “What do you do when you are hungry?” “What do you do when you are tired?” “What do you do when you are cold?” Score a YES for this item if child can answer with responses for 2 or more of the questions.
		29. Understands the adjectives such as “faster” ategela tsilomo tsekhulekhanisa nga “mukhangu”) a car or a bicycle?” Show the child the car and the bicycle when asking this question. Score as YES if child responds “car.”
		30. Can do 4 syllable recall. (anyala khukhebulila bilomo bine bino “pa” chi, tu, go) SEE ITEM 27. Answer YES if child can repeat all FOUR (4) e.g., “Pa, Chi, Tu, Go.” [PASS = AUTOMATIC PASS FOR #27]

		31. Child can understand prepositions and follow tasks related to this. (umwana ategela byesi umubolelela lundi alondelela byesi umulakila bili nga bino) Get the cup and a bottle cap out of the basket. Place the cup upside down in front of the child. Give the child the bottle cap. Tell the child, “Put the bottle cap under the cup,” “Put it on the cup,” “Put it next to the cup,” “Put it behind the cup.” “Put the bottle cap under the cup,” “Put it on the cup,” “Put it next to the cup,” “Put it behind the cup.” Wait after each statement to allow the child to perform the action. Child needs to be able to do at least 3 of the 4 of these to score a YES.
		32. Understands the concept of opposites (wamanya bibindu bikhafanana nakhafwiti khari ta) ey’ekyendawulo) e.g. A boy is big, a baby is _____. If the sun comes up in the day, the moon comes up _____. A cheetah is fast, a turtle is _____. The sun is hot, ice is _____. A boy is big, a baby is _____. If the sun comes up in the day, the moon comes up _____. A cheetah is fast, a turtle is _____. The sun is hot, ice is _____. Score a YES if child correctly provides 2 opposites.
		33. Knows quantities – can count at least 3 objects (wamanya bukali bwebibindu-nyala khubala bibindu bitaru oba khubirakho) Line up 12 blocks in a row. Ask the child, “Can you tell me how many are here? Count them for me.” “Can you tell me how many are here? Count them for me.” Write down the maximum the child can count. Child MUST be able to correctly count objects, and is not assigning numbers incorrectly to objects. Score as a YES if child can correctly count 3 or more.
		34. SEE ITEM 33?” (Score as a YES if child can count 5 or more objects. [PASS = AUTOMATIC PASS FOR #33]

GROSS MOTOR

	1. Lifts chin off floor. (enyusa sillevu khukhwama asi) Put the child on his/her stomach on a flat surface. See if the child can at least lift his/her head so that the chin is off the surface for a short period of time. NOTE: IF FAILS THEN STOP.	2&5
	2. Prone (on tummy), can lift head up to 90 degrees.(Akonela khumoyo wamalaa wasuta kumurwe mungaki nga kwatererire) Put child on his/her stomach on a flat surface. See if the child is able to lift head up so that his/her face makes a 90 degree angle with the mat for several seconds. The child may support themselves on their forearms. [PASS = AUTOMATIC PASS FOR #1]	1&5
	3. Holds head upright for a few seconds. (anyalisa khusuta kumurwe khumala obutikitiki bufwiti) Hold the child in the sitting position. See if the child is able to hold his or head upright and steady for at least several seconds.	1&2
	4. Pulls to sit with no head lag (enyukha wekhala ne kumurye sikunyukha ta) Put the child on his/her back on a flat surface. Hold the child's hands and pull the baby up to a sitting position. See if the child's head comes with the body and does not lag or fall behind while the body is being pulled up.	
	If it does from early on, stop. 5. Lifts head, shoulders and chest when prone (asuta kumurye, kamakhono, ni sifuba nga wakonile walolile mungaki) Put the child on his/her stomach on a flat surface. See if the child is able to lift his/her head and chest off the surface using their arms for support so that he/she is looking ahead or even upwards. [PASS = AUTOMATIC PASS FOR #1 & #2]	
	6. Bears weight on legs when held in standing position (emikha nga wamuwambile wamwimisile) Hold the child up as if they were standing with their feet on the table/mat. See if the child supports his/her weight on the legs for a few seconds. Do not let go of the child.	
	7. Sits with help (ehakhala nga bamuyetile). Put the child in the sitting position on mom's lap or on the floor between mom's legs. See if the child will sit with the help of mom with a nice straight back and good neck control. [PASS = AUTOMATIC PASS FOR #1-5]	
	8. Rolls over from back to front (ayukha umwene khukhwama imugogo wakobola iburangisi) See if the child rolls over any time during the examination. “Does your baby roll over from back to front?”	
	9. Sits without help for a short time (ekhala nga siba muyetile ta khumala imbuka ifiti). Put the child in the sitting position on a flat surface. See if the child is able to sit for a short time unsupported (seconds) with a nice straight back and good neck control. [PASS = AUTOMATIC PASS FOR #7]	10

		10. Sits by self well (umwene ekhala). Put the child in the sitting position on a flat surface. See if the child can be left sitting and maintain balance in this position by self for a long period of time with a nice straight back and good neck control. [PASS = AUTOMATIC PASS FOR #7 AND #9]	9
		11. Crawls in any way (anfuula musambo tsosi). Is able to get about either by shuffling on bottom or on all four limbs. See if the child crawls any time during the examination. “Does your baby crawl or move around in a sitting position by pushing with his legs?”	
		12. Pulls self to stand/trying to get to standing (ekhweesa umwene akhaka emikhe yengene) Will grasp hold of furniture or other objects and pull self to standing position. Does not need to stay there for any length of time and may fall back down quickly. [PASS = AUTOMATIC PASS FOR #7 AND #9-10] “Can your baby pull himself to stand when holding onto furniture (not your hands)?”	
		13. Able to stand well if holding onto things (Anyala khukenda bulayi nga weyambile khubindu) See if the child can stand and hold on to a solid object such as a chair for a few seconds. May pass this without getting themselves to the standing position. “Can your baby stand for a few seconds if he/she is holding onto furniture (not your hands)?”	
		14. Walks using both hands of someone (Akenda nga weyambile khu mikhono gy’omundu kibilli) If you hold both hands to balance the baby, can they take several steps without tripping or falling? [PASS = AUTOMATIC PASS FOR #13]	
		15. Walks with help (using somebody’s hand as if led or a piece of furniture) (akenda nga weyambile khumukhono kwomundu oba khusisala) See if child can walk with the help of the mother holding out one hand to the child. See if the child will take a few steps with help or on the furniture, but not alone. [PASS = AUTOMATIC PASS FOR #13-14]	
		16. Walks, but falls over at times (akenda ne akwa kimilundu kimikali buuliyimbuka) Child is able to walk but not that confidently yet and falls over at times/quite often still. [PASS = AUTOMATIC PASS FOR #13-15]	
		17. Stoops and recovers falling (enamilila lundi wenyukha wema) See if the child is able to bend over and pick up a toy and return to a standing position without holding on to things around them or sitting down. (Picks up object off floor without falling) “Can your child take a few steps on his own?”	
		18. Walks well (akenda bulayi). See if the child walks well without falling over often with good balance. [PASS = AUTOMATIC PASS FOR #13-16]	
		“Does your child walk well on his own without falling?”	

		19. Basic running, may fall over. (khutima kwabushele, anyala wakwa) Able to get about quickly but not completely confident and falls over occasionally. (Amathamanga mwapang'ono pang'ono kugwa nthawi zochepa) [PASS = AUTOMATIC PASS FOR #18] To child: "Can you run for me?" To mother: "Can your child run, even if he falls occasionally?" 20. Kicks ball, tries to kick ball. (Asamba kumumpila, akhakakho k
		usamba kmupiila) 24 Can kick a ball by trying to move leg forward to meet it or by walking into it. Not necessarily kicking well with a really good swing of the leg. Can be demonstrated. Not To child: "Can you try to kick this ball?" To mother: "Can your child kick a ball or try to move the ball forward by walking into it?" 21. Runs well, stopping and starting without falling. (Atima bulayi, wakaama lundi watandikha khutima nga Sakwa ta)
		Runs with confidence with feet lifted up behind him/her as legs go forward. [PASS = AUTOMATIC PASS FOR #19] To child: "Can you run for me?" To mother: "Can your child run well, stopping and starting without falling?" 22. Kneels and gets up without using hands. : (afukhama lundi wenyukha nga sarambisa kamakhono ta) Able to get down on to his/her knees staying in an upright position and then get up without using hands. Can be demonstrated.
		To child: "Can you kneel down? Now can you get up?" To mother: "Can your child kneels from a standing position and then get backup without using his hands?" 23. Throws a ball into a basket (at least one of 3 times) 1 meter away. (Amwata kumumpila musikapo kimilundu kibirakho kitaru) kkubirisawo imita indywela) Stands one meter away from examiner's basket and is able to throw the ball in on at least one of three tries. Can be demonstrated.
		Can use meter long string to measure. "See how I throw the ball in the basket? Now you try." 24. Runs, stops and is able to kick a ball some distance. (atima, wakama lundi wasamba kumumpila kwatima) Able to run up to the ball and kick it a good distance with a good swing forward of the leg and balancing on one foot. Can be demonstrated. 20
		[PASS = AUTOMATIC PASS FOR #20-21] To child: "Can you run towards the ball and try to kick it?" To mother: "Can your child run, stop and kick a ball?" 25. Jumps with feet together off the ground. : (Asuna ni bikele bibili nga sitila aasi khwiloba ta) Able to jump with both feet leaving the floor together. Needs to get both feet off the ground. Can be demonstrated. Not
		To child: "Can you jump with both of your feet together?" To mother: "Can your child jump with both feet off the ground?" 26. Jumps over line/string on the ground. (anyalisa khusuna ilayini oba khakoye nga bakhare aasi) Able to jump well lifting both feet off the ground together over a string/line painted on the ground. Not a hop or skip. Feet should remain together and both feet reaching the floor at the same moment. Can be demonstrated. [PASS = AUTOMATIC PASS FOR #25]
		"Can you jump over this line/string with both feet?"

	27. Stands on one foot for less than 5 seconds. (emikha ni sikele sitwela ne sabirisa tsisekendi tsirano ta) 32 Ask child to raise one foot usually by bending his knee and maintain a good balance on his other foot for at least a second – up to 5 seconds. Can be demonstrated. “Can you stand on one foot for as long as you can?”
	28. Walks on heels for 6 + steps. (Akendela khukhukunyu kumala kamambaka kasesaba) . Can walk 6 steps on heels easily. Can be demonstrated. To child: “Can you walk on your heels for as many steps as you can?” To mother: “Can your child walk 6 steps on his heels?”
	29. Jumps over a piece of paper (widthways)(anyalisa khusunila khukngaki lupapula (mububalayi) Put a piece of paper (A4 size) on the ground. Ask the child to stand close to the paper with both feet together and to jump over the less wide part of the paper, landing with both feet together. Both feet need to come off the ground. Can be demonstrated. [PASS = AUTOMATIC PASS FOR #25-26] “Can you jump over this piece of paper?”
	30. Walks on tip toes for six or more steps. (Anyalisa khukendela tsitsala khumala kamambaka kasesaba oba khubirawo) Able to balance on tip toes and walk 6 steps keeping up on the toes well with good balance. Can be demonstrated.
	“Can you walk on your tip toes for as many steps as you can?” 31. Hops on one foot without support, has to go 3 steps. (Akongoodheraku mugulu mulula aghazira kughanirirwa, agya ebigere bisatu) Makes three consecutive hops with the same leg raised throughout. Can be demonstrated.
	“Can you hop on one foot for as many steps as you can?” 32. Stands on one foot for a longer time – (at least 5 seconds and up to a minute). (emikha nisikele sitwela khumala imbuka indeyi- sifwiti tsisekendi tsirano khukwola indakika indwela .) Ask child to raise one foot usually by bending his knee and maintain a good balance on his other foot for more than 5-10 seconds, up to a minute or two counts. Can be demonstrated. [PASS = AUTOMATIC PASS FOR #27]
	“Can you stand on one foot for as long as you can?” 16. Can throw a ball up in the air and catch it with 2 hands. . (Anyalisa khumwata kumupiila mumbewo lundi wakuukama ni kamakhono kabili?) Can throw the ball up a good distance and catch it with two hands together. May try 3 times. Can be demonstrated.
	To child: “Can you throw a ball of in the air and catch it with 2 hands?” To mother: “Can your child throw a ball of in the air and catch it with 2 hands?” 33. Heel/toe walk with one foot behind the other along the string with good balance: (akenda ni sikele sitwela nga sisindi sili iyuma ne sakwa asi ta. Can walk along the same line but this time heel to toe with his feet touching with good balance. Can be demonstrated.
	To child: “Can you walk along this line heel to toe?”

