UPTAKE, PERCEPTIONS AND ASSOCIATED FACTORS ON PREMARITAL SICKLE CELL TRAIT (SCT) TESTING SERVICES AMONG MARRIED INDIVIDUALS IN MITYANA MUNICIPALITY MITYANA DISTRICT

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DECLARATION

I, Martha Dorcas Nalweyiso, declare that this dissertation is entirely my work and to the best of my knowledge, it has never been submitted by anyone for a professional award.

I have therefore submitted it for a Master's in Public Health award.

All references made are acknowledged.

Signature  Date 1st September 2025

(Researcher)

DEDICATION

This work is lovingly dedicated to my dear family, the Kikootis, whose unwavering love, encouragement, and prayers have been my source of strength throughout this journey. To my parents, siblings, and loved ones — your support has been the foundation upon which I have built my resilience and determination. May this achievement reflect your sacrifices, faith, and endless belief in me.

APPROVAL

This is to certify that this research titled “Perceptions, uptake and associated factors on premarital sickle cell trait (SCT) testing services among married individuals in Mityana Municipality, Mityana District” has been done under my supervision and is now ready for external review.

Signature……  Date: September 1, 2025

REV. CANON EVATT M. MUGARURA

(Supervisor)

ACRONYMS/ABBREVIATIONS

SCT	Sickle Cell Trait
REC	Research Ethics Committee
SCD	Sickle Cell Disease
SCTT	Sickle Cell Trait Testing
WHO	World Health Organisation
HBM	Health Belief Model
HLA	Human Leucocyte Antigen
UN	United Nations
SDA	Seventh Day Adventist
PI	Principal Investigator
IRB	Institutional Review Board

DEFINITION OF TERMS

Sickle cell trait (SCT) is a genetic condition that occurs when a person inherits one normal haemoglobin gene (HbA) and one abnormal haemoglobin gene called haemoglobin S (HbS) from their parents.

Sickle Cell Disease (SCD) is a genetic disorder that affects the haemoglobin molecule in red blood cells. Haemoglobin is responsible for carrying oxygen from the lungs to various tissues and organs in the body. In individuals with sickle cell disease, a mutation in the gene that codes for haemoglobin causes the red blood cells to become deformed and take on a crescent or "sickle" shape under certain conditions.

Pre-marital sickle cell trait testing refers to genetic testing for sickle cell trait before marriage.

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ABSTRACT

Introduction: Sickle Cell Disease (SCD) is one of the biggest health challenges worldwide. Sub-Saharan Africa is where the greatest burden exists and where 75% of the world's SCD occurs. Preventive approaches include screening couples intending to have children by inexpensive and reliable blood tests in addition to genetic counselling. However, there is a lack of information about the adoption of these approaches to aid in creating meaningful, tailored interventions.

Objective: To determine the uptake of premarital sickle cell trait testing, explore the perceptions and factors associated among married individuals in Mityana Municipality, Mityana District.

Methods: We employed a convergent parallel mixed-methods design. The quantitative component employed a cross-sectional design, involving 272 consecutively sampled married individuals who had married between January 2023 and December 2024. Uptake was summarised as a proportion, along with its associated 95% confidence interval (95% CI). Mixed effects modified Poisson regression was used to determine the factors associated with the uptake of SCTT. The qualitative component employed an exploratory descriptive design using in-depth interviews with 17 purposively selected married individuals. Data were analysed using deductive thematic analysis.

Results: The uptake of SCTT was identified among married individuals at 14.71% (95% CI: 9.03-23.04). Multivariable analysis results revealed that, age of 18-30 years (adjusted prevalence ratio (aPR): 1.23, 95%CI: 1.08-1.40, P=0.004), being Muslim (aPR: 1.10, 95% CI: 1.07-1.14, P<0.001), a family history of SCD (aPR: 1.17, 95% CI: 1.07-1.27, P=0.001) and not attending antenatal (ANC) visits (aPR: 0.92, 95% CI: 0.86-0.98, P=0.009). Qualitative findings revealed perceptions around SCTT, i.e. perceived barriers highlighting health care and socio-cultural issues hindering testing, perceived benefits highlighting socio-cultural issues favouring testing, perceived severity highlighting especially around the presentation of SCD, perceived susceptibility highlighting the possible causes/transmission of SCD, perceived threats highlighting

family issues around testing or SCD, and cues for action highlighting the concerns for improvement of SCT testing.

Conclusion: The study revealed a low uptake of SCTT among married individuals living in Mityana Municipality, Mityana District. Younger age groups, being Muslim, a family history of SCD and attending antenatal care visits were associated with better uptake rates. The perceptions are multifaceted, highlighting that complex patterns influence the uptake of the test. These findings highlight the need for community sensitisation of SCT testing, improve awareness among religious leaders, improve access to sickle cell testing facilities, and emphasise the need for premarital SCT testing during hospital and church marriage counselling.

CHAPTER ONE: INTRODUCTION

1.1 Background

Sickle Cell Disease (SCD) is one of the biggest health challenges worldwide (Lee, 2022). SCD causes severe lifelong morbidity that requires prolonged hospital exposure (Foanor and Anthony, 2020). Consequences vary among individuals but include acute renal failure, gallstones, jaundice, asplenia, stroke, and acute chest syndrome etc. Treatment of the disease necessitates prolonged admission, which contributes to a high emotional and financial burden on several families in Africa (Kalamba Gbeneol, 2015).

Globally, estimations show that out of 400,000 children born with SCD every year, 300,000 are from within the Africa continent (Ojelabi, 2024). The greatest burden exists in Sub-Saharan Africa, where 75% of the world's SCD cases occur, and it is projected to increase by 2050. Sub-Saharan African countries experience the death of children born with SCD in the range of 50% and 90% (Egesa et al., 2022). The SCD burden poses a risk for death in the under 5 years of life, with approximately 50% of deaths occurring between the ages of 6 months and 1 year (Babalola *et al.*, 2019). Evidently, Sickle cell trait is documented to show a protective effect against malaria, which may justify the high prevalent among the African population. Individuals with SCD survive Malaria episodes therefore continue transmitting HbS gene among the populations (Ngou et al., 2023). Uganda is documented among the top countries with a large burden of SCD. A nation-wide survey revealed the burden of sickle cell trait among children to reach as high as 19.8%, higher in the central and northern regions of the country (Ndeezi et al., 2016).

While developed nations have implemented successful newborn screening initiatives, sub-Saharan Africa often lacks the necessary infrastructure for widespread testing, leaving many cases undiagnosed (Musuka et al., 2024). This infrastructural deficit is compounded by deeply ingrained social and cultural factors. SCD carries a significant stigma in many African communities, often unfairly targeting mothers of affected children, and the prospect of screening can exacerbate existing social tensions, potentially leading to marital discord, violence, or even relationship dissolution (Marsh et al., 2011). Fear of social repercussions, prevalent misconceptions about SCD,

including assumptions about spousal carrier status, beliefs about children's susceptibility, and misperceptions about the screening process itself (Bhatt-Poulose et al., 2016), contribute significantly to low screening uptake. Furthermore, potential relationship implications, such as the fear of losing a prospective spouse due to unfavourable results, further deters individuals from seeking testing (Boadu, 2018). Many individuals are unaware of SCD within their family history, and low screening rates among people engaged in relationships which could lead to marriage and childbearing implies that many are unaware of their sickle cell trait (SCT) status. Premarital screening for the sickle cell trait has been considered as one of the effective methods of preventing SCD among new-borns (Oluwole et al., 2022). The possibility of the lack of awareness threatens to perpetuate the cycle of transmission within the continent.

The World Health Organization (WHO) issued a comprehensive report on the prevalence of SCD, overall management and prevention within the African continent (WHO, 2024). The report emphasized the need to implement more of the preventive approaches than curative options. Preventive approaches would include screening couples intending to have children by inexpensive and reliable blood tests in addition to genetic counselling (WHO, 2024). These approaches would contribute to improved sickle cell awareness, disease prevention, and early detection to lower the burden of the disease. Despite this guidance, ministries of health lack of accurate data about the adoption of these approaches to aid in creating meaningful tailored interventions (Musuka et al., 2024).

Therefore, this study aimed to study the uptake, factors associated and perceptions on SCT testing in Mityana municipality, Mityana district, Uganda.

1.2 Problem statement

Uganda is ranked fifth in Africa for its high burden of sickle cell disease, with an estimated 13.3% of children carrying the sickle cell trait (SCT) and between 5,000 and 20,000 babies born with sickle cell disease (SCD) each year. Sadly, about 80% of these children die before reaching their fifth birthday (Namukasa et al., 2024). When both parents carry the sickle cell trait (SCT), there is a 25% probability that their child will be born with sickle cell disease (SCD) and a 50% likelihood that the child will also inherit the trait, becoming a carrier(Schultz et al., 2020).

The Ugandan Ministry of Health (MoH) has taken efforts to improve pediatric outcomes of SCD, focused on prenatal diagnosis and genetic counselling. However, previous studies on SCD and SCT conducted in Uganda report the prevalence of SCD among different sub-populations including secondary and university students (Namukasa et al., 2024), which would have been avoided if premarital sickle cell testing was conducted. This means that couples join marriage without testing for SCT. Treating a child with SCD causes severe lifelong morbidity that requires prolonged hospital visits which is extremely mentally draining and expensive for most families within the county.

Most of the sickle cell trait screening programmes so far have been directed among infants where the effects have already surfaced or are just manageable with costly treatment. This maintains the trait within the population which hinders achievement of the global goal to reduce deaths due to sickle cell disease (Zapfel et al., 2023).

Preventative approaches which include premarital sickle cell trait screening have been identified to be an effective method for the reduction of the SCD burden in developing countries (Dilli et al., 2024).

Despite these interventions, the prevalence of SCD has remained high, estimated at around 2% of the population. However, the contributing factors and adoption of premarital SCT testing are not well understood. Therefore, the purpose of this study is to determine the uptake, explore perceptions, and identify factors associated with premarital Sickle Cell trait testing among newly married individuals in Mityana Municipality, Mityana District, to inform future programming.

1.3 STUDY OBJECTIVES

1.3.1 General Objective

To determine the uptake of premarital sickle cell trait testing, explore the perceptions and associated factors among married individuals in Mityana Municipality, Mityana District.

1.3.2 Specific Objectives

1. To determine the uptake of premarital sickle-cell trait testing services among married individuals in Mityana Municipality, Mityana District.
2. To explore the perceptions towards premarital sickle cell trait testing among married individuals in Mityana Municipality, Mityana District.
3. To establish the factors associated with the uptake of premarital Sickle Cell Testing among married individuals in Mityana Municipality, Mityana District.

1.4 Research Questions

1. How is the uptake of premarital Sickle-Cell trait testing among married individuals in Mityana Municipality, Mityana District?
2. What are the perceptions towards Sickle Cell trait testing services among married individuals in Mityana Municipality, Mityana District?
3. Which factors are associated with uptake of Sickle Cell trait testing services among married individuals in Mityana Municipality, Mityana District?

1.5 Conceptual Framework

This conceptual framework illustrates the multifaceted influences on the outcomes of sickle cell trait testing (SCTT). It identifies sociodemographic characteristics as factors that impact both institutional and socio-economic elements. Institutional factors include awareness and accessibility of SCTT services, while socio-economic factors encompass income, partner support, transportation costs, testing costs, and distance to testing facilities. These factors collectively shape individual beliefs and perceptions about SCTT, guided by the Health Belief Model (HBM), which considers perceived threat, susceptibility, severity, benefits, and barriers. These beliefs, influenced by the intersecting sociodemographic and institutional factors, ultimately are associated with the uptake of SCTT services.

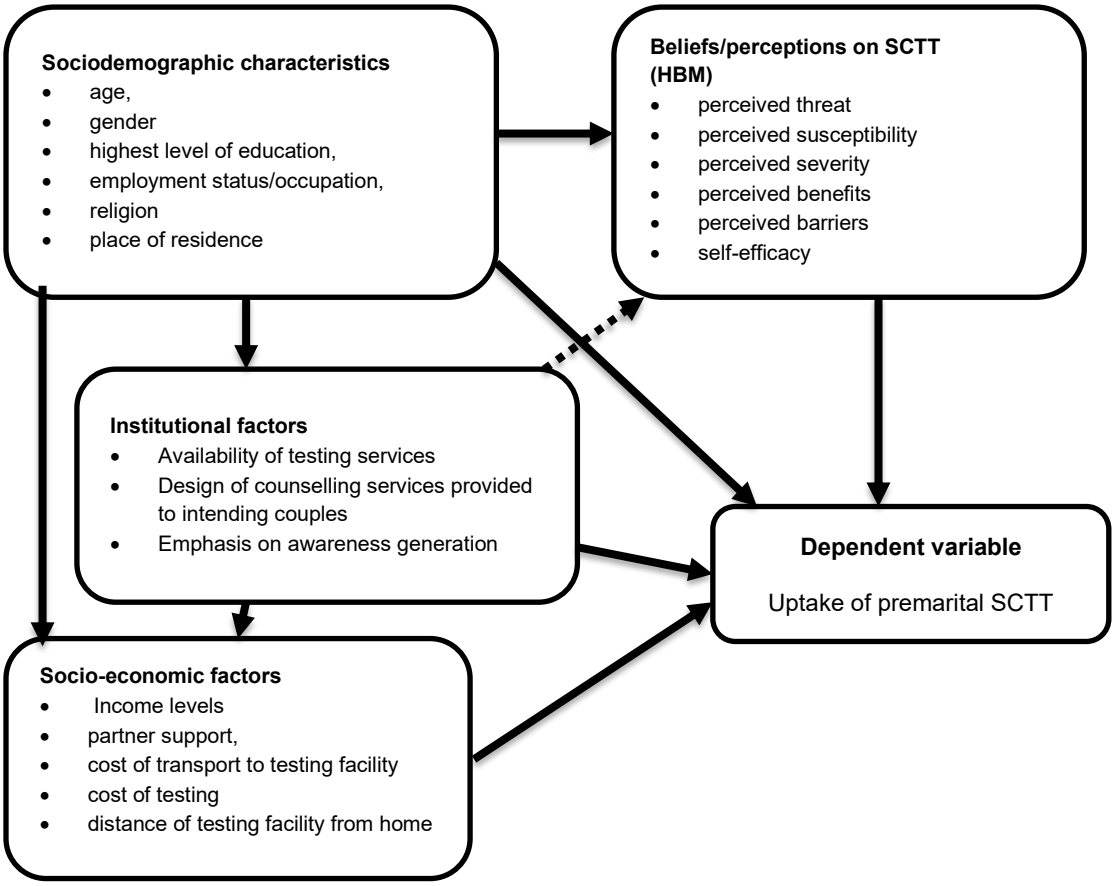

Figure 1: A conceptual framework showing the interlinkage of independent and dependent variables

1.6 Study Scope

1.6.1 Geographical scope

The study was conducted in Mityana Municipality, Mityana District, located in Central Uganda. The district is around 77 kilometres to the west of Kampala, the capital city. Mityana is bordered by Kiboga to the north, Nakaseke to the northeast, Wakiso to the east, Mubende to the west, Mpigi District to the southeast, and the districts of Butambala and Gomba to the south. The district has twenty-five licensed venues to conduct official marriages, including Catholic, Anglican, Seventh-day Adventist, Pentecostal, and Born-Again churches, as well as mosques. Given that most of these places of worship are concentrated within the municipality, it was an appropriate site for assessing premarital sickle cell trait testing among married individuals, as marriage institutions play a central role in counselling and premarital preparations.

1.6.2 Time scope

This study focused on the period from 2021 to 2025, encompassing both data collection and literature review. The participants were married between January 2023 and December 2024, making the findings reflective of current practices. The literature consulted largely falls within the last five years (2021–2025), ensuring that the background, problem statement, and discussions are anchored in up-to-date knowledge on Sickle Cell Disease (SCD), its prevalence, preventive strategies such as premarital testing, and the socio-cultural barriers to uptake. The time scope ensures that the study responds to contemporary public health concerns and provides evidence relevant for guiding future programming and interventions.

1.6.3 Content scope

The study focuses on premarital sickle cell trait testing (SCTT) among newly married individuals in Mityana Municipality. Specifically, the dissertation examined:

- The uptake of SCTT, measuring the proportion of individuals who underwent the test before marriage.
- Perceptions toward SCTT, guided by the Health Belief Model, exploring perceived susceptibility, severity, benefits, barriers, threats, and cues for action.

- Factors associated with SCTT uptake, including socio-demographic characteristics (age, education, religion), socio-economic elements (income, partner support, costs), and institutional influences (awareness, access, antenatal care attendance).

The scope was deliberately restricted to newly married individuals, as this group represents a critical window where premarital testing could prevent the transmission of SCD to offspring. By focusing on uptake, perceptions, and associated factors, the study aimed to generate insights that could inform policy and community-based interventions for improving premarital testing practices in Uganda.

1.7 Justification of the study

In 2008, the United Nations General Assembly recognised sickle cell disease (SCD) as a public health priority, prompting the launch of various projects, programs, and community-based organisations in low- and middle-income countries (LMICs). However, many of these initiatives have not been consistently maintained or expanded to address the growing burden of the disease adequately (Zapfel et al., 2023). The United Nations Sustainable Development Goals set a target to eliminate preventable child and newborn deaths by 2030, emphasising the urgent need for countries to adopt and implement interventions for sickle cell disease (SCD). Key among these measures are enhancing premarital and newborn screening, which remain insufficiently embraced across sub-Saharan Africa (Esoh et al., 2021).

Previously run programs to improve SCT testing/screening in Uganda have focused on screening children for the trait and disease (Hernandez et al., 2021). However, there is no current policy highlighting the need for premarital SCT testing despite it being advocated for.

This study, therefore, aimed to provide current knowledge on the uptake of SCT testing, factors associated with it, and perceptions among married individuals in a semi-urban setting of Uganda.

1.8 Significance of the study

This study generates empirical evidence on the uptake, perceptions, and factors associated with premarital sickle cell trait testing (SCTT) among newly married individuals in Mityana Municipality. By highlighting the socio-cultural, demographic, and institutional influences on SCTT, it provides insights that can inform culturally sensitive awareness programs, strengthen marriage counselling services, and guide policy makers and health planners in designing targeted interventions. Ultimately, the findings contribute to Uganda's efforts to reduce the burden of Sickle Cell Disease, improve child survival, and advance national and global health priorities such as the Sustainable Development Goals.

CHAPTER TWO: LITERATURE REVIEW

The literature review is conducted in accordance with the study's objectives and conceptual framework.

2.1 Burden of Sickle Cell Disease (SCD)

Sickle Cell Disease (SCD) is predominant and yet neglected disease among people from African, Asian, Arabian and Mediterranean countries; nonetheless it is a global health problem because of population migration since the world is now a global village (Anie, Egunjobi and Akinyanju, 2010). The global burden of SCD increased by 41·4% from 5·46 million in 2000 to 7·74 million in 2021 representing 300 million people with have hemoglobin disorders (Thomson *et al.*, 2023). The greatest burden is seen in Sub-Saharan Africa, where more than 75% of all sickle cell disease occurs, projected to increase by 2050 (Ndeezi *et al.*, 2016). In Uganda, out of 900,000 thousand children born annually, approximately 2.8% (15,000) have sickle cell anemia (Ndeezi *et al.*, 2016). This number contributes 16.2% of all children (123,000) who die annually in Uganda (Okwi *et al.*, 2010). Amongst the Sub-Saharan countries, Uganda ranks fifth with the highest SCD burden (Mandu *et al.*, 2018).

2.2 Etiology and clinical history of SCD

Sickle Cell Disease (SCD) is one of the biggest health challenges worldwide (Lee, 2022). SCD is a common single-gene disorder most prevalent among persons of African descent (Gustafson *et al.*, 2007). SCD is a group of inherited red blood disorders transmitted from parents to their offspring and results when an individual inherits two abnormal hemoglobin genes, one from each parent (Uche *et al.*, 2017) and (Foanor and Anthony, 2020). Normally, healthy red blood cells are round and move through small blood capillaries carrying oxygen to all body parts but since Sickle cells are shaped like a sickle, they can get jammed in small blood vessels and block blood and oxygen flow to organs in the body. These blockages cause repeated episodes of severe pain, organ damage, serious infections, or even stroke (Lee, 2022). Sickled Red Blood Cells (RBCs) are destroyed within 10-17 days in comparison to the normal 120-day lifespan of non-sickled RBCs.

SCD manifests in early infancy and typically persist throughout the lifespan. Clinical manifestations include intermittent excruciating pain, increased morbidity, and mortality, yet has received less recognition in the public domain (I and T, 2018). These chronic and acute episodes of pain result in tremendous suffering, prolonged absence from regular duties such as work, school, etc (Foanor and Anthony, 2020). Others symptoms include chronic anemia, hemolysis cerebrovascular events and formation of pigment gallstones which is a major risk factor for death in SCD patients (Babalola *et al.*, 2019)and(Gustafson *et al.*, 2007). The one cure-bone marrow transplantation is available to a limited number of patients with a human leukocyte antigen (HLA)-matched sibling (Treadwell, McClough and Vichinsky, 2006). These medical procedures are costly for majority of the families in Sub-Saharan Africa.

SCD causes severe lifelong morbidity that requires prolonged hospital exposure (Foanor and Anthony, 2020). Isah *et al*. (2016) document that SCD affects almost every organ in the body. Consequences include acute renal failure, gallstones, jaundice, asplenia, strokes, and acute chest syndrome among others. The many complications of SCD can make every stage of life extremely challenging for individuals with the disease (Sokoto, 2016). Pathological features of SCD include, delayed growth and development, growth retardation, congestive heart failure, pulmonary infection, fat or bone marrow embolism, sickle cell lung disease, pulmonary hypertension, iron overload, viral hepatitis, acute and chronic renal failure, and retinal detachment (Foanor and Anthony, 2020)

2.3 Uptake of premarital sickle cell trait testing

Testing for the sickle cell trait is among the most effective preventive measures for sickle cell disease before marriage or producing children. The SCD has a predominant in sub-Saharan region recorded at about 75% of its occurrence in Africa. Prevention of birth of children with SCD is a critical public health goal which can be evaluated through sickle cell testing before marriage (Gbeneol et al., 2015). In Africa, uptake of premarital screening is taken seriously such as Nigeria, however, in some countries such as Uganda, most individuals are ignorant of their partners genotypes.

A systematic review on the practice of premarital screening reviewed 15 papers and observed a continental pooled sickle cell trait testing uptake of 47.82% ranging from as low as 11.72% to 86.67%. As observed few studies were included coming from countries of Cameroon, Ghana, Nigeria and Uganda (Dilli et al., 2024). Cameroon had the lowest uptake of SCT of 11.71% followed by Uganda at 22.82% whereas Nigeria recorded the highest pooled prevalence of 56.44%. Despite the low uptake from Uganda, results were pooled from a study in a school setting and community subgroup in an urban area (Kisakye et al., 2022; Tusuubira et al., 2018). This implies that these results are not representative of semi-urban or rural settings which could have a whole set of unknown influences which would hinder the effectiveness of proposed programs. Testing for the sickle cell trait is among the most effective preventive measures for sickle cell disease before marriage or producing children. The SCD has a predominant in sub-saharan region recorded at about 75% of its occurrence in Africa. Prevention of birth of children with SCD is a critical public health goal which can be evaluated through sickle cell testing before marriage (Gbeneol et al., 2015). In Africa, uptake of premarital screening is taken seriously such as Nigeria, however, in some countries such as Uganda, most individuals are ignorant of their partners genotypes.

2.4 Perceptions of sickle cell trait testing (SCTT)

The Health Belief Model (HBM) is a framework for understanding behavioral change that includes seven key elements: perceived threat, perceived susceptibility, perceived severity, perceived benefits, perceived barriers, cues to action, and self-efficacy (Rosenstock, 2000).

The perceived susceptibility aspect highlights an individual's belief regarding their risk of developing a condition; for example, someone who believes they are at risk for sickle cell disease (SCD) is more inclined to accept screening for sickle cell trait (SCT) compared to those who do not share this belief. The perceived severity component addresses the potential seriousness of a condition like SCD, which can significantly impact an individual's willingness to undergo SCT screening.

Perceived benefits refer to an individual's recognition of the effectiveness of interventions available to mitigate health threats. If SCT screening is viewed as beneficial, individuals are more likely to agree to it. Conversely, the perceived barriers component involves the individual's assessment of obstacles that may hinder acceptance of SCT screening. There is considerable variability in how individuals perceive these barriers, which leads them to conduct a cost-benefit analysis where they weigh the effectiveness of the screening against potential risks (such as side effects), discomfort (like pain), time requirements, or logistical challenges (such as accessibility issues).

In conclusion, the Health Belief Model (HBM) explains health behavior through factors like perceived threat, susceptibility, severity, benefits, barriers, cues to action, and self-efficacy (Rosenstock, 2000). Individuals who recognize their risk (susceptibility) and the seriousness (severity) of sickle cell disease (SCD) are more likely to undergo sickle cell trait (SCT) screening. However, perceived barriers such as pain, accessibility, and time constraints can discourage screening, requiring a balance between perceived benefits and obstacles to influence decision-making.

2.5 Factors associated with the uptake of premarital sickle cell trait testing

Few studies have reviewed the possible factors associated with uptake of premarital SCTT. However, these factors were categorized into socio-demographic, socio-economic and institutional factors (Kyakuha et al., 2024). Socio-demographic factors include; the age, gender, highest level of education, employment status/occupation, religion and place of residence. Socio-economic factors include; monthly income, partner support, cost of transport to testing facility, cost of testing and distance of testing facility from home among others. Institutional factors include having heard about SCTT, having knowledge about SCTT, and place where SCTT service is accessible.

A study carried out among 334 systematically sampled pregnant women receiving antenatal care at Hoima regional referral hospital Uganda revealed a 11.4% uptake of SCT testing/screening services (Kyakuha et al., 2024). It also revealed that the education level, partners support and knowledge towards SCTT were significantly

associated with uptake of the screening services. Notable associations such as family history of SCD and awareness of the disease were also observed.

Another study carried among 326 final year undergraduates in a tertiary institution in South-West Nigeria. These students were conveniently sampled and it was revealed that having good knowledge about sickle cell disease was associated with having good attitude of sickle cell trait testing (Adesina et al., 2022). This was similar to a study carried out among 285 local government workers in ile-ife, Nigeria where participants education level was associated with having a favorable attitude to premarital sickle cell screening (Abioye-Kuteyi et al., 2009).

A Ugandan cross-sectional study carried out among 315 university students revealed an uptake rate of 24.4%. It also revealed that participants with the age 25 to 29 years were more likely to have SCTT, indicating a close association between the age and the uptake rate (Kisakye et al., 2022).

A somewhat similar study among 400 university students in Benin investigated the acceptability of premarital screening for sickle cell disease. It revealed that influence by religious belief had a borderline association with the acceptability of the premarital sickle cell testing (Omuemu et al., 2013). This indicates that religion may have an impact on the uptake rate of premarital sickle cell trait testing.

In conclusion, the factors influencing the uptake of premarital sickle cell trait testing (SCTT) include socio-demographic (age, education, residence), socio-economic (income, partner support, cost), and institutional (awareness, accessibility) factors.

2.6 Tribal prevalence of SCD in Uganda

Even within countries, SCD prevalence also differs among tribes (Ndeezi *et al.*, 2016). For Uganda's case, districts of Sironko and Tororo had a varying prevalence of 17.5% and 19.5%, respectively (Mandu *et al.*, 2018). Additionally, a SCD prevalence of 5% for Hamites in the southwest Uganda was reported compared to more than 20% for the northern Nilotics. Some Bantu tribes had even higher rates, including 45% of Bamba living in the western region (Ndeezi *et al.*, 2016). Additionally, reports from Okwi *et*

al., (2010) indicated that the concentration of the SCT was found to be highest in specified sub-populations likely due to tribal conservative marriages (Okwi *et al.*, 2010). Traditional conservative marriages contribute more to to the propagation of Sickle Cell Disease than other marriage types because there are no counselling and pre-marital screening practices performed.

2.7 Marriage and SCD burden

As nature dictates, the moment you become and adult, there is need for you to reproduce and take care of your offsprings through marriage to receive companionship, support and procreation (I and T, 2018). Reports document that more than half of married couples enter into marriage unaware of their hemoglobin genotypes, which is not any different in Uganda (McGann, Hernandez and Ware, 2017). This increases the risk of bearing children with SCD due to the unawareness of the Sickle Cell status of both parents. Children born to two parents with Sickle Cell Trait (SCT) have a 25% chance of having Sickle Cell Disease and a 50% chance of having SCT also known as a Sickle Cell Carrier (Treadwell, McClough and Vichinsky, 2006). Considering this fact, information about the premarital sickle cell screening and counseling before marriage could serve as an important tool towards preventing sickle cell disorder (Anie, Egunjobi and Akinyanju, 2010). It could also help to achieve the desired level of knowledge and a change in attitude.

In low - income countries, where the condition is most prevalent, approaches like carrier identification and genetic counselling remain the only representative approach to reduce the impact of the disease and allows better use of available resources (Abioye-Kuteyi *et al.*, 2009). Prospective control of SCD by heterozygote detection through marital screening, which is vital to the identification of the couples at risk is of utmost importance (Abioye-Kuteyi *et al.*, 2009). However, undertaking premarital sickle cell screening and counseling may depend on individual's knowledge of the sickle cell disorder (Anie, Egunjobi and Akinyanju, 2010). Although the knowledge gained about premarital sickle cell screening/counseling could help to prevent SCD but positive attitudinal behavior of the intending couples towards screening/counseling could lead

to eradication of the sickle cell genetic disease in African countries (Anie, Egunjobi and Akinyanju, 2010)

Based on Uganda's high prevalence of SCD, there is an urgent need to increase awareness of SCD and importance of SCTT among the population, especially those intending to get married in all registered ways, to avert the situation. Most countries in Sub-Saharan Africa, experience increasing Under 5s mortality rates attributed to SCD. These high death rates are not in tandem with UN Sustainable Development Goal IV, which aims at ensuring health lives and promoting well-being for all at all ages (Bindhani, Devi and Nayak, 2020).

2.8 Interventions by the Ministry of Health

Preliminarily, the Ministry of Health (MoH) identified improved pediatric outcomes of SCD as a key health priority, focused on prenatal diagnosis and genetic counseling, newborn screening with a proposed program to diagnose affected children early in life and follow-up care for affected children (Uganda Ministry of Health, 2023). However, the most cost-effective strategy to reduce the SCD burden in Uganda would be to focus on primary prevention of the disease as earlier mentioned (Uche *et al.*, 2017). This can be through public education and health awareness programs among others. Adequate knowledge is required among the populace in general and individuals with the sickle cell trait in particular. This will enable them make informed decisions on whether to have more children (Green *et al.*, 2016). In there is provision of free routine drugs such as folic acid and Paludrine as well as equipment such as automated full blood count machines (Uche *et al.*, 2017).

However, awareness and uptake of Sickle Cell Testing among those intending to get married could be hindered by cultural beliefs and social and economic barriers which may contribute to a lack of interest and support for Sickle Cell Testing and genetic counselling among youths (Gustafson *et al.*, 2007). Yet, families predominantly suffer the consequences of raising a child born with a Sickle Cell trait and disease. A study from Ghana by I & T, (2018) assessed the knowledge among university students and concluded that a higher level of education and knowing a relative with sickle cell trait

(SCT) or SCD was significantly associated with high knowledge of SCD ($p<0.05$) and the reverse is true (Sokoto, 2016).

WHO report on SCD within the African Region states that preventing the inheritance of a double sickle cell gene is much better than any healthcare provided to patients. Therefore, the recommendation to member states was to design and implement a comprehensive and integrated national program for the prevention and management of the disease (Drusin, 1995). Countries were encouraged to strengthen national programs focusing on advocacy, prevention and counselling, early detection and treatment, data collection, surveillance and research, and community education and partnership (Drusin, 1995).

Since Uganda holds the fifth position in the burden of SCD, the country needed to double its response efforts. During the commemorated the World Sickle Cell Day on 22nd June 2023, the Hon. Minister of Health, informed that during the 76th World Health Assembly in Geneva, Switzerland, the Global Sickle Cell Coalition was launched. Uganda was chosen as a flagship country in Sub-Saharan Africa for best practices in Sickle Cell Disease programming and recommended for funding, based on exceptional nationally framed sickle cell plan. She advocated for pre-marital screening to reduce the incidence of Sickle Cell Disease in the country (Uganda Ministry of Health, 2023). Therefore, it is impactful to prevent the occurrence of SCD among the populations that address the complications which come along with the SCD hence we set out to determine the levels of awareness and uptake of Sickle Cell Testing among the pre-marrieds to avert this situation.

CHAPTER THREE: METHODS

3.1 Study design

The study employed a convergent parallel mixed method cross-sectional design employing a multi-stage sampling technique to select the study participants. It involved the simultaneous collection of both quantitative and qualitative data. The qualitative component involved use of an exploratory descriptive design.

3.2 Study area

The study was conducted in Mityana municipality, Mityana district between March to April 2025. Mityana District is one of the districts in central Uganda (https://mityana.go.ug/health). The district is located approximately 77 kilometers (48 miles), by road, west of Kampala, Uganda's capital and largest city. It is bordered by Kiboga district to North, Nakaseke District to the northeast, Wakiso district to the east, Mubende District to the west, Mpigi District to the southeast, and Butambala and Gomba Districts to the south (Uganda Bureau of Statistics, 2006).

The district has twenty-five licensed places to conduct official marriages which include two (2) Born Again churches, three (3) Catholic churches, six (6) Seventh Day Adventist (SDA) churches, seven (7) Pentecostal and seven (7) churches belonging to the Church of Uganda and no Arthodox church. In addition, most of the churches are situated in the municipality (Church, 2016). The are also several mosques within Mityana constituency that will need to be sampled as well.

3.3 Study population

The reference population involved individuals who are residents of Mityana municipality and who got recently married within a period of two years. These should have registered with the various official marriage places across all religious denominations within the district. Various religious dominations like Born Again, Pentecostal, Church of Uganda, Seventh Day Adventist, Catholic, Muslim and even those married through the office of the Chief Administrative Officer, were considered.

3.4 Eligibility criteria

3.4.1 Inclusion criteria

Married couples who got married within the past two years and are still living in Mityana municipality, and who consent to respond to the interview questions, were considered for this study.

3.4.2 Exclusion criteria

Married couples not feeling well to participate in the interview were to be excluded. However, none of the respondents met this criterion, and therefore, no participant was excluded from the study.

3.5 Study Setting

The study participants were contacted, and interviews were carried out at places of convenience that provided confidentiality to the respondent.

3.6 Sample size determination

The sample size was computed using the modified Kish Leslie's formula for sample size determination using the proportion of individuals (due to multi-stage sampling and clustering by place of worship) who took up the sickle cell test from the study by (Namukasa et al., 2024) of 17.8% as shown below;

$$n = \frac{Z^2{}_{(1-\alpha)} p(1-p)}{d^2} xDE$$

Where;

- n is required sample size
- d is tolerable sampling error 5% (0.05)
- p is the estimated proportion of those who screened for SCT of 17.8%.
- Z-alpha is the standard normal value corresponding to set 95% level of confidence= (Z=1.96)
- DE-Design effect = 2 (to adjust for method of sampling; multi-stage)
- **n=450 participants**

Accounting for a 10% non-response, yields a required sample size of 495 participants. However, the calculated sample size wasn't achieved as 272 participants were achievable for the study period.

3.7 Sampling procedure

The sampling frame included individuals who registered and got married within the space of two years at places of worship within Mityana municipality, Mityana district. A multi-stage sampling procedure was used to select the study participants. The places of worship were stratified according to religious denominations present within the Municipality.

Proportionate sampling was employed to select individual records of those who got married in the considered period as per the places of worship. Within the records, a consecutive sampling procedure was utilized until the appropriate sample size per place of worship's proportion was achieved.

For the qualitative component (perceptions), purposive sampling with maximum variation was employed to select the married individuals who will provide extra information. Both husband and wife were considered as individuals in this study to assess their perceptions and whether they did the premarital sickle cell test.

3.8 Data collection techniques.

3.8.1 Quantitative data

A semi-structured questionnaire was used to collect data on the uptake of premarital SCTT among married individuals within Mityana district. The questionnaire was administered by three (3) trained research assistants with support from the principal researcher. The data entry was done using ODK data collection tool to capture real time data.

3.8.2 Qualitative data

In-depth interviews were used to collect information on the perceptions married individuals have towards premarital sickle cell trait testing (SCTT) using the interview guide. The in-depth interview guide comprised of 3 sections. The interviews were audio-recorded and later transcribed verbatim with the assistance of a translator.

3.9 Study Variables

3.9.1 Independent variables

These will include;

- Socio-demographic factors such as age group, highest level of education, sex/gender, occupation, religion, tribe and residence.
- Institutional factors such as the knowledge on SCD, family history of SCD, having any children before marriage, number of children, attending antenatal visits.
- Socio-economic factors such as partner's support, cost of SCT test, monthly income.

NB: Knowledge/awareness on SCD was assessed using 12 questions on SCD. A participant was scored as having adequate knowledge on SCD if he/she scores correctly on 6 or more of the questions. Otherwise, the participant was scored to have inadequate knowledge about SCD.

Variables were collected and summarised in the types shown in the table1.

Table 1: Showing variable types

Variable	**Type**
Age	Numerical
Education level	Ordinal
Gender	Nominal
Occupation	Nominal
Religion	Nominal
Tribe	Nominal
Residence	Nominal
knowledge/awareness on SCD	Nominal
family history of SCD	Nominal
having tested for SCT before	Nominal
having children before marriage.	Nominal
partner's support	Nominal
cost of SCT test	Numerical
monthly income	Nominal

3.9.2 Dependent variable

The uptake of premarital SCT testing among married individuals within Mityana municipality was the main outcome variable. It was collected as a binary variable (yes/no) as to whether they did the SCT test prior to marriage.

3.10 Data analysis

3.10.1 Quantitative Data

Data was cleaned and prepared for analysis using STATA version 17. Continuous variables were summarized using median and interquartile ranges. Categorical/nominal variables were summarized using frequencies and percentages. All analysis was carried out while catering for the hierarchical nature of the sampling.

Binary mixed effects modified Poisson regression (with robust standard errors) was used for analysis to identify the factors associated with uptake of premarital sickle cell trait testing. Variable selection for multivariate analysis was done by identifying variables with p-values less than 0.2 at bivariate analysis. At multivariable analysis interaction was assessed by forming interaction terms between significant variables and comparing interaction and reduced models using the likelihood ratio test. Confounding was assessed by comparing the prevalence ratio (PR) of significant variables in the crude and adjusted models. Variables with a p-value <0.05 were considered significantly associated with the outcome (uptake of premarital SCT testing).

3.10.2 Qualitative Data

The transcripts were imported into Open Code version 4.03, and a deductive thematic analysis was carried out, guided by the Health Belief Model. The process followed the six phases of thematic analysis outlined by Braun and Clarke (2013). These six steps are: familiarisation with the data, generating codes, generating themes, reviewing themes, defining and naming themes (Braun & Clarke, 2013). The PI and a social scientist read the transcripts independently, identifying and highlighting themes and patterns. The data was then systematically coded to generate codes. The initial codes were grouped into potential sub-themes by examining emerging patterns and relationships, which were subsequently aligned and structured under the themes outlined in the Health Belief Model.

This rigorous approach ensured that the study's conclusions are based on a comprehensive and trustworthy analysis of the married individuals' perceptions towards pre-marital SCT testing.

3.11 Quality control and assurance

The survey instruments were pre-tested to identify any issues with the questions, instructions, or translations, ensuring that the same procedure was followed when administering the questions. Research assistants were trained on the study protocol, ethical principles, and data collection techniques over three days before data collection began. Data collection was supervised throughout the data collection period to ensure adherence to the study protocol and ethics. Data quality checks were included in the tool to ensure completeness of the required information.

3.12 Ethical considerations

The data collection instruments (questionnaire and consent forms), prepared in both English and translated versions, were submitted to the Uganda Christian University Research Ethics Committee (REC) for ethical clearance. In addition, formal administrative approval was obtained from the respective places of worship in Mityana District. Written informed consent, outlining the purpose and objectives of the study, was obtained from each respondent to confirm their voluntary participation. To maintain confidentiality, access to the collected information was restricted, and participants were identified using unique codes rather than personal identifiers.

CHAPTER FOUR: RESULTS

Sociodemographic characteristics

More than half of the study participants were male (51.1%, n=139). The median age of the participants was 40 years (IQR: 33-49). A considerable number had attained secondary level education (34.9%, n=95). The highest proportion of the participants had informal employment (70.2%, n=191). Most of the participants belonged to the Christian faith denomination (94.1%, n=256). The Baganda tribe was predominant among the study participants (65.1%, n=177). Table 1 summarizes the sociodemographic characteristics.

Table 2: Sociodemographic characteristics for the 272 married individuals in Mityana municipality

Variable	n (%)	Median (IQR)
Gender		
Male	139 (51.1)	
Female	133 (48.9)	
Age of participant		40 (33-49)
Education level		
Secondary level	95 (34.9)	
Vocational/Certificate	66 (24.3)	
Diploma/Degree	60 (22.1)	
Primary level	46 (16.9)	
None	5 (1.8)	
Employment		
Informal	191 (70.2)	
Formal	61 (22.4)	
not employed	20 (7.4)	
Religion		
Christian	256 (94.1)	
Muslim	16 (5.9)	
Tribe		
Acholi	1 (0.4)	
Iteso	2 (0.7)	
Lugbar	1 (0.4)	
Mufumbira	1 (0.4)	
Muganda	177 (65.1)	
Mugishu	4 (1.5)	
Mukiga	10 (3.7)	
Mukonzo	4 (1.5)	
Munyankole	16 (5.9)	
Munyarwanda	22 (8.1)	
Munyoro	7 (2.6)	
Musamya	1 (0.4)	
Musoga	22 (8.1)	
Mutoro	4 (1.5)	
Residence		
Urban	207 (76.1)	
Rural	65 (23.9)	

Institutional characteristics

Of the 272 participants, 83.5% (n=227) had adequate knowledge on SCD. A small proportion had a family history of SCD (13.2%, n=36). A similar proportion reported to have had a sickle cell test done before the premarital test (13.97%, n=38). About seven percent (n=20, 7.35%) didn't have any children before marriage. The median number of children was 4 (IQR: 2-5).

Table 3: Institutional characteristics for the 272 married individuals in Mityana municipality

Variable	n (%)	Median (IQR)
Knowledge on SCD		
Adequate	227 (83.5)	
Inadequate	45 (16.5)	
Any family members who have had SCD		
No	236 (86.76)	
Yes	36 (13.24)	
SCT test before the premarital test		
No	234 (86.03)	
Yes	38 (13.97)	
Had any children before marriage		
Yes	252 (92.65)	
No	20 (7.35)	
Number of children		4 (2-5)
Attended antenatal visits while pregnant		
Yes	214 (78.68)	
No	38 (13.97)	
N/A	20 (7.35)	

Socio-economic characteristics

Only 40 participants (14.71%) carried out the SCT. Of these, majority had their test done from a public health facility (n=23, 57.5%) and tested together with their partners (n=39, 97.5%). Most of the participants didn't know their partner's SCT status (n=231, 84.9%). Among those who did the premarital SCT test, most reported that it was free of charge (n=25, 62.5%) as seen in Table below.

Table 4: Socio-economic characteristics for the 272 married individuals in Mityana municipality

Variable	n (%)
Where the test was carried out (n=40)	
Public health facility	23 (57.5)
Private health facility	17 (42.5)
Tested together with your partner (n=40)	
Yes	39 (97.5)
No	1 (2.5)
Know your partner's sickle cell trait status	
No	231 (84.9)
Yes	41 (15.1)
Cost of the sickle cell test (n=40)	
100,000/=	2 (5.0)
15,000/=	1 (2.5)
20,000/=	4 (10.0)

30,000/=	3 (7.5)
5,000/=	1 (2.5)
Antenatal cover	2 (5.0)
Free	25 (62.5)
Insurance	2 (5.0)
Approximate monthly income	
< 500,000/=	153 (56.2)
501,000 - 1,000,000/=	99 (36.4)
above 1,000,000/=	20 (7.4)

Objective one: Uptake of premarital sickle cell trait testing among married individuals in Mityana municipality, Mityana district

The uptake of premarital sickle cell trait testing among the married individuals is 14.71% (95% CI: 9.03-23.04).

Objective two: Factors associated with the uptake of SCTT among the married individuals in Mityana municipality, Mityana district

Bivariate analysis

Variables with p-values less than 0.2 were selected for multivariable analysis as shown in the following sections.

Associations with Sociodemographic characteristics

Age group, education level, and religion had p-values less than 0.2 and thus were included in the multivariable analysis.

Table 5: Bivariate analysis for the Sociodemographic characteristics for the 272 married individuals in Mityana municipality

Variable	Premarital SCT uptake Yes n (%)	No n (%)	cPR (95% CI)	P-value
Gender				
Male	19 (13.7)	120 (86.3)	1.00	Ref
Female	21 (15.8)	112 (84.2)	1.02 (0.98-1.06)	0.383
Age of participant				
31-59	25 (11.7)	188 (88.3)	1.00	Ref
18-30	14 (37.8)	23 (62.2)	1.23 (1.12-1.36)	<0.001
60 and above	1 (4.6)	21 (95.4)	0.94 (0.88-1.00)	0.04
Education level				
Secondary level	16 (16.8)	79 (83.2)	1.00	Ref
Vocational/Certificate	8 (12.1)	58 (87.9)	0.96 (0.80-1.15)	0.653
Diploma/Degree	12 (20.0)	48 (80.0)	1.03 (0.95-1.11)	0.515
Primary level	4 (8.7)	42 (91.3)	0.93 (0.90-0.96)	<0.001
None	0 (0.0)	5 (100.0)	0.86 (0.78-0.94)	0.001

Employment				
Informal	26 (13.6)	165 (86.4)	1.00	Ref
Formal	12 (19.7)	49 (80.3)	1.05 (0.97-1.44)	0.218
Not employed	2 (10.0)	18 (90.0)	0.97 (0.89-1.06)	0.480
Religion				
Christian	36 (14.1)	220 (85.9)	1.00	
Muslim	4 (25.0)	12 (75.0)	1.10 (1.05-1.14)	<0.001
Tribe				
Muganda	25 (14.1)	152 (85.9)	1.00	Ref
Others	15 (15.8)	80 (84.2)	1.01 (0.93-1.10)	0.735
Residence				
Urban	34 (16.4)	173 (83.6)	1.00	Ref
Rural	6 (9.2)	59 (90.8)	0.94 (0.81-1.09)	0.403

Associations with Institutional factors

Knowledge on SCT, family history of SCD, SCT test before premarital test, had children before marriage, number of children, and attending ANC visits had p-values less than 0.2 and thus were selected for multivariable analysis.

Table 6: Bivariate analysis for the Institutional characteristics for the 272 married individuals in Mityana municipality

Variable	Premarital SCT uptake		cPR (95% CI)	P-value
	Yes n (%)	No n (%)		
Knowledge on SCT				
Adequate	37 (16.3)	190 (83.7)	1.00	Ref
Inadequate	3 (6.7)	42 (93.3)	0.92 (0.87-0.97)	0.001
Family history of SCD				
No	29 (13.4)	188 (86.6)	1.00	Ref
Yes	11 (30.6)	23 (69.4)	1.16 (1.04-1.30)	0.008
Had any children before marriage				
Yes	34 (13.5)	218 (86.5)	1.00	Ref
No	6 (30.0)	14 (70.0)	1.15 (1.05-1.25)	0.003
Number of children			0.98 (0.96-0.99)	0.008
Attend ANC visit				
Yes	33 (15.4)	181 (84.6)	1.00	Ref
No	1 (2.6)	37 (97.4)	0.89 (0.82-0.96)	0.004
N/A*	6 (30.0)	14 (70.0)	1.13 (1.02-1.24)	0.017

*Didn't have any children

Associations with socioeconomic factors

Monthly income was not selected for multivariable analysis since it had a p-value greater than 0.2.

Table 7: Bivariate analysis for the Socioeconomic characteristics for the 272 married individuals in Mityana municipality

Variable	Premarital SCT uptake Yes n (%)	No n (%)	cPR (95% CI)	P-value
Monthly income				
<500,000	22 (14.4)	131 (85.6)	1.00	Ref
501,000-1,000,000	14 (14.1)	85 (85.9)	1.00 (0.95-1.05)	0.934
Above 1,000,000	4 (20.0)	16 (80.0)	1.05 (0.88-1.25)	0.586

Multivariable analysis results

Age group, religion, SCT test before premarital test, had any children before marriage and Attend ANC (Antenatal Care) visits were significant (P<0.05) at multivariable analysis.

Table 8: Multivariable analysis results for the 272 married individuals in Mityana municipality

Variable	Category	aPR	95% CI	P-value
Age group				
	31-59	1.00	Ref	Ref
	18-30	1.23	1.08-1.40	0.002
	60 and above	0.97	0.94-1.00	0.062
Religion				
	Christian	1.00	Ref	Ref
	Muslim	1.10	1.07-1.14	<0.001
Family history of SCD				
	No	1.00	Ref	Ref
	Yes	1.17	1.07-1.27	0.001
Attend ANC visits				
	Yes	1.00	Re	Ref
	No	0.92	0.86-0.98	0.009
	N/A*	1.01	0.88-1.16	0.908

Objective 3: Explore the perceptions towards premarital sickle cell trait testing among married individuals in Mityana Municipality

In-depth interviews were conducted with 17 married individuals to explore the perceptions around premarital sickle cell trait testing. The characteristics of the individuals are summarized in Table below.

ID	Sex	Religion	Tribe	Age	Took the test
B1/09	Female	Born again	Muganda	26	Yes
B1/10	Male	Born again	Musoga	34	No
B1/93	Male	Born again	Munyankole	37	No
B2/12	Male	Born again	Muganda	34	No
B3/13	Male	Born again	Muganda	45	No
B19/139	Female	Born again	Munyarwanda	36	Yes
B19/140	Male	Born again	Munyarwanda	36	Yes
C159	Male	Catholic	Mugishu	50	Yes
P1/50	Male	Protestant	Muganda	24	Yes
P1/51	Female	Protestant	Mukonzo	23	Yes
P2/52	Female	Protestant	Muganda	28	Yes
P3/54	Female	Protestant	Muganda	34	No
P3/55	Male	Protestant	Munyoro	39	No
P5/33	Male	Protestant	Munyarwanda	47	No
P5/34	Female	Protestant	Munyarwanda	32	No
P9/85	Male	Protestant	Muganda	39	Yes
P10/112	Male	Protestant	Muganda	43	No

Themes and sub-themes generated according to the health belief model

The study findings on perceptions around premarital sickle cell testing were summarized according to the health belief model with main themes on cues for action, perceived barriers, perceived benefits, perceived severity, perceived susceptibility and perceived threats as shown in the table below.

Themes	Sub-themes	Codes
Cues for action	**Concerns for improvement around SC testing**	After falling in love couple should test first Church helps its members Churches and schools for SCD campaigns Community is educated when people test Increase awareness through social media Increase awareness through VHTs Increase number of counselors Increased access to testing facilities Must test before marriage Not good to get married when both are carriers Offer counselling sessions Policy to present SCT results before marriage SCD will continue without intervention Sensitize about mass testing and effects of not Should enroll for treatment instantly Should not compromise on testing Subsidize cost of test for common man Terminate the relationship if both are carrier Trust teaching from religious leaders
Perceived barriers	**Health care issues hindering testing**	Alot of emphasis on HIV and not sickle cell Didn't get information about SCT before marriage Didn't test because I know the signs Don't know SC test cost Lack of access to testing center Lack of awareness about sickle cell testing Majority test for gonorrhea and HIV Rare to get free test in private health center
	Socio-cultural issues hindering testing	Couples marry without testing Didn't test because I know the signs Doesn't test because of the consequences Don't know effects of producing children with Don't reveal/test family SCD not to lose partners Fear of family history and find out they have Fear to test Fear to test because of shame/embarrassment Fear to test due to commitment Ignorance Lack of money hinders testing My/partners family didn't have the health problem

		Patient is always on treatment (expensive) Poor counselling causes fear for others to test Refused to test alleging no family SCD case Religious leaders encourage HIV test not SCD Religious leaders not well versed with SCD Self-stigma refusing to test Testing is low in non-official marriages
Perceived benefits	**Socio-cultural issues supporting testing**	Cost of test is affordable Everyone that cares for their life is concerned Feared the disease and decided to test Good to know your status may be unaware Reduces the disease burden Testing avoids meeting people with sickle cell Testing helps to end new sickle cell cases You get peace of mind/don't worry of future
Perceived severity	**Presentation of Sickle cell disease**	Always have stunted growth Child doesn't concentrate/absent at school Child doesn't stay longer Child gets bone pains Child is always bed ridden which is exhaustion Child suffocates most of the time Children cannot live beyond 18 years Girls are very weak/go through a lot of pain Loss of pregnancy People suffer with the disease Usually faint in cold weather
Perceived susceptibility	**Causes/transmission of SCD**	Culture ties exist Is a blood disorder Marriage in the same totem May be witchcraft No connection to tribe/culture Not witchcraft Sickle cell is genetic/hereditary Think can get sickle cell through intercourse Trait change over time depending on immunity Transmitted through blood
Perceived threats	**Family issues due to SCD or SC test**	Can affect the entire family

Friction and confusion with sickle cell child
Leads to divorce
Men abandon families
Mistrust between partners in homes
Women become responsible for family

Perceptions around premarital sickle cell testing among married individuals in Mityana Municipality, Mityana District

1. **Perceived susceptibility**

Causes/Transmission of sickle cell disease (SCD)

Majority of the individuals highlighted that SCD is genetic or is hereditary. This was supported by the thought that it is spread as a result of links to culture as shown below;

"*Sickle cell is genetically passed on especially from parents who are carriers….*" (B1/10).

"*The disease is hereditary in nature…….*" (P2/52)

An individual also noted "*People think that the sickle cell disease is culturally influenced….*" (P1/50).

Another highlighted, *"……or you married in the same totem*" (P3/55)

Despite this, some highlighted that there are no linkages to culture in terms of tribe.

"*…. tribes do not have any connection to the disease….*" (B2/12)

Some of the individuals thought the disease could be as a result of witch craft whereas some said it's not the case.

"*Some people think it is witch craft that causes sickle cell……*" (P3/55).

"*…… is a blood disorder and cannot bewitch someone and gets sickle cell disease….*"

An individual highlighted that some people think sickle cell disease could be obtained through sexual intercourse.

"…the man thinks he shall also get sickle cell when they have intercourse." (P9/85).

Such issues highlight possible drivers that could influence premarital sickle cell testing patterns.

2. **Perceived severity**

Presentation of sickle cell disease

The data revealed that most respondents perceived a sickle cell patient to be a child

who is always bed ridden.

A participant said "……*staying with a sickle cell kid is always bed ridden is so exhausting*…." (B1/10).

One also highlighted that *"…society believes children with the disease cannot live beyond 18 years and this alone causes stigma and fear*." (P2/52)

Some participants also highlighted that patients with sickle cell disease are always stunted.

One participant said "*Sickle cell patients are always stunted*……" (B3/13).

These concerns reveal the present variation in thoughts about the severity of the disease which could influence uptake of the test.

3. **Perceived threats**

Family issues due to SCD or SC test

The results of the test could lead to breakdown or issues within the family structure. Such is highlighted through family disputes which could suffice due to the disease or test which influence the choice to test.

A participant revealed that mistrust between partners could result due to the result of the test or presence of a sickle cell child.

"*There is a lot of animosity and confusion with accusation and mistrust on who caused such a situation at home…"* (B19/140).

Another noted that "... *most men have abandoned families and left the women to look after the children."* (B1/93).

The likelihood of such family events could influence one's decision to perform the test.

4. **Perceived benefits**

Socio-cultural issues supporting testing

Majority of the participants said that testing is beneficial as it helps one to know their status and produce children free of the disease.

"…. *It is very good to know your sickle cell status because you may be a carrier and you are unaware."* (B1/09).

Another highlighted the peace of mind that comes after knowing your status *"… when you carry out the test, you get peace of mind instead of worrying about your life*

ahead.” (P1/51).

An individual highlighted that the more that testing helps to reduce the disease burden. “*It reduces the disease burden……”* (P3/54).

5. Perceived barriers

Barriers to premarital sickle cell testing were two-dimensional ie Socio-cultural issues and Health care issues hindering testing.

Health care issues hindering testing

The most commonly highlighted issues included lack of awareness about sickle cell testing, lack of access to testing centre and a lot of emphasis on HIV and not sickle cell. This was revealed by some views shown below;

“… possible because even lack of awareness is there as people put emphasis on HIV testing not sickle cell.” (B1/10).

“Lack of awareness and accessibility especially where sickle cell testing can be done” (P3/54).

Socio-cultural issues hindering testing

Most participants highlighted that poor financial status could hinder premarital testing for sickle cell.

“…everyone would want to know their status but don’t due to lack of money” (B1/10).

One highlighted that some wouldn’t carry out the test, knowing they have a family history of SCD, because they didn’t want to lose their partners.

“…. don’t want their partners to know about their family sickle cell history……because they do not want to lose him” (B1/09).

Some highlighted the importance of religious leaders in premarital testing, however, revealed that religious leaders are not well versed about the disease and emphasis HIV testing over SCD.

“…. Religious leaders have been majorly encouraging pre-marrieds to test for HIV and not sickle cell ….” (B1/93).

“*… it is unfortunate that religious leaders rarely talk about sickle cell disease and its underlying consequences…*” (P3/55).

A participant highlighted that knowledge of no sickle cell disease in the family hindered testing for sickle cell.

"….. refused to test alleging that in family, there has never been a single sick cell disease." (B2/12).

Some participants highlight fear to test due to having already committed could be one of the reasons.

"…. may find it hard to test if they are blinded by love and have gone so deep into the relationship." (P3/55).

6. Cues for action.

Concerns for improvement around SC testing

It was highlighted that increased awareness through sensitization about sickle cell testing would improve testing rates. This could be via the village health teams (VHTs) or through social media as revealed below.

"...increase awareness through village health teams that deny our people good life." (B1/10).

Another highlighted that as couples prepare for marriage, partners should promptly test for sickle cell disease.

She said *"the couples preparing for marriage must go and test for sickle cell disease so that they produce children that are free from sickle cell disease"* (B19/139).

Creating awareness of testing facilities to couples before marriage could also improve testing while involving churches/religious leaders.

"… create more awareness especially where to get such services" (P3/54).

"…churches and schools should champion the sickle cell disease awareness campaign…" (P5/34).

A participant highlighted the need to create a policy that encourages presentation of an SCT result before marriage especially in churches.

".. for example, they introduce a policy that before marrying a couple, the couple must present approved and authentic SCD results from a recognized health centre." (P3/54).

CHAPTER FIVE: DISCUSSION

The uptake rate among the married individuals in Mityana municipality was 14.71% (95% CI: 9.03-23.04). The uptake rate is low, indicating that for every 10 married individuals, at least one has taken the premarital sickle cell test in Mityana municipality, Mityana district. Few studies have reported on uptake of premarital SCT testing in Africa, however, the observed uptake rate is significantly lower than that which was presented in a systematic review, which highlighted a pooled uptake rate of 47.82% (Dilli et al., 2024). It is also below that reported in a study carried out among students at a tertiary institution in Uganda who reported an uptake rate of 24.4% (Kisakye et al., 2022). The uptake rate is similar to that carried out in Hoima district, i.e. 14%, although it involved pregnant women receiving antenatal care at a referral hospital (Kyakuha et al., 2024). It is significantly higher than that recently carried out in Bushenyi district, among pregnant women, with an uptake rate of 2.82% (Dilli et al., 2025).

The differences highlighted above may be due to variations in the study population and area, despite the limited number of available studies. For instance, tertiary institutions have better access to health education and thus greater awareness about SCD, which may explain why the uptake rate was significantly higher than that observed in this study. On the other hand, studies carried out in community settings have shown lower uptake rates. This observation is consistent with findings from a similar study conducted in Hoima District, Uganda. However, the present study further revealed that the low uptake of SCT testing increases the likelihood of continued transmission of the trait, thereby posing a barrier to the long-term elimination of SCD cases in the population. This can be supported by some participants' reported family histories of the disease, indicating its presence within family lines. The study was conducted among married individuals who attended places of worship. These individuals may differ from those who didn’t attend places of worship, such as those in cohabitation marriages, who are less likely to take the test. Therefore, there is a need for promptly designed interventions to improve the uptake rate in not only semi-urban areas, as in this study, but also rural areas where rates could be significantly lower, as observed in the study carried out in Bushenyi district, Uganda.

Factors associated with the uptake of premarital SCT testing among the married individuals

Age group

Participants aged 18-30 years were 14% more likely to have undergone the premarital test compared to older age groups, i.e., 31-59 years. This is possibly because young adults have better access to health education, which increases their awareness about genetic conditions like SCD. This could be as a result of better access to information via the internet and social media, which is lower among older age groups (Obeagu & Adias, 2024). Additionally, peer influence significantly affects practices among young adults, which could stimulate taking the test before marriage. This finding reveals that youth are highly receptive to health promotion information, and strategies should be devised to improve uptake rates among older adults.

Religion

Uptake rates were 10% higher among Muslim participants compared to Christians. Among Islamic communities, there is a strong religious and ethical emphasis on preventing harm to future generations to guarantee the continuity of worshipping God. This has been made "policy" stemming from the core message of Islam (Shammout et al., 2017). This possibly explains why Muslim individuals exhibited higher uptake compared to Christians. This finding highlights the high influence religion has on premarital sickle cell testing. Therefore, future interventions should involve religious leaders to facilitate quick adoption of sickle cell testing and the disease. As all of the individuals who participated in the qualitative interviews were Christian, some highlighted that religious leaders are not well-versed in SCD, and most emphasised HIV testing over SCT testing. This could, in turn, explain the relatively lower uptake of SCT testing among the Christian individuals.

Family history of SCD

Uptake of premarital SCT test was 17% higher among individuals with a family history of SCD compared to those without any family history. This finding is similar to that reported in a study among married and unmarried youths in Nigeria, where screening for SCT was higher among those with a family history of SCD (Rasheed et al., 2018). Another study carried out among primigravida mothers at Mulago reported similar results i.e. premarital SCT testing was 6.04 times more likely among those with a positive history of family SCD (Namukasa, 2015). Such individuals have firsthand experience with the disease and take precautionary measures to test for the trait's absence. This is done to be certain that the children born will be free of the disease. This finding is corroborated by the qualitative results where some participants highlighted that they decided to test because they feared the disease, which could be a result of a family experience. However, the qualitative findings also revealed that some participants did not perform the test due to fear that their partners might reject them based on their family history, which could influence their test results. This explains why some of those with family history didn't perform the test.

Attended antenatal care visits

The uptake rate was 8% lower among Individuals who didn't attend antenatal visits compared to those who attended. This is likely since interactions with health workers during pregnancy emphasize the need for knowing one's sickle cell trait status, which would stimulate one to take up the premarital test. For instance, despite the focus on pregnancy, antenatal visits can include discussions about genetic conditions and testing options, further improving awareness and willingness to take up the test (Brown et al., 2011). This finding emphasises the importance of health workers providing information about SCT testing, which can increase testing rates.

Perceptions around premarital sickle cell testing among the married individuals

According to available literature in Uganda, few studies have investigated the perceptions toward SCT testing. In this study, perceptions were qualitatively investigated using the Health Belief Model, with themes and subthemes generated based on perceived susceptibility, perceived benefits, perceived severity, perceived barriers, perceived threats, and cues for action. The study findings revealed a wide variation in perceptions towards the uptake of premarital sickle cell testing in Mityana municipality, based on these domains.

Uptake of the premarital test was identified to be influenced by the perceived susceptibility towards having the trait and/or bearing children with the disease. Cultural beliefs appeared to be highly recognised when deciding to take up the test. The perpetuation of SCT has been reported among consanguineous families i.e. marriages involving individuals in certain parts of the world (AlBitar et al., 2024). Findings in this study revealed that individuals recognised cultural influence with marriage in the same family totem, which, when not practised, may lead to one not taking up the test. However, SCT isn't inherently a function of tribe/culture to which some participants highlighted. It was noted among the study participants that SCD is a hereditary condition, which aligns with the scientific literature.

Concerning the perceived severity, most participants highlighted that sickle cell disease presents among children with uncomfortable outcomes, i.e. leading to stunted growth, pain, and often being bedridden, among others. This severity would insinuate better uptake of the test, although the observed uptake rate is low. This highlights the potential for a lack of awareness about the testing services or the test itself. This conclusion is corroborated by the fact that lack of access to testing centres and information about the test stood out as the healthcare perceived barriers hindering uptake of the test. The lack of awareness is maintained by emphasis on HIV testing, thereby neglecting the impacts of the SCD. Socio-cultural issues were also among the barriers hindering the uptake of the test, with fear being the most predominant. This fear of carrying out the test was tied to the outcome of the test, destroying long-term relationship investments (i.e. commitments). This finding is consistent with a multi-

country qualitative study (Munung et al., 2024). This highlights a gap in community counselling services around the outcomes of the test, to which some participants reported to be poor, which further incites fear to carry out the test among community members. Genetic counselling plays a crucial role in addressing the outcomes of tests involving genetic conditions to facilitate adoption and acceptance (Aneke & Okocha, 2016). Financial challenges were linked to poor uptake of the test. This finding is similar to what was highlighted in a critical review study that investigated the challenges associated with the sickle cell disease burden (Adigwe et al., 2023).

Furthermore, perceived threats around the sickle cell results could hinder uptake, especially concerning family issues. Test results can lead to divorce, with women taking up the burden of an untoward test result. This can lead to mistrust within homes, which could have cascading effects on the rest of the family (Alswaidi et al., 2012). Such thoughts could limit the adoption of the test, which maintains the trait and disease within the population despite the perceived benefits.

Ways forward were also suggested, mostly encompassing improving awareness through social media and/or VHTs, improving counselling services, and involving religious and/or community leaders. This has shown positive effect in other parts of the world and the impact would be tangible as people trust communications by religious leaders (Dennis-Antwi et al., 2018) and health workers which some participants highlighted.

In conclusion, the study revealed complex perceptions influencing the uptake of premarital SCT testing. While many participants recognized SCD as hereditary, others attributed it to culture, witchcraft, or even sexual intercourse, reflecting misconceptions that hinder testing. Perceived severity was linked to beliefs that children with SCD are often bedridden, stunted, or unlikely to live beyond 18 years, fueling stigma and fear. At the same time, testing was viewed as beneficial for peace of mind, reducing disease burden, and planning for healthy children. Barriers included limited awareness, poor counseling, lack of access to testing, financial constraints, and fear of losing a partner, while threats of family mistrust and marital breakdown also discouraged testing. However, cues for action, such as sensitisation through churches,

schools, village health teams, and policies requiring SCT results before marriage, highlight opportunities for intervention. These findings underscore the need for comprehensive, culturally sensitive, and multi-sectoral strategies to improve uptake of premarital SCT testing.

CHAPTER SIX: CONCLUSION AND RECOMMENDATIONS

6.1 CONCLUSION

- The uptake of premarital SCT testing is low, i.e. among 10 married individuals, at least one had carried out the test.
- Uptake was associated with age group, religion, family history of SCD and whether one attended antenatal care visits.
- The perceptions influencing uptake of the SCT test are complex and involve health care-related and socio-cultural dimensions explained by the health belief model.

6.2 RECOMMENDATIONS

1. There is a need to emphasise premarital sickle cell trait testing during marriage counselling sessions at places of worship and in health care settings.
2. The Ministry of Health should facilitate the increase in the number of sickle cell trait testing sites to improve access.
3. There is a need to improve community awareness around sickle cell trait testing to improve testing rates through sensitisation, possibly using social media platforms.
4. There is a need to provide family counselling services for partners who are positive for the test to improve community perspectives on the test results.

Study limitations

The study findings may be subject to selection bias due to the exclusion of individuals in non-official marriages from the study population. This would, in turn, bias the uptake rate positively, i.e. the true uptake rate would be lower than would be observed. Individuals marrying in places of worship are more likely to be prompted to carry out the test compared to cohabiting relationships. Nevertheless, the study findings still present relevant information that could be used to modify interventions to improve SCT uptake rates.

There is a possibility of random error, reflected in the wide confidence intervals of the uptake proportion, because of an insufficient sample size compared to that anticipated.

Information bias based on self-reporting is likely as study participants had to recall whether they performed the test and regarding some study variables. However, this was reduced by only including participants who had got married in the previous two years, meaning the events would still be fresh in their memories.

This study was conducted in a peri-urban setting and a relatively small administrative unit, which may limit the generalizability of the study findings to similar areas.

Trustworthiness of the qualitative findings

The researcher took the following steps to enhance the trustworthiness of the qualitative findings:

Credibility: The research team engaged with the participants over an extended period (~30 minutes) during interviews. To validate the research conclusions, the researcher shared interpretations with participants to check for accuracy and resonance with their perspectives.

Transferability: A detailed description of the research context, study participants, data collection procedures, and analysis was provided.

Confirmability: A clear audit trail of research decisions, data collection, and analysis processes was maintained. Direct narrative quotes from participants were included in the final report of the study findings.

Dependability: Data was analysed by the principal investigator, but an expert in qualitative research was consulted to review the findings and analysis. The research process, along with any changes to the research plan, was documented.

Reflexivity: The researcher, being an active health worker with extensive experience, acknowledged and set aside all personal biases and experiences related to sickle cell disease.

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APPENDICES:

Appendix 1: Consent form

Ugandan Christian University

Faculty of Public Health, Nursing and Midwifery

Consent Form for Research Participation

Dear respondent, my name is Nalweyiso Martha Dorcas, a student from Uganda Christian University pursuing a Masters of Public Health. I am conducting a research study titled **"Premarital sickle cell trait (SCT) testing among married individuals in Mityana district: perceptions, uptake and associated factors."**. The results of this study shall greatly be used in designing appropriate intervention measures to prevent the spread of SCD within the country as the disease is extremely expensive to manage and treat. For more information, kindly contact me on my telephone number Tel: 0785832362 and email: nalweyisomartha@gmail.com

1) I…… ……voluntarily agree to participate in this research study.
2) I understand that even if I agree to participate now, I can withdraw at any time or refuse to answer any question without any consequences of any kind
3) I have had the purpose and nature of the study explained to me in writing and I have had the opportunity to ask questions about the study.
4) I understand that participation involves answering all the interview questions asked in the right manner
5) I understand that I will not benefit directly from participating in this research.
6) I agree to my interview being audio-recorded.
7) I understand that all information I provide for this study will be used to find solutions to the challenges faced.
8) I understand that in any report on the results of this research my identity will remain anonymous. This will be done by changing my name and disguising any details of my interview which may reveal my identity or the identity of people I speak about.

9) I understand that disguised extracts from my interview may be quoted in the published papers, journals etc.
10) I understand that if I inform the researcher that I or someone else is at risk of harm they may have to report this to the relevant authorities - they will discuss this with me first but may be required to report with or without my permission.
11) I understand that signed consent forms and original audio recordings will be retained for four months until the data is analyzed into any statistical package.
12) I understand that under freedom of information legalization I am entitled to access the information I have provided at any time while it is in storage as specified above.
13) I understand that I am free to contact any of the people involved in the research to seek further clarification and information.

---------- ----------

Signature of participant Date

I believe the participant is giving informed consent to participate in this study

---------- ----------

Signature of researcher/assistant Date

Interview guide

Introduction

Good morning/afternoon/evening and thank you for accepting to participate in this interview. My name is Martha Dorcas Nalweyiso, a year 2 student at Uganda Christian University pursuing a Master of Public Health. I am conducting this interview as part of a study entitled "**Premarital sickle cell trait (SCT) testing among married individuals in Mityana district: perceptions, uptake and associated factors**". This interview will take between 30 minutes to 1 hour, and your responses will remain confidential. Do I

have your permission to record the conversation?

Demographic Information

Age (complete years) …….

Gender…….

Level of education

a) None
b) Primary level
c) Secondary level
d) Tertiary level
e) Others (specify)

Number of children (if any) ……

Perceptions of Premarital Sickle Cell Trait Testing

1. Did you undergo premarital SCT testing? If yes, what motivated you to do so?
2. What advice were you given during the pre-marital counseling sessions?
3. What are your thoughts on the necessity of premarital SCT testing for couples planning to marry?
4. How do you perceive the benefits of premarital testing in relation to having healthy children?

Cultural and Social Influences

5. What cultural beliefs influence your views on premarital SCT testing?
6. Do you think that religious beliefs play a role in how people perceive SCT testing? If so, how?

Barriers to Testing

7. What do you think are the main barriers preventing couples from undergoing premarital SCT testing?
8. Have financial considerations influenced your decision or the decisions of others regarding testing?
9. Do you believe that stigma or fear of rejection affects individuals' willingness to get tested?

Impact on Relationships

10. How do you think knowledge of sickle cell trait status affects relationships and marriage decisions?
11. Have you or someone you know faced challenges in relationships due to SCT results? Can you share an example?
12. In your opinion, does knowing one's sickle cell status before marriage help or hinder relationship dynamics?

Future Perspectives

13. What changes would you like to see in how premarital SCT testing is perceived in society?
14. Would you encourage others to undergo premarital SCT testing before marriage? Why or why not?
15. How do you envision the future of sickle cell testing in your community?

Questionnaire

Title: Premarital sickle cell trait (SCT) testing among married individuals in Mityana municipality**: perceptions, uptake and associated factors**

Date: ----------

Section A: SOCIO-DEMOGRAPHIC CHARACTERISTICS

1. Gender

☐Male☐Female

2. Age (complete years) …….

3. Education levels

☐ None ☐ Primary level ☐ Secondary level ☐ Vocational level

(Certificate level) ☐ Diploma/Degree level☐Others (specify)

4. Employment status

☐yes ☐No

5. If employed,

☐Formal ☐Informal

6. Religious denomination

☐Christian☐Muslim ☐Others(specify)……

7. Tribe

……..

8. Residence

☐Urban ☐Rural

Section B: INSTITUTIONAL FACTORS

Awareness of Sickle cell disease (SCD)

Statement	TRUE	FALSE
1.SCD is a blood disorder		
2.SCD is a hereditary disorder		
3.SCD affects all age groups		
4.SCT can change into SCD overtime		
5.SCD can be transmitted by direct body contact		
6.SCD can be transmitted by mosquito bite		
7.SCD can be transmitted caused by the act of witches/wizards		
8.Father or Mother only can transmit the SCD gene to the child but not both		
9.If one parent has sickle cell disease and the other doesn't, all children will be carriers.		
10.If both parents are carriers, each child has a 25% of having SCD or being a carrier.		
11.SCD has a cure		
12.Premarital sickle cell testing prevents having a child with SCD		

9. Do you have any family members who have had Sickle cell disease/trait?

☐Yes ☐ No

10. Did you test for sickle cell trait before the premarital test?

☐Yes ☐ No

11. Do you have any children?

☐Yes ☐ No

12. If yes, how many children do you have?

……

13. Did you go for antenatal visits while pregnant?

☐Yes ☐ No

14. Were you given any information regarding sickle cell testing?

☐Yes ☐ No

15. How best would you like to receive this information?

☐Yes ☐ No

16. What do you think about SCT?

……

UPTAKE OF SCTT AND SOCIO-ECONOMIC CHARACTERISTICS

17. Did you test for SCT before your marriage/wedding?

☐Yes ☐ No

18. If yes, where did you carry out the test from?

☐Private health facility ☐ Public health facility

19. Did you carry out the test together with your partner?

☐Yes ☐ No

20. Do you know your partner's Sickle cell trait status?

☐Yes ☐ No

21. What was the cost of the test?

…….

22. What is your monthly income?

☐<500,000/= ☐ 501,000-1,000,000/= ☐ >1,000,000/=

23. Would you prioritize SCT in case incase an opportunity to test arises?

☐Yes ☐ No

Translated tools

Appendix 1: Consent form
ENDAGANO Y'OKUKKIRIZA OKUTWALIRIZIBWA MU KUNONYEREZA
Yunivasite ya Uganda Christian
Ekibiina ky'eby'obulamu obw'abantu bonna, Eby'obujjanjabi n'abazaalisa
Endagano y'okukkiriza Okutwalirizibwa mu Kunonyereza
Omwagalwa omuzuulibwa, erinnya lyange nze **Nalweyiso Martha Dorcas**, omuyizi ku Yunivasite ya Uganda Christian nga njjukira diguli ya **Masters of Public Health**. Nnina okunonyereza kwe nkola okuyitibwa **"Okukebera Akabonero ka Sickle Cell Trait (SCT) mu Bakwanjula mu Disitulikiti y'e Mityana: Ebirowoozo, Okukkiriza, n'Ensonga ezigenderera"**. Ebiva mu kunonyereza kuno bijja kkozesa okukola enteekateeka ezituufu ez'okumalawo okusaasaana kw'obulwadde bwa Sickle Cell mu ggwanga kubanga buvaamu ensaasaana nnyingi okulongoosa n'okujjanjaba. Okufuna obubaka obw'enjawulo, nsobola okutuukirizibwa ku nnamba yange: **0785832362** oba email: **nalweyisomartha@gmail.com**.

1. Nze …… ……nnasiima okwetaba mu kunonyereza kuno nga tewali kunnyigiriza.
2. Ntegeera nti wadde nsiimye okwetaba kati, nsobola okuvamu oba okuwakanya ekibuuzo kyonna nga tewali kibonerezo kyonna.
3. Ntegeera nti empisa n'ekigendererwa ky'okunonyereza bino nnyonnyoddwa mu buwandiike era nfumitiddwa obusobozi okubuuzako ebibuuzo.
4. Ntegeera nti okwetaba kwange kutekeddwamu okuddamu ebibuuzo byonna ebibuuza mu ngeri entuufu.
5. Ntegeera nti sijja kufuna kye mpa mu lujjudde olw'okwetaba mu kunonyereza kuno.
6. Nsiima okuyingiza eddoboozi lyange mu mateeka n'okukwatibwa ku kasette.
7. Ntegeera nti obubaka bwonna bwe mpadde mu kunonyereza kuno bujja kukozesebwa mu kunoonya ensonga ezikaluubiriza abantu.
8. Ntegeera nti mu lipoota yonna erijja okuva mu kunonyereza kuno, engeri yange ejja kuba nga efumbiddwa, n'amannya gange n'ebyokulabirako byange bijja kuba biggiddwamu okusobola okutangira okutegerekeka kwange oba abalala be njogeddeko.
9. Ntegeera nti ebimu ku bigambo byange biyinza okuvumbululwa mu bubonero obiwandiikiddwa, emizannyo gy'okutendeka, n'ebitabo.
10. Ntegeera nti bwe mbuulira omunonyereza nti nze oba omuntu omulala ali mu kabi, bayinza okuteekwa okutegeeza abantu ab'obuyinza. Kyokka, bajja kunyumiza naye oluvannyuma nga balina okutegeeza wadde nga siwakirizza.
11. Ntegeera nti endagano eno gye nsigna omukono n'ebiragiro ebikuweebwa audio bijja kubikomerera okumala emyezi ena okutuusa obubaka bwe bunonyerezeddwa obulungi.

12. Ntegeera nti wansi w'amateeka agawa obulungi mu kulaba obubaka, nnina eddembe okukikozesa bwe mbagala nga bukyali mu kifo ekirambikiddwa waggulu.
13. Ntegeera nti nnina eddembe okujjukizibwa abantu bonna abetabye mu kunonyereza kuno ku nsonga ezirimu n'okufuna obubaka obulala obutusa ku nsonga eyo.

-_____

Mukono gw'omwetabizi Olunaku

Nkkiriza nti omwetabizi aweereza obuyigirize obumala n'akukkiriza okwetaba mu kunonyereza kuno.

_____

Mukono gw'omunonyereza/omuyambi Olunaku

EBIBUUZO BY'OMUWEZI WA BY'OMU MUMAKA

Okutandika

Wasuze otya/wasibye otya/osiibye otya? Weebale okukkiriza okwetaba mu kwogeraganya kuno. Erinnya lyange nze **Martha Dorcas Nalweyiso**, omuyizi wa mwaka gwa kubiri ku Yunivasite ya Uganda Christian nga njjukira diguli ya **Masters of Public Health**. Nkola okunonyereza kungeri **"Okukebera Akabonero ka Sickle Cell Trait (SCT) mu Bakwanjula mu Disitulikiti y'e Mityana: Ebirowoozo, Okukkiriza, n'Ensonga ezigenderera"**. Okwoogeraganya kuno kuliyitamu eddakiika 30 okutuuka ku ssaawa emu, era ebirivamwo bijja kusigala nga bya kyama. Okirizza nkunyige eddoboozi lyo?

Ebikwata ku muntu

1. Emyaaka gyo (gituukirira) …….
2. Obusajja/Obukazi …….
3. Omusomo gwe wayitaamu a) Tewali
   b) Ky'omulamwa
   c) Ssekendule
   d) Waggulu
   e) Ebirala (laga)
4. Omuwendo gw'abaana (singa guliwo) ……

Ebirowoozo ku Kukebera Akabonero ka Sickle Cell Trait nga tonawasa

5. Wakolako kukebera akabonero ka SCT nga tonawasa? Singa ye, kiki ekyakutwala okukkiriza okukikola?
6. Ki bye baakubuulira mu nkubiriza y'okuwoowa nga tonakeberwa?
7. Olowooza ki ku bukulu bwa kukebera SCT eri abaagala okuwasa?
8. Omutindo ki gw'osibako ku kukebera nga ekkubo eri abaana abalamu?

Empisa n'Obuwangwa ku Kukebera SCT

9. Empisa ki ezikwata ku by'obuwangwa eziteeka mu maaso oba ezitaganya kukebera SCT nga tonawasa?
10. Olowooza nti eddiini erina engeri gy'eyingiramu abantu okukiraba? Singa ye, etekamu bitya?

Obuzibu Obuli mu Kukebera

11. Olowooza nti buziibu ki obusinga okutangira abantu okukebera SCT nga tonawasa?
12. Enfuna y'ensimbi yakukosa oba abantu abalala engeri gye baasalawo ku kukebera?
13. Olowooza nti abantu batya okusosolwa oba okwabulwa lwakukebera SCT?

Engeri SCT gy'Ekosaamu Enkolagana y'Abawasa

14. Olowooza nti okumanya oba omuntu alina akabonero ka SCT kyandibadde kikosa enkolagana y'awasa n'engeri gye bakwataganamu?
15. Waliwo omuntu gw'omanyi eyafuna okusoomoozebwa mu bufumbo olw'ebiva mu kukebera SCT? Singa ye, soma ekyokulabirako.
16. Mu ndowooza yo, okumanya akabonero ka SCT kisanidde kuyamba oba kyinza okuleeta enjawukana mu bufumbo?

Ebirungi eby'omu Maaso

17. Olowooza nti abantu bandikyusa batya engeri gyebalaba kukebera SCT nga tonawasa?
18. Osobola okuwa amagezi abalala okukebeza SCT nga tonawasa? Lwaki oba lwaki si?
19. Mu birowoozo byo, olowooza ki ku by'omu maaso by'okukebera SCT mu kitundu kyo?

Omubuulizi W'omwetabizi

Mukono gw'omwetabizi Olunaku

Omubuulizi W'omunonyereza/Omuyambi

Mukono gw'omunonyereza/omuyambi Olunaku

Questionnaire

EBIBUUZO BY'OKUNOONYEREZA
Omutwe: Okukebera Akabonero ka Sickle Cell Trait (SCT) mu Bakwanjula mu Mityana Municipality: Ebirowoozo, Okukkiriza n'Ensonga Ezigenderera
Olunaku: ----------
Ekitundu A: EBIKWATA KU MUNTU (SOCIO-DEMOGRAPHIC CHARACTERISTICS)

1. Obuzaale

☐Omusajja ☐ Omukazi

2. Emyaaka gituukirira …….
3. Omusomo gwe wayitaamu

☐Tewali ☐Ky'omulamwa ☐Ssekendule ☐Okwetereka (Ekibonerezo kya Certificate) ☐Diploma/Diguli ☐Ebirala (laga)

4. Omulimu gw'olina

☐Yee ☐Nedda

5. Singa okola, obukozesa bwo

☐Obwa mateeka ☐Obutalina mateeka

6. Eddini gy'okkiririzaamu

☐Omukristaayo ☐Omusiraamu ☐Endala (laga) ……

7. Eggwanga/Olulyo lw'ovaamu ……..
8. W'obeera

☐Mu kibuga ☐Mu kyalo

Omubuulizi W'omwetabizi

Mukono gw'omwetabizi Olunaku

Omubuulizi W'omunonyereza/Omuyambi

Mukono gw'omunonyereza/omuyambi Olunaku

Section B: INSTITUTIONAL FACTORS
EBY'OKUMANYA KU SICKLE CELL DISEASE (SCD)

Statement	Yee	Nedda
1. SCD kye kirwadde ky'Omusaayi		
2. SCD kye kirwadde eky'okusikira		
3. SCD ekosa abantu b'emyaaka gyonna		
4. SCT kisobola okukyuka ne kiba SCD mu kiseera		

5. SCD esobola okusasana nga omuntu akwatiddwa omuntu omulala		
6. SCD esobola okusasana nga akukutte ensiri		
7. SCD esobola okujjibwa ebyokuseerebwa n'obulogo		
8. Kitaawe oba Maama yokka basobola okutwala akabonero ka SCD eri omwana naye si bombi		
9. Singa omu ku bazadde alina SCD ate omulala talina, abaana bonna bajja kuba bakikwasiddwa		
10. Singa bombi bazadde balina SCT, buli mwana alina obuweereza bwa 25% okufuna SCD oba okuba mukikwasiddwa		
11. SCD erina eddagala		
12. Okukebera SCT nga tonawasa kuyamba mu kutangira okufuna omwana alina SCD		

EBIBUUZO EBIRALA

1. Waliwo omu ku b'eka yammwe eyalina oba alina Sickle Cell Disease/trait?
   ☐Yee ☐Nedda
2. Wakolako kukebera akabonero ka Sickle Cell Trait nga tonawasa?

☐Yee ☐Nedda

3. Olina abaana?
   ☐Yee ☐Nedda
4. Singa ye, abaana bameka?
   ……
5. Wagenda mu nsisinkano za ba mama abali embuto?
   ☐Yee ☐Nedda
6. Wawa omubaka ogw'okumanyisa ku kukebera Sickle Cell?

☐Yee ☐Nedda

7. Okyagala okufuna obubaka buno mu ngeri ki ey'asingayo?

☐Yee ☐Nedda

8. Olowooza ki ku Sickle Cell Trait (SCT)?

OKUKWATAKO KU KUKOZESA KWE KUSIGALA KWA SIKLE CELL TRAIT (SCTT) N'EBY'OBULAMU OBULI KU NNOOFA

24. Wakebelebwa SCT nga temunafumbirwa?

☐Yee ☐ Nedda

25. Singa yee, wakelebwa wa?

☐Private health facility ☐ Public health facility

26. Wagenda mu dwaliro no mwami/ mukyala wo?

☐Yee ☐ Nedda

27. Omanyi omwagalwawo wayimilidde nobulwadde bwa SCT?

☐Yee ☐ Nedda

28. Test yali ya sente meka?

…….

29. Ofuna sente meka buli mwezi?

☐<500,000/= ☐ 501,000-1,000,000/= ☐ >1,000,000/=

30. Wandi yagadde okwebeza SCT singa wabawo omukisa gwona ogujja?

☐Yee ☐ Nedda

Key Informant Interview Guide

1. Obulwadde bya SCD obumanyi?
2. Olowoza obulwadde bya SCT bukosa butya abafumbo?
3. Okubiliza otya abo abagenda okufumbirwa okugenda okwekebeza SCT?
4. Singa wabawo omu ku bafumbo nga mulwadde sickle cells oba omu kubbo, obawa magezi ki?
5. Oyambe otya abafumbo nga balina abana abalwadde bya SCD?

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SCHOOL OF RESEARCH & POSTGRADUATE STUDIES

DISSERTATION CORRECTION COMPLIANCE REPORT BY THE CANDIDATE (POST VIVA FORM)

Date: 19th September 2025

Name of Candidate: Nalweyiso Martha Dorcas **Reg. No:** RM23M21/014

Title of Dissertation: **UPTAKE, PERCEPTIONS AND ASSOCIATED FACTORS ON PREMARITAL SICKLE CELL TRAIT (SCT) TESTING SERVICES AMONG MARRIED INDIVIDUALS IN MITYANA MUNICIPALITY, MITYANA DISTRICT**

COMMENTS BY EXTERNAL EXAMINER

SN	COMMENTS BY EXTERNAL EXAMINER	page	ACTION TAKEN	INDICATOR
1	Typos: There were typos that needed to be addressed.	Throughout the document.	Typos and grammatical errors throughout the dissertation have been corrected.	Clean and proofread text
	Sextion1.5 Conceptual framework; Some clarifications are needed. The framework on page 5 as per the extract below indicates that sociodemographic characteristics influence Institutional factors which in turn influence socio-	Page 5	This has been explained in the framework. For example respondents with higher education may better navigate health systems, demand SCD testing and	These have been added to that section.

	economic factors? Please explain how this happens.		also influence how health facilities structure information flow. Again women seek health services more than men which affects facility workload and gender sensitive design of counselling programs.	
2	Some of the citations cannot be verified because the sources are not clear. For example, "WHO report on SCD within the African Region states that preventing the inheritance of a double sickle cell gene is much better than any healthcare provided to patients. Therefore, the recommendation to member states was to design and implement a comprehensive and integrated national program for the prevention and management of the disease (Drusin, 1995)".		The updated references has been used and added. Durosinmi, M., Odebiyi, A. I., Adediran, I., Akinola, N., Adegorioye, D., & Okunade, M. (1995). Acceptability of prenatal diagnosis of sickle cell anaemia (SCA) by female patients and parents of SCA patients in Nigeria. *Social science & medicine*, *41*(3), 433-436.	Revised justification section
	It is not clear what the reference "Uganda Ministry of Health, 2023" indicated	Under section 2.8, page 15	It is a report and the document has been updated.	Revised and updated.

	on page 16 is. Please clarify, is it a report or a publication?			
3	*Sample size:* The modified Kish Leslie's formula was used to estimate the required sample size of 495 after adjustment for 10 percent non-response rate. There is no description of the process for arriving at the number of participants to consider for the qualitative study component.	Page 19	The 17 interviews were purposively selected.	This has been updated in the document.
4	A multi-stage sampling procedure was used to select the study participants and the sample was stratified according to religious denominations present within the Municipality. The sampling procedures are, however, not fully described. For example, the number of places of worship which were considered during proportionate sampling is not stated.	Page 17	All places of worship were considered for proportionate sampling in addition to those who got married from the office of the Chief Administrative Officer.	Updated in the document
5	*Ethical clearance:* Although the study protocol is reported to have been submitted to the Uganda Christian University Research Ethics Committee (REC) for ethical clearance, no information is provided whether clearance was granted. If clearance was granted, there is need to attach a copy of the clearance letter.		The letter for ethical clearance will be attached.	The letter will be attached.
6	*Dissemination of study results:* No description on how the findings would be	Page 19	The dissemination plan has been updated.	Updated.

	disseminated.			
7	The discussion ended with consideration of some limitations of the study. However, the inability to attain the desired sample size of 495 has not been included in the list of limitations. Given the implication of the sample size limitation, it should be reflected in the limitation section of the report.	Page 43	The limitation, as advised, has been added.	Updated.
8	A number of references that were cited do not appear in the list of references/bibliography, for example, I and T, 2018 cited in pages 10 and 14, McGann, Hernandez and Ware, 2017 on page 14, Treadwell, McClough and Vichinsky, 2006 on page 14, Treadwell, McClough and Vichinsky, 2006 on pages 10, 14 and 15, Uche *et al.*, 2017 on page 15, Anie, Egunjobi and Akinyanju, 2010 on page 15, Sokoto, 2016 on page 16, WHO report on SCD and Drusin, 1995 on page 16, etc. Given the above, the must the list of references/bibliography be re-written.	45, 46 and 47	Added to the references list.	Updated and re-written

COMMENTS BY VIVA VOCE PANEL

SN	COMMENTS BY VIVA VOCE PANEL	Page	ACTION TAKEN	INDICATOR

1	**What was your study population?**	17	The study population was highlighted in the document. It is individuals who are residents of Mityana municipality who recently got married within a space of two years.	The study population is well elaborated on Page 17.
2	**You kept on mentioning students, how did they come into this research?**		The only research available was for university students, which was what we could compare with at the moment.	The reviewed literature was referenced.
3	**Did you compare your study with any other study?**		Yes, the study was compared to several studies carried out in Uganda. There was a study carried out in Hoima among pregnant women and also in Bushenyi district still among pregnant women.	Under the discussion session, all the discussion centres around other studies.
4	**Your study was among the married individuals yet in finding you included those who were not. What were your inclusion criteria?**	Page 18	Married couples who got married within the past two years (January 2023 to December 2024) and are still living in Mityana municipality, and who consent to respond to the interview questions, were considered for this study.	This was well stated under methodology (3.4.1)
5	**What are the types of marriage that are recognized in Uganda? Why did you go for only those who are faith related?**		Besides the faith based marriages, also those who got married from the office of the Chief Administrative Officer were considered. However, those who got married through customary means were not considered because it was a challenging to acquire the lists from	This was well detailed under section 3 part 3.3

			the Office of the Local Chairperson.	
6	**You should have included those marriages which are not faith based eg the cultural, registrars etc**		Marriages from the office of the Chief Administrative Officer was considered. However, as mentioned above, customary marriages were not included.	This was well detailed under section 3 part 3.3
7	**Objectives: did you get answers for your objectives?**		Yes all my objectives were answered. For uptake, the percentage was shown, the perceptions were captured through the Key Informant Interviews and for associated factors, the bivariate and multi-variate analysis with logistic regression was presented.	All the objectives were well answered.
8	**In discussion you repeated the presentation of findings.**		This was an oversight and noted. This is also corrected in the final manuscript.	This section is improved as per the guidance.
9	**How did you come to conclusions in objective 2?**		Using the Health Belief Model, the responses were captured through Key Informant Interviews, In depth Interviews and Focus Group Discussions. The PI and social scientists read the transcripts, identified and highlighted themes.	This is well detailed on Page 21.
10	**Get your data and transcribe all of it and anlyse it if you want to publish. Get different people to transcribe and discuss to come out with meaning.**	13	This was well noted and will act accordingly while preparing a manuscript for publication.	Guidance was well received.
11	**You need to do interpretation of findings during**		.	Dependent variable results

	discussion not findings.			presented
12	**What new knowledge has your study brought about in health sector?**		The study has documented that factors associated with pre-marital sickle cell testing among marrieds in Mityana district, the perceptions and uptake which can be leveraged to make policies emphasing mandatory sickle cell trait tasting among pre-marrieds.	The Ministry of Health can leverage this information to come up with a policy on pre-marital sickle cell testing.
13	**What kind of information did you want people to know?**		I want people to test Sickle cells before agreeing to have children.	This is stated.

Nalweyiso Martha Dorcas — Rev. Canon. Evatt Mugarura

Candidate's Name & Signature — **Supervisor's Name &Signature**