

**KNOWLEDGE AND ATTITUDES TOWARDS SICKLE CELL TRAIT TESTING
AMONG YOUTH AGED 18-30 YEARS IN JINJA WEST MUNICIPALITY, JINJA
DISTRICT**

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DECLARATION

I, Nabwire Betty Lynn do hereby declare to the best of my understanding that this research study report entitled “**Knowledge And Attitudes Towards Sickle Cell Trait Testing Among Youth Aged 18-30 Years In Jinja West Municipality, Jinja District**” is an original piece of my work and has never been presented to this University or any other institution of higher learning for scholarly award of any kind and that due acknowledgement has been made where work from other authors is presented.

Signature_____

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Date_____

APPROVAL

This research report titled, “**Knowledge And Attitudes Towards Sickle Cell Trait Testing Among Youth Aged 18-30 Years In Jinja West Municipality, Jinja District**” was done by Nabwire Betty Lynn, a student who is pursuing a bachelor in nursing science degree under my supervision as the University supervisor.

Signature_____

Ms. Catherine Lwanira

SUPERVISOR

Date_____

DEDICATION

Dedicated to my mother

Mrs. Barbara Makumbi Kawooya

As an appreciation for her never ending supporting in my academic life

Thank you

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OPERATIONAL DEFINITIONS

The following are the operational definitions that were used in this study.

Knowledge: is defined as the information that a person has about sickle cell disease, sickle cell trait and sickle cell trait testing.

Attitude: is the way one feels about sickle cell trait testing or the opinion that they have about sickle cell trait testing.

Sickle cell trait testing: a blood test that is performed to find out if the person has either sickle cell trait or sickle cell disease.

Uptake of sickle cell trait testing services: the action of physically going and testing for sickle cell trait at the places where it is offered.

Sickle cell disease prevention: the actions through which future occurrence of disease among new-borns can be reduced or stopped.

Youth: a young adult between the ages of 18 years and 30 years.

LIST OF ABBREVIATIONS

SCD	-	Sickle Cell Disease
SCT	-	Sickle Cell Trait
SCTT	-	Sickle Cell Trait Testing
RBCs	-	Red Blood Cells
HC	-	Health Centre
Hb	-	Haemoglobin
MoH	-	Ministry of Health
NGO	-	Non-Governmental Organization
PMS	-	Premarital Screening
GC	-	Genetic Counselling
PND	-	Prenatal Diagnosis
NBS	-	New Born Screening
UBOS	-	Uganda Bureau of Statistics
WHO	-	World Health Organization
IHSU	-	International Health Sciences University
RR	-	Regional Referral hospitals
USCRF	-	Uganda Sickle Cell Rescue Fund

ABSTRACT

Introduction: Sickle cell disorders' can be controlled cost-effectively by programmes that integrate treatment with early carrier detection through screening and genetic counselling. However sickle cell disease (SCD) is not well known or recognized by many individuals as a significant health problem with major complications, thus a large number of Ugandans are carriers of the trait but are unaware of their status. Therefore this study sought to determine the level of uptake of sickle cell trait testing (SCTT) and the knowledge and attitudes towards SCTT among youth in Jinja west municipality. Results from this study may be useful in devising interventions that can improve uptake of SCTT among youth.

Method: This was a descriptive cross sectional study among 401 youth aged between 18-30 years in Jinja municipality west, Jinja district. Participants were selected from the six villages constituting Jinja west municipality through probability sampling. Data was collected from the study participants using self-administered questionnaires that were organized in line with the study objectives. Data analysis was done using SPSS version 20 and only descriptive statistics were used.

Results: Only 25% of the youth in the study had tested for SCT. The level of knowledge about SCD and SCTT was moderate with average scores of 56.6% and 63.2% respectively. However, 71.6% were aware of the availability of the SCTT services. Generally, the youth had a very positive attitude towards SCTT as a way of preventing SCD and the benefits of SCTT with a general mean overall mean attitude score of 4.08 although their attitudes towards the uptake of SCTT were neutral (with a score of 3.14).

Conclusion and recommendations: The uptake of SCTT by the youth was low, although youth had moderate knowledge about SCD and SCTT. The youth had very positive attitude towards SCTT as a way of preventing SCD and the benefits of SCTT; but the attitudes towards uptake of SCTT were neutral. Therefore continuous education of youth about the disease and the importance of sickle cell trait testing is needed. Also, sensitizing the youth about the availability of the services at free cost in all public health facilities would help to improve the uptake since a good number of youth thought that these services are paid for.

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CHAPTER ONE: INTRODUCTION

1.0 Introduction

This chapter presents the background, problem statement, objectives, research questions, significance, and conceptual framework of the study on knowledge and attitudes towards sickle cell trait testing among the youth of Jinja district, Uganda

1.1. Background of the study

Sickle cell disease (SCD) defines a set of hereditary haemoglobin disorders characterised by a high proportion of abnormal sickle haemoglobin in Red blood cells. Sickle cell anaemia (SCA), which is the most common and most severe form of SCD results from homozygous inheritance of the sickle haemoglobin gene (S) from both parents and such a person presents with signs and symptoms of the disease (Ghimire, 2016). Red blood cells (RBCs) usually have a crescent/sickle shape due to deformation of the normal RBC shape by intracellular polymerisation when these sickled RBCs get deoxygenated. This leads to them being detected and destroyed by the spleen resulting in haemolytic anaemia. Other symptoms of the disease include vaso-occlusion that characteristically causes tissue ischemia, severe pain, and acute chest syndrome or organ failure among others (Rees, Williams and Gladwin, 2010).

Sickle cell trait (SCT) is a carrier state arising from the inheritance of one gene of sickle cell “S” from one parent and one gene of normal haemoglobin “A” from the other parent. Such a person typically does not show the symptoms of sickle cell disease (SCD), although they will be able to pass the trait on to their offspring (Centers for Disease Control and Prevention, 2017). It is estimated that 400,000 babies are born with SCD each year, and that 300,000 of these are born with sickle cell anaemia with majority of these births occurring in regions endemic to malaria, mainly Africa, the Middle East, and South Asia (Piel et al., 2013). In the U.S.A, an estimated 100,000 Americans have SCD and it is said to occur in 1 of every 365 African-American births and in 1 of every 16,300 Hispanic-American births with the Sickle cell trait occurring in 1 of 13 Black or African-American babies born (Centers for Disease Control and Prevention, 2016). The

number of people living with SCD in the United Kingdom is between 12,500 and 15,000 people and it is increasing due to immigration and new births (National Institute for Health and Care Excellence, 2014).

The greatest burden of SCD is in sub-Saharan Africa, where more than 75% of all sickle cell disease occurs, with this proportion projected to increase by 2050 (Piel et al., 2013). SCT prevalence is estimated to be at 18.3% and SCD at 1.4 % in the Democratic Republic of Congo (Tshilolo et al., 2008). In Gabon, the SCT prevalence is at 28%, with SCD between 1-2% (Délicat-Loembet et al., 2014). In Ghana, 25–30 % of the population carries the SCT and 2 % has SCD (Ohene-Frempong et al., 2008). The prevalence of SCT is at 24%, with SCD between 2 to 3% in Nigeria (Taiwo, Oloyede and Dosumu, 2011). The SCT prevalence in Tanzania is at 13% (Makani et al., 2011).

Uganda has a varying distribution of SCD according to regions and districts with the overall disease prevalence at 0.7% and the SCT average at 13.3% with an estimate that at least 15,000 babies are born each year with sickle cell disease in Uganda (Ndeezi et al., 2016) and that 80% of these babies die before reaching 5 years of age. Overall, SCD contributes 15% to the under-five mortality rate in Uganda which stands at 64/1000 live births; with the infant mortality rate standing at 43/1000 live births (Ssali, 2017). Northern Uganda has the highest prevalence of sickle cell trait at 18.6%, East-Central regions come second at 16.7%, then Mid-Eastern region at 16.5% and lastly South-Western regions with 4.1% (Kyotalengerire, 2014). Fourteen districts in Uganda have the highest sickle cell disease burden in total at 47% and these are; Kampala, Gulu, Lira, Jinja, Tororo, Luweero, Wakiso, Apac, Iganga, Mayuge, Buikwe, Oyam, Masaka and Masindi. The highest sickle cell trait prevalence is found in the districts of; Alebtong at 24.3%, Buliisa at 22.1%, Bundibugyo at 21.9%, Lira at 20%, Gulu at 19.6%, Tororo at 19.5%, and Jinja at 18.9% (Emorut, 2015).

Campaigns that educate screen and counsel the different communities about SCD have been and are still being conducted in several districts so as to increase awareness about the disease. These are carried out by Ministry of Health (MoH) and a number of various Non-Governmental organizations (NGOs) that include Uganda Sickle Cell Rescue fund (USCRF) among others (Ministry of Health of The Republic of Uganda, 2016). From Piel et al., projection that current

burden of SCD in Africa would increase by 2050, it becomes important to plan more aggressive interventions that can reduce the number of new neonatal births with SCD (Piel et al., 2013). Whereas SCT is asymptomatic and a person with it leads a normal life, there is scientific evidence that if a woman has SCT and she conceives from a man who has SCT, there is a 25% chance that the child she is carrying will be born with SCD and a 50% chance that the child will be a carrier of SCT with only a 25% chance that the child will inherit normal haemoglobin genes (CDC, 2017). Thus, increased intermarriages between people with SCT who lack the proper knowledge about SCD due to lack of premarital screening and genetic counselling services will lead to an increase in the prevalence of SCT and SCD.

A study that was done in Nigeria showed that even though the youth have heard about SCD, many are not so knowledgeable about what causes it, how to prevent it or even how it is diagnosed (Olakunle et al., 2013). Another study by Okwi et al., showed that majority of the respondents from Eastern Uganda were knowledgeable about SCD, but only 3.6% of them knew their sickle cell status and just 18% knew they could have a child with SCD in the future (Okwi et al., 2009). Having few youth knowing their sickle cell status; with minimal knowledge of the disease and how it could be prevented implies that many youth would likely enter relationships without testing their sickle cell status. This in turn increases the likelihood of having more children born with the sickle cell disease. Therefore there is need for assessment of knowledge and attitudes of youth towards sickle cell trait testing, so that strategies for improving uptake of sickle cell trait testing services can be devised.

1.2. Statement of the Problem

Sickle cell disorders' can be controlled cost-effectively by programmes that integrate treatment with early carrier detection through screening and genetic counselling, and the WHO has recommended global development of these services. Carriers of SCT can be easily detected by routine haematological screening methods and can be forewarned of their reproductive risk and any possible ways of reducing it (Modell and Darlison, 2008).

SCD is not well known or recognized by many individuals as a significant health problem with major complications, thus a large number of Ugandans are carriers of the trait but are unaware of

their status. It is particularly important for individuals with SCT to understand its implication towards reproductive health that is; that they can have a child with SCD in future and that they can also give birth to a child with SCT.

In Uganda, most diagnoses of SCD are only made when a child presents with signs and symptoms of the disease. This has in turn led to a high morbidity and mortality from sickle cell disease. The frequent hospital admissions due to emergencies from a crisis or routine health care coupled with increased demands from maintaining the health of their SCD born children at home inclusive of the expected short life expectancy of these children puts an enormous psychological stress on the parents of these children (Cousino, Hazen, 2013). On average, a family will spend 111.67 United States dollars which is an equivalent of 402,102 Ugandan Shillings per episode of a crisis requiring hospital admission due to SCD (Ngolet et al., 2016). All the above can be avoided if people get to know their SCT statuses and they make informed choices.

Sickle cell screening was put in place in most government health centres starting from health centre III's up to the national referral hospitals and a good number of private hospitals and laboratories as well screen for the disease. Despite the massive campaigns that educate, screen and counsel the different communities in Uganda about SCD by the Ministry of health and NGOs' that have been and are still on-going in various districts, only few youth are aware about their sickle cell status. Jinja district where this study was conducted has a high sickle cell trait prevalence of 18.9% and it is among the fourteen districts with a high sickle cell disease burden (Emorut, 2015). From an earlier study that was done in Uganda by Okwi et al., (2009), only 3.6% of the respondents from the East had screened for SCD and only 1.4% of these knew their sickle cell genotype, yet no studies have been undertaken to assess the youth's knowledge and attitudes towards sickle cell trait testing. Therefore this study sought to evaluate the knowledge and attitudes towards sickle cell trait testing among the youth in Jinja west municipality, Jinja district. Understanding the level of knowledge and the different attitudes of the youth is important because various studies have shown that a high level of understanding of SCD will usually lead to one having a positive attitude towards SCD and SCT testing. This is important if uptake of sickle cell trait testing by the youth is to be improved.

1.3. Research Objectives.

1.3.1. General objective

To assess the knowledge and attitudes towards sickle cell trait testing among the youth 18-30 years in Jinja west municipality, Jinja district from April to June 2018.

1.3.2. Specific Objectives

- 1) To determine the uptake of sickle cell trait testing services among the youth 18-30 years in Jinja west municipality, Jinja district between April and June 2018.
- 2) To assess the level of knowledge of youth 18-30 years regarding sickle cell trait testing in Jinja west municipality, Jinja district between April and June 2018.
- 3) To determine the attitudes of the youth 18-30 years towards sickle cell trait testing in Jinja west municipality, Jinja district between April and June 2018.

1.4. Research Questions

- 1) What is the level of uptake of sickle cell screening services by the youth 18-30 years in Jinja west municipality, Jinja district between April and June 2018?
- 2) What is the level of knowledge of youth 18-30 years regarding sickle cell trait testing in Jinja west municipality, Jinja district between April and June 2018?
- 3) What are the attitudes of the youth 18-30 years towards sickle cell trait testing in Jinja west municipality, Jinja district between April and June 2018?

1.5 Significance of the Study

The study aimed at assessing the knowledge and attitudes towards sickle cell trait testing among the youth of Jinja west municipality, Uganda.

The results of this study will give an insight into the level of knowledge and attitudes that the youth of Jinja west municipality, Jinja district have about sickle cell disease, the availability of screening services for the sickle cell trait and give an estimate of how many youth actually know their sickle cell status. This information can be used by other researchers, local and central

government and other interested organisations to devise channels through which knowledge about sickle cell disease and sickle cell trait as well as the importance of sickle cell trait testing can reach the people in Uganda including sensitization of places that people can get these screening services.

The study findings will determine the need to correct peoples' attitudes and misconceptions towards sickle cell disease and sickle cell trait testing so that cultural, community and personal biases about the disease can be overcome.

It is also hoped that the study will enable the youth to know that they can play a very big role in reducing the incidence, prevalence, and mortality of sickle cell disease and its trait depending on the choices they make in regards to their reproductive rights and the care that they give those with the disease.

1.6 Conceptual framework

The dependent variable in this study is sickle cell trait testing whereas the independent variables are; knowledge and attitudes of the youth regarding sickle cell trait testing. It is believed that the uptake of sickle cell trait testing could largely depend on the knowledge and attitudes that the youth have towards sickle cell trait testing.

A conceptual framework showing the relationship between the dependant variable and the independent variables in the study

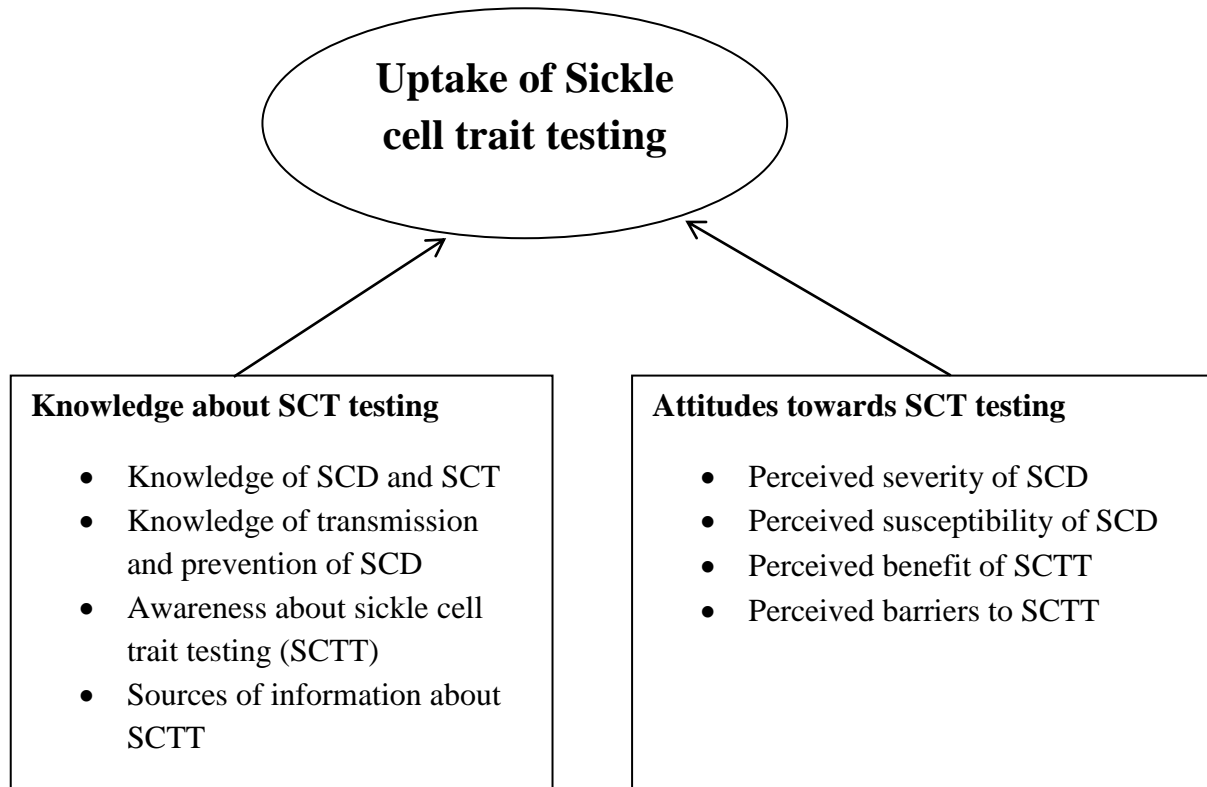


Figure 1: A conceptual framework showing the relationship between the dependent variable and the two independent variables.

CHAPTER TWO: LITERATURE REVIEW

2.0 Introduction

This chapter will describe the different studies done in regards to knowledge and attitude towards sickle cell trait testing.

2.1 An overview on sickle cell disease and sickle cell trait, their transmission and screening.

Sickle Cell Anaemia (SCA) is an inherited lifelong disorder that affects the quality of life of the affected individuals and their families in a negative way (Menezes et al., 2013). It occurs due to a missense mutation in the beta-globin gene whereby Glutamic acid (an amino acid) replaces Valine (another amino acid) in its 6th position in the beta-globin chain. This mutation will make the body to produce abnormal haemoglobin (haemoglobin S) which is structurally different from normal adult haemoglobin (haemoglobin A). In low oxygen levels, Haemoglobin S polymerises making the red blood cells (RBCs) to change shape from their biconcave shape to the sickled “C” shape hence the name “sickle cell” (Rees, Williams and Gladwin, 2010). Each person needs two genes in order to make the beta-globin chain found in normal haemoglobin, meaning each of our parents provides one beta-globin gene to make the two genes that we need (Centres for disease control and prevention, 2017). A “sickler carries two sickle cell genes (is homozygous) and is symptomatic because their body only produces RBC’s with abnormal haemoglobin (Menezes et al., 2013).

Sickle cell trait (SCT) is a carrier condition that arises when a person only inherits one sickle cell gene from one of the parents and a normal beta-globin gene from the other parent (is heterozygous). A person with SCT has RBCs with both normal and abnormal haemoglobin that is why s/he does not have symptoms of SCD and leads a normal life however this person can pass this gene unto his/her children (centres for disease control and prevention, 2017). A person with SCT is usually called a “carrier”.

Since sickle cell genes only exist in the recessive form, one needs two sickle cell genes (one from each parent) in order for them to get SCD (Lervolino et al., 2011). When two people that

both carry the SCT decide to have children together, each child that they will have together will have a 50% chance of having the SCT (inherits only one sickle cell gene), a 25% chance of having sickle cell anaemia (inherits both sickle cell genes), and a 25% chance of having neither SCT nor SCD. If only one of the parents carries the SCT, each child that these parents have together will have a 50% chance of either carrying the SCT or not (Centres for disease control and prevention, 2017).

The number of children born with SCD can be reduced through preventive measures like premarital/preconception screening (PMS) and genetic counselling (GC) unlike the new born screening (NBS) programme that aims at limiting morbidity and mortality from SCA (McGann, 2016). Premarital screening identifies persons who carry the sickle cell gene through the use of a low-cost laboratory test to detect the sickle cell haemoglobin in their RBCs. Genetic counselling is a type of counselling/therapy that educates couples with SCT about their genotype and its consequences like being able to have a child with SCD and the ways how they can avoid or reduce the consequences by making informed decisions that they are comfortable with (Gbeneol, Brisibe and Ordinioha, 2015). Prenatal diagnosis (PND) of SCD can also reduce the number of SCA births however it is applied less due to uncertainties and the level of invasiveness involved. It involves taking samples from a foetus in-utero and analysing them (Weatherall, 2010).

There are a number of reliable haemoglobin-based tests that give an actual diagnosis and they include Isoelectric Focusing (IEF), Capillary Zone Electrophoresis and High Performance Liquid Chromatography (Cordero and Velazquez-Berumen, 2011). The patient provides a blood sample that is analysed after which the results are sent back to them. IEF is a long-established diagnostic method that is appropriate for large scale screening. Sickle solubility tests are also sometimes used to diagnose SCD but these cannot tell the exact genotype of SCD for a positive solubility test so the patients have to be referred elsewhere where they can carry out a haemoglobin electrophoresis test to confirm if they are actually carriers or sicklers and the SCD genotype they carry (World Health Assembly, 2006).

2.2 Uptake of sickle cell trait testing services

The uptake of SCT screening services varies in different areas depending on a number of combined factors. However, various studies have highlighted that the uptake of sickle cell trait testing services are low despite many of the people having good knowledge about SCD with a good number of them being aware that these services exist and some are even for free.

In a study that was carried out online amongst young African women aged 17-29 years who were studying in different universities within the USA, about half of the women had screened for SCT; 5% of the women had SCT, 42% lacked the SCT and 52% did not know their carrier status. Less than a fifth (16%) reported having family members with SCT while 22% claimed none of their family members had the trait and 62% said they didn't know. Almost half (44%) of those who didn't know their carrier status did not want to find it out while 56% were willing to find out if the results were obtainable (Harrison, Walcott and Warner, 2017).

In another study carried out in Northern Manhattan in New York (USA) among people of reproductive age, when the study respondents were asked whether they had the SCT; 7% of the African American parents said that they have SCT, 88% stated they didn't have the SCT and only 5% reported that they did not know their SCT status. Two fifth (43%) of the Dominican parents stated that they had the SCT, 52% said they didn't have the trait and only 5% said they didn't know their trait status. One third (33%) of the Dominican youth aged 14-24 years mentioned that they carried the SCT while 62% revealed that they were not trait carriers and only 5% didn't know their carrier status. When these same respondents were asked if anyone in their family had the SCT; 21% of the African American parents said yes, 56% said no and only 23% said they did not know while 37% of the Dominican parents said yes, 54% said no and only 9% said they didn't know. A quarter (26%) of the youth said yes, 66% said no and just 8% said no (Siddiqui et al., 2011).

Another cross-sectional study that was carried out in Chicago, USA amongst the parents of children with SCD and those who were awaiting screening results from various health units affiliated to the University of Chicago, 89% of the parents knew that they carried the SCT, 6% knew that they did not carry the SCT while only 6% did not know whether they carried the trait or not. Of those that knew their trait, 36% found out while they were attending antenatal

screening, 26% were screened after their new-born had a positive NBS result, 8% were screened during childhood and were told the results by their parents later on, 6% had been screened during their childhood, 8% had been screened through other means and 6% were not aware of their status. 51% of these parents had a child born with SCD, 42% had a child with SCT while 25% had a child with neither SCD nor SCT. These parents had an average age of 32 years (Acharya, Lang and Ross, 2009).

In an exploratory study that was carried out amongst members of the UK sickle cell society that is found in the UK, only 43 of the 61 members had been screened for the SCT, of which 41.3% of them had screened because SCT or SCD existed in their family while 7% had screened during the process of trying to conceive. Half (51.2%) of those that screened had been screened involuntarily during the preparation for an operation and after a miscarriage (Millan, Teijlingen and Eboh, 2006).

A cross-sectional study that was carried in a province called Al-Seeb that is found in Oman reported less than a quarter (24.4%) of the adults aged 18-58 years in Oman had screened for SCD of which 19.1% of these carried the SCT even though 85.1% perceived screening to be valuable, and 60% were aware that only a blood sample was needed as even though the screening services were for free in the health centres found in this region (Al-Azri et al., 2016).

More recently in Saudi Arabia, a cross sectional study carried out in Jeddah City revealed that two thirds (64.2%) of the study population did not know their carrier status, 9.4% knew that they had the SCT and 26.4% were aware that they didn't have the SCT. Of those that knew their carrier status, 3.3% had the C-trait and 6.8% had the Beta-thalassemia trait (Alturaifi et al., 2018).

Even though 98.6% of the university students had heard and were quite knowledgeable about SCD at the University of Ghana, only 39.1% of the students had ever screened for SCD of which less than a third of these (30.3%) knew their genotype; 16.9% carried the "AS" genes, only one (0.9%) student had SCD (SC genotype) while the rest (82.1%) carried the "AA" genes. This study was a cross sectional study carried out in Ghana involving university students with many aged between 18-20 years (Boadu and Addoah, 2018).

Elsewhere, a study (cross sectional) carried out amongst students taking a nursing course at a nursing and midwifery school in Sokoto (north west of Nigeria) with a mean age of 22.2 years made known that 71.3% of them were sure of their SCD genotype of which 73.1% were AA, 10.1% AS, and 0.8% had AC although 16% stated their blood groups. Only 41.8% were unaware that genotype testing using a blood sample confirms SCD (Isah et al., 2016).

Results from a cross sectional study carried out amongst married couples with an average age of 30 years in Choba found in South-South Nigeria showed that 72.8% of the study participants had screened for SCT with their partners before they got married of which majority (87.2%) had been advised to screen by their churches, 6.64% screened because they wanted, 4.27% were advised by a health worker and 1.9% had been requested to screen by their parents (Gbeneol, Brisibe and Ordinioha, 2015).

A cross-sectional study by Adewoyin and others amongst fresh graduates in Benin City that is found in Edo State, Nigeria who were doing their National Youth Service Corps found that almost all of the graduates had screened for SCD; 77.6% were AA, 13.5% AS, 2.7% SS, 0.3% SC, other genotypes (0.5%) and only 5.4% had not screened. These graduates were between the ages of 26-29 years with those that had screened for SCD stating reasons like; it was a requirement for school admission (32.7%), they screened out of curiosity (18.1%), the doctors' requested that they screen for SCT (17.8%), a few had screened before getting employment (3.2%), some had been screened in infancy (7.0%), 13.2% had screened before getting married while 2.4% had screened for other reasons (Adewoyin et al., 2015).

A descriptive cross sectional study that was carried out in North Central Nigeria in a town called Jos Metropolis amongst secondary school students with a mean age of 17 years publicised that nearly two thirds (59.2%) of these students had screened and knew their particular genotype. Of those that ascertained knowledge of their genotype, 59.2% did not have the SCT (AA), 11.1% were carriers (AS) while the other 29.6% had the other rare genotypes of SCD. Sadly, only 2 students (1.4%) knew that screening was carried out using a blood sample. Slightly above a half (55.5%) pointed out that it was done through a urine test while 43.1% said they didn't know how SCT was diagnosed even though 89.6% of the students said that somebody ought to identify their SCT status (Olakunle et al., 2013).

According to a cross sectional study carried out in Tamale found in Northern Ghana involving public servants above 20 years of age, 62.7% of were aware of their own carrier status with 49.8% being aware of that of their partner at the time of the study. In addition, 38.1% had screened their children for SCD. Just a tenth (12.2%) had pursued genetic screening for SCD before marriage while 24.4% screened after marriage. A half (52%) were requested by a health staff to screen, 21.6% personally decided to screen, 21.6% were screened before they could receive a blood transfusion and 4.8% had been screened through compulsory screening (Ameade et al., 2015).

A cross-sectional study involving households in Kordofan state that is located in the western region of Sudan discovered that only 6.1% of the parents in the study had ever screened for SCT preceding the study (Daak et al., 2016).

However in Uganda, there are no documented studies on the uptake of sickle cell trait screening services in Uganda. Only one particular cross sectional survey carried out in the districts of Mbale and Sironko found in eastern Uganda and Ntungamo and Mbarara found in western Uganda with the respondents aged 18-60 years revealed that 2.5% of the households, 1 student (1.6%) and 13.8% of the health workers from the east had screened for SCD unlike 1.1% of the households, no student and 9.4% of the health workers from the west. Only 6.3% of the western health workers knew their genotype. A good number (91.8%) of the eastern households together with 83.2% of their students were willing to be screened for SCD in comparison with 87.4% of the western households and students (85.9%). Only 8.2% of the households and 14.8% of the students from the east were unwilling to screen for SCD compared to 11.7% of the household respondents and 21.1% of the students from the west (Okwi et al., 2009).

2.3 Knowledge of the youth about sickle cell trait testing

Knowledge is the information that a person/group of people has about a particular subject. It can be gained through studying or experience. Increased community awareness and knowledge about SCD will reduce the burden of the disease (Ware, 2013). Knowledge about SCD, how it is inherited, how it affects health, the reproductive implications of having SCT, the stigma from the community towards sicklers and carriers, and the use of recognised genetic educational resources

by both adults and children are significant determinants of whether the correct information will be passed on to other family members (Acharya, Lang and Ross, 2009).

An elevated awareness about SCD more so in regards to its genetics and disease severity is related to a high level of acceptance of its screening services (Gustafson et al., 2007). A quasi-experimental study involving graduates that were doing their youth service in Lagos state in Nigeria with an average age of 25 years showed that the amount of knowledge about SCD among the individuals in the test group increased by 64.1% (initially, it was at 25.3%) after the intervention which was education about SCD and so did their attitudes towards screening leading to an 11.9% increase in the number of people who knew their genotype. Initially, 83% of the participants in the test group already knew their genotype before being educated. This shows that the right amount of knowledge will increase the chances of one screening for SCD (Orajekwe and Maduekwe, 2017). These attributes will be explored in the citation of literature on knowledge regarding sickle cell trait testing that follows.

An online study carried out in the USA among African Americans with a mean age of 19 years attaining an education at diverse universities highlighted that 55% of the women inaccurately alleged that SCT is capable of turning into SCD; that it leads to a wide range of health complications (58%), is a cause of numerous annual deaths (41%), leads to a lot of painful episodes (37%) with 25.6% alleging that carriers of SCT live short unhealthy lives. The average knowledge score was moderate (68%) and only 47% of the respondents knew and had undergone SCT testing. Many (62%) of them were not aware if SCT existed within their families and 44% did not wish to learn about their personal carrier status (Harrison, Walcott and Warner, 2017).

A cross sectional survey carried out in Northern Manhattan, USA among parents of children below 5 years of age, revealed that majority of the people within the reproductive age had little appropriate information about SCD and this was mostly seen in the Dominican parents surveyed where by less than a third (27%) of them suitably mentioned that SCD was an inherited disorder of blood while 73% could not define SCD; 27% of the parents that failed to define SCD said it was an infection of blood while 45% said that they did not know SCD and they thought SCD is a form of leukemia or acquired HIV infection. In comparison, three quarters (76%) of the African American parents that were surveyed in the same study were able to correctly define SCD with

only 10% incorrectly defining it and 14% saying they didn't know what SCD is. Over 43% of the Dominican parents had less knowledge about sickle cell trait testing and had not screened for SCT, 37% were not aware if the trait existed within their family compared to only 7% of the African American parents that had not screened for SCT and only 21% of them did not know if SCT existed in their family (Siddiqui et al., 2011).

According to a cross sectional study carried out in the USA among parents to children with either SCD or SCT (mean age of 32 years) that were visiting the different health units of the university of Chicago, parents to sicklers were more knowledgeable about SCD (78%) because they had received a lot of information from formally trained staff at the sickle cell clinics and some got more information from the internet. In this study, Parents to carriers were less knowledgeable about SCD (58%) because they had not received genetic counselling services and were not aware about sickle cell trait testing. Almost three quarters (73%) of the parents in the study said a carrier is someone who has the SCT with 65% of them correctly knowing that carriers of SCT cannot develop SCD later on in life. Nearly a half (46%) of the parents correctly knew that a SCT test that turns out negative means the person without a doubt lacks the SCT and 58% of them knew that SCT is not a moderate form of SCD (Acharya, Lang and Ross, 2009).

A study carried out in the UK revealed that 95.1% of the members in the sickle cell society in the UK correctly stated that SCD is an inherited disorder that is passed on to children from their parents. Almost all the members (96.7%) correctly answered that SCD disorders are disorders affecting the Red Blood Cells and 73.8% of them said SCT is when somebody carries the sickle cell gene and may possibly pass it on to their children. In this study, nearly all the members (96.1%) correctly identified that one can find out their SCT status from a simple blood test (Millan, Teijlingen and Eboh, 2006).

A cross sectional study carried out among the population that was residing in Jeddah city in Saudi Arabia showed that just about a half (51.4% %) of the population had good knowledge about SCD. Almost all (86.3%) of the study participants had ever heard about SCD before with 3.8% having been around a child with SCD. More than half (55.7%) of the participants rightly knew that SCD is a blood disease, however less than a quarter (17.5%) could state that it can be diagnosed by a blood test. Since the residents were not so knowledgeable about SCD and many

were not aware that it can be screened for using a blood test, only 35.8% had screened for SCD prior to the study (Alturaifi et al., 2018).

A knowledge and attitude cross-sectional study carried out in Jos Metropolis found in North Central Nigeria among secondary school students whose mean age was 17 years found that nearly all (97.4%) of the secondary school students were aware of SCD, with 83% knowing it affects RBCs and 80% identified it as an inherited blood disorder. Unfortunately, only 1.4% (2) of the students were aware that it was diagnosed using a blood test with many 55.5% stating a urine test and 43.1% admitting they had no idea although 59% were aware of their genotypes (Olakunle et al., 2013).

Unfortunately, there are no documented studies in regards to knowledge about SCD and SCT in the region except for one cross sectional involving adults (18-60 years) living in the districts of Ntungamo and Mbarara from the west and Sironko and Mbale from the east which publicised that only 72.9% of the household respondents, 70.5% of the students and 85.3% of the health workers from Eastern Uganda were aware of SCD compared to only 59% of the household respondents, 58.8% of the students and 76.2% of the health workers from the West. The low levels of SCD awareness led to an extremely low uptake of screening services among all the study participants coupled with the fact that few of the health workers; 51.7% from the east and 50% from the west were aware of the correct screening methods for SCT (Okwi et al., 2009).

A recent cross-sectional study carried out in Jeddah City, Saudi Arabia in which the study participants had a mean age of 24 years revealed that the participants acknowledged that SCD causes; cruel pain that calls for hospitalization (71.7%), life threatening infections (42%), renal failure (41.5%), stroke (39.6%) and poor school performance (67.9%). Nearly a half (42.5%) admitted that they were not aware if SCD was curable while 32.1% stated that it was incurable. The uptake of screening services was low in the study at 35.8% which is not surprising because just about a half (51.4%) of the participants were quite knowledgeable about sickle cell trait and it's testing (Alturaifi et al., 2018).

A different cross sectional study carried out in Saudi Arabia in a region called Albaha that involved adults with an average age of 33 years illustrated that participants who claimed to have been around a person with SCD were more knowledgeable about complications and precipitating

factors compared to those who had not. The participants in the study generally had good knowledge about SCD and SCT testing that is why nearly three quarters (72.6%) of the participants had screened for SCT of which 87.5% of those who had been around a child with SCD had screened compared to only 20.6% of those who had not (Alghamdi et al., 2017).

Only a few Omani adults (20.2%) with a modal age of 26 years living in Al-Seeb Province found in Muscat the capital city of Oman knew that SCD can cause acute pain sometimes, 26.4% were aware that it leads to “sickling” of RBCs and 20% knew that it can lead to serious infections, organ damage and strokes. The mean knowledge score of the study participants was 2.24 out of 6 which is rather low and that is why less than a quarter (24.4%) of the study participants had undergone screening and knew their sickle cell status (Al-Azri et al., 2016).

A cross sectional study involving a fifth of “sicklers” and four fifths of carriers who were aged 18 years to 70 years from Pombhurna sub county, Chandrapur district in India found that sufferers of a disease have more correct knowledge about that disease compared to the carriers. Due to the good level of knowledge about symptoms of SCD, more than three quarters (77.8%) of the married study participants had gained knowledge about sickle cell trait testing and had thus screened their partners after discovering they personally carried the SCT (74.34% of the carriers and 100% of the sicklers) even though only 6.77% (28% of sicklers and 3.28% of carriers) had screened their partners for SCT before marriage (Patil et al., 2017).

Another study carried out in central Nigeria in a place called Jos Metropolis that included secondary school students (mean age of 17 years) showed that 44.5% of the students claimed not to know any sign and symptom of SCD. This low knowledge about signs and symptoms of SCD was believed to have led to the moderate uptake (59%) of SCT screening services among the students because many did not fully understand the effect of SCD on affected individuals and had little knowledge about sickle cell trait testing given only 1.4% knew that all they need for a screening test is a blood sample (Olakunle et al., 2013).

Results from an online study involving African American women aged 11-29 years in different universities found in USA showed that only 48% of the women had knowledge about SCT testing and had ever screened for SCT even though four fifth of them had correct knowledge about SCD transmission. Majority (81.8%) of them correctly understood that persons with SCT

carry only a gene of sickle haemoglobin from only one of their parents and 95.4% said carriers can pass on this gene to their children. However, 26% of the women wrongly believed that all children born to carriers have the SCT while 23.3% of them said SCT is passed onto infants by their mothers (Harrison, Walcott and Warner, 2017).

The UK sickle cell society members who participated in a survey which was carried out in the UK had moderate knowledge about the inheritance patterns of SCD or SCT. About three quarters (70.5%) had good knowledge about sickle cell trait testing and had screened for SCT. Only 57.4% of them correctly stated that none of the children would be born with SCD when they were asked what the chances were for each pregnancy that a child will be born with SCD in case only one of the parents carried the SCT. In cases where both parents carried the SCT, 52.5% of the members correctly stated that a 1 in 4 (25%) chance existed for each pregnancy that the child will be born with SCA (Millan, Teijlingen and Eboh, 2006).

In Oman, a cross sectional research study that engaged many adults in the age bracket of 18-29 years that lived in Al-Seeb province, Muscat discovered two thirds (67.8%) of the adults correctly knew that SCD is a genetically inherited disease. However, only 29.6% knew that one needed a gene from each parent to acquire SCD. In this study 75.6% had low knowledge of sickle cell trait testing and had thus not screened for SCD (Al-Azri et al., 2016).

In a cross sectional study carried out in Sokoto state amongst nursing students aged 16-25 years who were studying at the Sokoto School of Nursing and Midwifery found in north western Nigeria, 97.6% of the students had good knowledge about the pattern of transmission of SCD and 70.3% were found to have good knowledge about sickle cell trait testing and had screened for SCD (Isah et al., 2016).

Elsewhere, a study done in Jos Metropolis, in the North central region of Nigeria amongst secondary school students many of whom were aged 15-20 years brought to light that the students were not knowledgeable about the transmission pattern of SCD. Observably, only 59.2% were aware about sickle cell trait testing and had undertaken screening for SCD. Less than a quarter of the students (21.2%) correctly knew that none of the children could have SCD in the case that only one of the parents had SCT while 66.9% declared that the genotype of one's

partner should not be considered an important factor in choosing a life mate (Olakunle et al., 2013).

In Western Sudan, a study that involved households in Kordofan state unearthed about four fifth of the parents were aware that both parents transmitted SCD onto their children. Many (69.5%) went on further to say that the practice of marriages involving close relatives amplifies the chances of having children with SCD. At the time of the study, no more than 6.1% of the parents had screened for SCT yet two thirds (68.5%) of them had moderate knowledge about the hereditary nature of SCD, but were not aware about sickle cell trait testing (Daak et al., 2016).

In a cross-sectional survey involving secondary school students (majority aged 15-17 years) in Banke district found in India, 30.3% of them said all babies should be screened for SCD after birth and that people in their reproductive years should go for genetic screening and counselling (31%) so as to control SCD. They were equally aware that SCD is a hereditary blood disorder (43.8%) and that SCT arises when a person carries one gene for SCD (33.8%). Nearly two thirds (63.1%) had knowledge of it being diagnosed by a blood test (Ghimire, 2016).

A study that was carried out among secondary school students aged 15-20 years in Jos Metropolis found in the North central region of Nigeria found that 40.2% of these students were able to correctly identify genetic counselling as a way of preventing SCD. Half of these students (51.9%) were also aware that a couple where both partners carry the SCT had to get genetic counselling before determining the fate of their relationship even though 23.4% wanted the relationship to end and 24.1% had no idea what the couple should do (Olakunle et al., 2013).

Even though nearly all (85.1%) of the study participants in a cross sectional study involving adults living in Al-Seeb province that is found in Muscat (Oman) whose mean age was 29 years said that premarital counselling was important in preventing SCD and 81.1% stated that they would reconsider their marriage should they find out their partner is a carrier of the SCT, only 24.4% had actually taken time off to screen for SCT and 68.2% admitted that the possibility of having a child with SCD scared them (Al-Azri et al., 2016).

In a cross-sectional study among fresh graduates from tertiary institutions in Nigeria, Edo state in Benin City, more than half (54.6%) of the graduates instead preferred that carriers should not be

allowed to marry each other, and 80.8% of the carriers were not willing to marry a fellow carrier of SCT. However, only thirteen per cent of these graduates had screened before marriage out of the total 94.6% that had screened for SCT, despite having good knowledge about sickle cell trait testing (Adewoyin et al., 2015).

Results from a descriptive cross-sectional study carried out among married couples with a mean age of 30 years that lived in Choba located in South-South Nigeria revealed that 78.97% of the participants were knowledgeable about SCD with 84.83% being aware about premarital screening. Almost all (95.86%) said it should be taken over by the government and made public to everyone while 88.97% recommended it should be one of the requirements from the government before a couple gets married. It is important to note that 72.76% of these study participants had carried out premarital counselling for SCT and majority had been encouraged to do so by the church (Gbeneol, Brisibe and Ordinioha, 2015).

In another study, half of the parents in Kordofan state found in western Sudan said they would not have married their partners who carried the SCT had they known earlier so that they could avoid having children with SCD. Only 6.2% of the parents knew their SCT status prior to the study because many of them had poor knowledge about the SCD (Daak et al., 2016).

In a study among African American women attending different universities in the USA whose mean age was 19 years, only 48.2% were knowledgeable about and had screened for the sickle cell trait. According to this online study, information about SCD and sickle cell trait testing had been obtained from one source (34%) or two sources (33%) which included schools (82%), the media (42%), family (30%), health staff (21%), friends (20%) and 3% indicated that they had never heard about sickle cell beforehand (Harrison, Walcott and Warner, 2017).

In a pilot study that was carried out among parents (mean age of 32 years) who were accessing the different health units attached to the University of Chicago found in the USA, parents that had a child born with SCD received information from the paediatricians (89%) and employees of private not for profit SCD organisations (78%). Parents whose children did not have SCD received most of the information from family (63%), paediatricians (38%) and 42% got it from gynaecologists and obstetricians. In this study, 89% of parents in total were aware of sickle cell trait testing as well as their carrier status (Acharya, Lang and Ross, 2009).

A study involving adults aged 16 to 24 years in Albaha, Saudi Arabia found that those participants with a SCD patient in the family were more knowledgeable about SCD because their knowledge sources were mainly health care staff (58.3%) and hospitals (16.7%) whereas those without a SCD patient gained information from the internet (27.3%) and family (24.2%). Almost three quarters (72.6%) were knowledgeable about SCT testing and had tested for the SCT. The adults suggested public health teaching about SCD/SCT through television, distribution of CDs and videos, and community meetings (Alghamdi et al., 2017).

In a study among adults (majority aged 18-29 years) in Oman that lived in Al-Seeb province in Muscat, 56.7% of the adults stated that there is inadequate material to educate the population about SCD with 43.3% having received most of their knowledge from schools and the media. In this study, only 24.4% of the adults had screened for the SCT (Al-Azri et al., 2016).

Nearly all the graduates aged 26-29 years in Benin City, Edo State situated in Nigeria who were doing their national youth service had heard about SCD and its ability to be screened from mass media health talk shows (45.9%). Nearly a quarter (23.2%) were told by an affected friend or family member, 14.1% had received some formal learning about SCD, 13.8% had got to know from literature and 1.4% had learned from other sources and it explains why 94.6% of these graduates had tested for and were aware of their SCD genotypes except for the 1.6% who did not know that they can screen for SCT (Adewoyin et al., 2015).

A descriptive cross sectional study carried out in North Central Nigeria in Jos Metroplis among secondary school students between the ages of 15-20 years discovered that most of the students (36.5%) had received most of their information about SCD from health professionals, 18.2% from family members, 13.8% from friends and 11.1% from the internet. Since most of them got the information from health professionals and family members, almost three fifths (59.2%) of the students had good knowledge about sickle cell trait testing and had screened for SCT (Olakunle et al., 2013).

In a study involving students at the University of Ghana, only 39.1% of the students had actually screened for the SCT. In this study, more than three quarters (84.6%) of the students many of which were aged between 18-20 years got their information about SCD and its screening from

schools while 12.6% had got it from radio and television and 2.9% got it from family, friends and health centres (Boadu and Addoah, 2018).

A documented study which involved persons in the districts of Mbale, Mbarara, Ntungamo and Sironko which are found in Uganda highlighted the major sources of information about SCD were the health workers and radio in rural areas whilst newspapers, television coupled with health workers and the community provided information in urban areas. Students got most of their information from health visitors, radio, television and the community respectively. Despite all these various sources of information about SCD, less than 5% of the total study participants had screened for SCT and some few were still unwilling to screen for it (Okwi et al., 2009).

2.4 Attitudes of youth towards sickle cell trait testing

Attitude is the way one feels about something or the opinion that they have about something. It usually manifests in one's behaviour. Attitude is usually influenced by a person's beliefs/perceptions about that particular subject. The uptake of screening services for many diseases has been thought to be influenced by the individual's perceptions which include: an individual's perceived susceptibility to the disease, an individual's perceived seriousness of disease, an individual's perceived benefit towards screening for the disease, and lastly, an individual's perceived barriers to screening for the disease. This was adopted from the Health belief Model (Gustafson et al., 2007).

Attitudes can be positive or negative. A positive attitude will lead to an increase in the uptake of the screening services while a negative attitude will lower the uptake of the screening services. Positive attitudes coupled with good knowledge about SCD will lead to an increase the uptake of the screening services. A person will easily screen for a SCD if this person believes that SCD is serious; s/he believes that they can acquire SCD or SCT and eventually spread it to their children; s/he deems screening for SCD to be advantageous (for example by reducing the chances of it being passed on to the children) and that the barriers towards screening for SCD are few.

People that consider SCD to be a very serious disease will find it important to go and screen for SCT. SCA causes serious health problems, shortens the life expectancy of the patients and it causes psychological and economic stress to the patient and their family.

In the USA, a study involving African American women above 18 years of age that were visiting Magee-Women's hospital which is found in Pittsburgh showed that less than a third (29.1%) of the women had screened for and were aware of their sickle cell status in spite of the fact that the women perceived SCD to be a serious disease with a severity score of 4.22 out of a total score of five. Many of them scored SCD as a serious disease (4.40) and the thought of having a child with SCD scared most of them (4.42). The belief that having a child with SCD will negatively change the women's life was common and it scored 3.81 on average (Gustafson et al., 2007).

Three quarters (74.2%) of the Omani adults whose age was 29 years on average in a study carried out in Al-Seeb province in Oman said SCD was a very serious disease that affects the child's performance at school (66.7%) and the individual lives of the parents (57.8%). The thought of having a SCD child scared 68.2% of these adults but less than a quarter of them had screened for SCT (Al-Azri et al., 2016).

Results from a study carried out among adolescents with SCD in Kingston, Jamaica publicised that 86% of these adolescents said SCD is a severe disease and 53% said their lives would be negatively affected should any of their future children have SCD. They were aware that their other family members could have children with SCD and they thus recommended them to go for sickle cell screening so that they can be aware of their status (Bhatt et al., 2011).

Another study carried out amongst the nursing students whose mean age was 22.2 years at the Sokoto School of nursing and midwifery in Sokoto state found in north western Nigeria revealed that 96.4% of the students acknowledged SCD as a serious disease because it leads to death (45%), is incurable (6.6%), causes anaemia (18.5%) while 29.8% stated other reasons. Less than a quarter (41.8%) of the students however had screened for SCT despite the high level of perceived severity (Isah et al., 2016).

A person who accepts that they are at risk of acquiring a disease will in most cases go on ahead and screen for it, therefore people who feel that they are not vulnerable to SCD will not go for

SCT testing. Studies have revealed that very many people are not aware that their children or those of other family members are susceptible to SCD and this could possibly explain some of the reasons for the low uptake of screening services in some study settings.

A cross sectional study that involved adult African American women attending Magee-Women's hospital in Pittsburgh, USA illustrated that few of the women (29.1%) took up screening services for SCT because they perceived a low susceptibility to SCD at 2.62 on a 5-point scale. A good number of them did not think their partners carried the SCT (2.45), or that they can have children with SCD (2.05) while the thought that SCD simply cannot occur in their families given a score of 3.3 occurred to most of the women (Gustafson et al., 2007).

A recent study carried out amongst adults aged 18-58 years in Al-Seeb province located in Muscat, Oman discovered that less than a third (20.2%) of them recognised that SCD could occur in their families, with only 33.8% of them stating there is a chance that their partner is a carrier of SCT and only 33.6% admitted that their child may be at risk of SCD. This low perceptibility towards SCD explains why not even a quarter of these adults had bothered to screen for SCD (Al-Azri et al., 2016).

According to a cross sectional study carried out in Kingston, Jamaica involving adolescents living with SCD, 27% of them believed that their partners were not carriers of the SCT while 19% felt that their children cannot suffer from SCD. Such beliefs can easily make them to forego screening of their partners in the future even though these participants clearly knew that they personally carried the genes for SCD (Bhatt et al., 2011).

There is limited literature in the region about perceived susceptibility to sickle cell disease and its trait. Results from a published descriptive cross sectional study which involved adults above 18 years up to 60 years living in the eastern districts of Sironko and Mbale plus the western districts of Ntungamo and Mbarara publicised that very few participants perceived that they and their families were susceptible to SCD as only 14.7% of the households from the east were aware of the possibility of having offspring with SCD unlike 17.4% from the west. This contributed to the low uptake of SCT screening among the household respondents which was at 2.5% in the east and 1.1% in the west (Okwi et al., 2009).

Screening of the youth is important because it allows for informed reproductive decisions which will in the long run reduce the number of children affected with SCD (McGann, Hernandez and Ware, 2016). People will most likely screen for SCD if they believe screening has an advantage or advantages as highlighted in the following studies.

A study carried out in the Pittsburgh metropolitan area in the USA at Magee-Women's hospital among African American women older than 18 years found that only 29.1% of the women had screened for SCD although there was a high benefits score to screening for SCD at 4.10 out of five. Majority of the women felt that it is important to know their own carrier statuses (4.32) and that of their partners (4.43) as it will determine the number of children that they shall have together (3.58) (Gustafson et al., 2007).

A cross-sectional study that was carried out among the adults (18-58 years) in Oman in a province called Al-Seeb that is found in Muscat city reported that only 24.4% of the adults had screened for SCD even though 85.1% perceived screening for SCD to be valuable and the screening services were for free in the health centres found in this region. The adults said it was important to know if they (80.7%) or their partner (77.8%) is a carrier of SCT with 65.3% stating that a possibility of having a SCD child would alter the number of children they would have wanted to have and 81.1% stated they would not marry someone who can increase the chances of having a SCD child (Al-Azri et al., 2016).

A cross-sectional study carried out in Kingston that is found in Jamaica among Jamaican adolescents who were SCD patients found that the adolescents' believed that screening for SCD was beneficial and 90% of them said everyone should screen for SCT while 93% recommended that everyone should know their partners genotype so as to avoid having children with SCD. They also stated that they encourage their relatives to screen for SCT (Bhatt et al., 2011).

Elsewhere, a study involving nursing students between the ages of 16-25 years that attended a nursing and midwifery school set up in Sokoto state in north western Nigeria demonstrated the students believed that screening for SCD; enables the person to know their haemoglobin genotype (16.3%), it prevents the person from marrying somebody with an unsuitable status (7.2%) and makes carriers of the SCT to acknowledge the fact that they can pass this trait onto their children (39.9%). Almost all (92.2%) of the students acknowledged that screening is

important in preventing SCD although only 80% were willing to go for screening with their partners while 94.5% stated they will encourage other people to screen for SCD. More than a half of the students in the study had screened for SCD (Isah et al., 2016).

A descriptive cross sectional study involving community members from Kordofan state in western Sudan highlighted that nearly three quarters (73.1%) of the parents stated all family members should be screened for SCD as its beneficial with a third (31.3%) of them deciding that knowledge of one's carrier status and that of their spouse reduces the chances of them transmitting SCD to their offspring. Regrettably, only 6.1% of the parents had screened for SCD at the time of the study even if many said screening was beneficial (Daak et al., 2016).

There was no documented literature about benefits of testing for sickle cell disease in Uganda

An object surrounded by a number of other objects will be hard for a person to get to. In this case, if people feel, see or assume very many obstacles around the screening activity, only a few will be moved to screen for it thus lowering the uptake of SCT testing services. Barriers towards the screening activity for SCT have been highlighted in different studies as follows.

Many of the Dominicans in a study carried out in Northern Manhattan among people of reproductive age mentioned that there was stigma towards "sicklers" and "carriers" because many perceived SCD as an African disease and they thus preferred not to reveal their positive carrier status to anyone who was not part of their family. Fortunately, only 5% of the Dominicans in the study had not screened for SCD because stigma was the only barrier they considered towards screening (Siddiqui et al., 2011).

A cross sectional study that included only African American women attending Magee-Women's Hospital located in Pittsburgh metropolitan, USA showed the women considered less barriers to screening for SCD which barriers had a combined score of 2.28 out of a maximum score of 5. These barriers included; the test was painful and difficult (2.18), it was hard to convince their partners to screen (2.10) and they were not willing to pay for the test (2.59). Only 29.1% of the women had screened for SCT because they perceived more than one barrier to screening (Gustafson et al., 2007).

An exploratory study carried out in the UK among members of the UK sickle cell society noted the major obstacles to screening for SCT were; the emotional anxiety one undergoes while waiting for the results, paying for the test as most health insurance companies did not cover them and lastly, they did not want to be stigmatized in case of a positive result. Just about three quarters (70.5%) had screened for SCT irrespective of the barriers identified (Millan, Teijlingen and Eboh, 2006).

Elsewhere, a cross sectional study amongst adults (29 years on average) in Muscat, Oman living in Al-Seeb province showed that 36% of the adults thought SCT screening was a difficult and painful process that is why only 24.4% had screened for it while 37.8% felt it would be hard to convince their partners to go for the screening (Al-Azri et al., 2016).

Many (85%) of the students in a study carried out at the university of Ghana were willing to go for SCT screening before marriage but half of them feared losing out on a good partner if the partners results returned positive while some others did not want their partners to find out their abnormal genotypes in fear the relationship would end. This fear contributed to the low screening rate (39.1%) in the study (Boadu and Addoah, 2018).

A cross-sectional survey that engaged nursing students (16-25 years) at the school of nursing and midwifery in Sokoto found in North West Nigeria brought to light some obstacles to screening among which were; the community is not aware of SCD (75.8%) while 15.2% cited other reasons like unwillingness to end a relationship. Of the 28.7% that had not screened for SCT, 9.7% were not willing to undergo premarital screening either personally or with their partners while 10.3% said they will only screen themselves because their partners might not understand the reason for screening (6.1%) and 3% said their partners will screen individually if they felt the need to (Isah et al., 2016).

There is limited published literature about barriers to SCT screening in the region and none in the district of the study setting. However, a study carried out amongst adults aged 18-60 years living in the districts of Mbale, Sironko, Ntungamo and Mbarara in Uganda showed that only half of the health workers surveyed in the study were aware of the screening tests for SCD in addition to these districts not offering SCT screening services even though four fifths of the study respondents were willing to screen. Some respondents thought SCD was similar to HIV and did

not want to be stigmatised in case their results returned positive. Only 2.54% of the study participants had screened for SCD (Okwi et al., 2009).

Many people have become knowledgeable and have appreciated the importance of screening for SCD and SCT with a good percentage of the participants in some studies recommending free widespread screening for SCD and its trait.

In a study carried out among the UK sickle cell society members, almost all the study participants agreed screening for SCD should be made universal, even if only 70.5% had screened for it in the study (Millan, Teijlingen and Eboh, 2006).

A study done in Kingston the capital city of Jamaica that only included adolescents who had SCD found that 93% of the adolescents said it is important for everyone to know if they have SCD or its trait and they recommended that screening services should be accessible to all people (Bhatt et al., 2011).

A descriptive cross sectional survey carried out amongst secondary school students studying in Jos Metropolis, North Central Nigeria majority of whom were around the age of 17 years highlighted that 89.6% of the students affirmed that every person should know their SCT status and that the governments should make it achievable for all. Fifty nine per cent of the students had screened for SCT and knew their genotypes (Olakunle et al., 2013).

Majority (73.1%) of the parents that were surveyed in a cross sectional study carried out in Kordofan state, found in western Sudan stated that screening of all family members for SCD was important since it is a genetic disorder that can be transmitted onto the children. At the time of the study, only 6.1% had screened for SCD (Daak et al., 2016).

CHAPTER THREE: METHODOLOGY

3.0. Introduction

This chapter details how the study was carried out. It includes the study design, study area, study population, sample selection, sample size calculation, sampling procedure instruments, reliability and validity, ethical concerns, data collection procedure, data management, data analysis study limitations and how the data will be disseminated.

3.1. Study design

This was a descriptive cross sectional study design because it was found appropriate enough in enabling the researcher to collect data about the level of uptake of screening services for SCD among the youth, their level of knowledge as regards to SCT and the different attitudes that they have towards testing for SCT at a single point in time.

3.2. Sources of data

Data was primarily obtained from the questionnaires that were administered to the youth in Jinja municipality west by the researcher and her assistants. Secondary data sources included published studies, reviews and surveys related to the subject matter that were used during literature review and discussion of the study findings.

3.3. Study area

The study was carried out within six villages that constitute Jinja west municipality in Jinja district Uganda. These villages included Gabula road, Army police, Nalufenya A, Amber court, Mpumudde market and Madhvani. Jinja district is located in south eastern Uganda and it falls under the Busoga sub region. According to degrees and minutes, Jinja municipality is located 00⁰ 27' North of the equator while it is 033⁰ 11' East of the prime meridian. It is found 1,230 metres above the sea level. Jinja municipality is found on the northern shore of Lake Victoria where the source of River Nile originates. The distance from Kampala to this municipality is about 80 kilometres. It covers 28 square kilometres of which 25 are land while 3 are covered by water.

The municipality is among the three counties that make up Jinja district together with Kagoma and Butembe (Map is shown in Appendix V).

To the north of the municipality is Bugembe trading centre, Lake Victoria shores in the east, Njeru town council in the south and Mafubira Sub County in the west. Jinja municipality has a total of 3 divisions namely; Jinja Central, Walukuba-Masese and Mpumudde-Kimaka which together give rise to 11 parishes and 54 villages. It is further divided into two political constituencies which are Jinja municipality east and Jinja municipality west. Nearly half of the people living in Jinja municipality were not born there. It has one regional referral hospital, two health centre (HC) IV's, one HC III and four HC II's plus a number of private clinics (Uganda Bureau of Statistics, 2017).

Jinja west municipality has an estimated population of 32,771 people with people aged 18-30 years accounting for 31.3% of the population of which 72.9% of its households are headed by men and the major sources of information in the households are radios (69.9%) and televisions (49.9%). Slightly above a half (54.3%) of the people aged 18-30 years are working and only 4.6% in this age group are illiterate. Most of the persons in Jinja municipality work in industries, supermarkets, retail shops, service shops, markets and workshops among others since it is an urban area. Only 29.3% are engaged in either crop or livestock farming. The crops grown include maize, coffee, beans, millet, sweet potatoes and matooke. The people carry out fishing as well (Uganda Bureau of Statistics 2017).

Jinja west municipality was chosen for the study since Jinja district has a high sickle cell trait prevalence of 18.9% and it is among the fourteen districts with a high sickle cell disease burden (Emorut, 2015), yet from an earlier study that was done in Uganda by Okwi et al., (2009), only 3.6% of respondents from the east had screened for SCT| with only 1.4% knowing their sickle cell genotype.

3.4. Study population

3.4.1. Target population

The target population included all the youth starting from 18 years of age to 30 years that were living in Jinja west municipality.

3.4.2. Accessible population

The youth in the different communities found in Jinja west municipality that fall in the age group of 18 to 30 years and were available during the study period.

3.5 Eligibility criteria

3.5.1 Inclusion criteria

The study included youth aged 18-30 years, both male and female, Ugandan or not, who had been staying in Jinja west municipality for at least 3 months at the time of the study and willingly consented to participate in the study.

3.5.2. Exclusion criteria

Youth who met the inclusion criteria but unfortunately were mentally ill, blind, or sick at the time of the study were excluded.

3.6 Sample size determination

The minimum sample size for the study respondents was calculated using a sample size formula developed by Kish and Leslie that is given below (Kish and Leslie, 1965).

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

Where:

n = minimum sample size required.

Z = is the required Z-value in 2 tails at $\alpha = 0.05$ which is approximately 1.96 given a 95% confidence interval.

d =level of precision whose value in this proposal is 0.05.

P = was taken as 0.5 because there was no documented literature about knowledge and attitudes of youth towards sickle cell trait testing at the time of proposal development.

Thus from the formula stated above;

$$n = \frac{1.96^2 \times 0.5 (1 - 0.5)}{0.05^2}$$

$$n = \frac{3.8416 \times 0.5(0.5)}{0.0025}$$

$$n = \frac{0.9604}{0.0025}$$

$$n = 384 \text{ participants.}$$

Therefore the minimum sample size that was required for the study was 384. To cater for non-respondents, the minimum sample size was adjusted by 4.2%.

$$\frac{4.2}{100} \times 384 = 16.128 \text{ respondents}$$

An additional 16 respondents plus 384 respondents adds up to a total of 400 respondents, which was the total number of respondents sampled in the study.

3.7 Sampling method

Probability sampling methods were used to select the study population. Six parishes constituting Jinja west municipality were sampled and 1 village was selected from each parish as a cluster to

represent all the villages in that parish. This led to a total of 6 villages representing all the 21 villages that are found in Jinja municipality west. Eligible youth who were residents in the selected villages were approached using simple random sampling until the total number of 400 respondents required for the study was attained. A minimum of 66 youth was obtained from each of the representative villages. Places that were surveyed are areas where youth often congregate and these included trading centres, markets, passers-by, shops, stores, sports fields, offices, and homes. The data was collected by the researcher and her three assistants for one week.

3.8 Study variables

3.8.1. Dependent variables

The dependent variable in this study was sickle cell trait testing among the youth of Jinja west municipality, Jinja district.

3.8.2. Independent variables

The first independent variable was knowledge about sickle cell trait testing among the youth of Jinja west municipality whereas the second independent variable was attitudes towards sickle cell trait among the youth of Jinja west municipality. Knowledge about SCT testing was obtained on different attributes that included awareness about SCD/ SCT, how is it transmitted, its prevention as well as awareness about SCT testing. Attitudes towards SCT testing included; use of test for prevention of SCD, perceived benefit of testing, perceived barriers to testing and if screening for SCT should be universal.

3.9 Data collection tools

Data was collected using a standardized questionnaire. This was administered to the study participants by the researcher and her trained assistants. The questionnaire was organised in accordance with the study objectives and consisted of four sections; 1) socio demographic details, 2) uptake of sickle cell trait testing services 3) knowledge about SCT testing, and 4) attitude towards SCT testing by the youth of Jinja west municipality. Most of the questions were

closed ended and the youth had to tick an option that best applied to them. A few open ended questions were included so that they can capture responses that cannot be obtained from closed ended questions. Attitude questions were assessed using a five point Likert scale.

The questionnaire was first pre-tested in Goma division in Mukono district to assess for its validity and reliability. Validity was checked by consistence of responses; whereas reliability was assessed using the test-retest method. Majority of the questionnaires were written in English with a few translated into Lusoga, the most spoken local language within the area.

3.10 Data collection procedure

Clearance and introduction letters were acquired from International Health Sciences University (IHSU) after which they were taken to Jinja Municipal Council offices for permission and clearance to carry out the research in their area. Three research assistants were selected from Jinja municipality and were personally trained by the researcher and showed how to collect data and handle the different aspects of the study.

The youth in the different communities were approached by the researcher or her assistants, explained to the purpose of carrying out the study, the procedure and any concerns explained. Those that agreed to participate in the study were asked to consent by either a signature or thumb print after which they were asked to personally answer the questionnaire. Questionnaires were checked for completeness before being collected back and taken for storage. Meetings between the researcher and the assistants were held after every day of data collection so the questionnaires can be handed over to the researcher and any challenges faced addressed.

3.11 Data Management

Questionnaires were received back and checked once again for completeness of information so as to ensure reliability by the researcher. They were then be stored by the researcher in a safety locker and would only be taken out again when the data was going to be fed into a computer system for better storage and later on analysis.

3.12 Data processing and analysis

The stored data was cleaned, coded and entered for analysis in the Statistical Package for Social Sciences (SPSS) version 20. Social demographic information was analysed to provide a descriptive basis for the study in form of frequencies and percentages. Summaries and averages were made to obtain knowledge and attitude scores. Knowledge scores were computed using the mean of the correct answers as; 0% - 25% = poor knowledge, 26% - 50% = fair knowledge, 51 - 75% = moderate knowledge and 76% - 100% = good knowledge.

Attitudes were measured using a 5 point likert scale that was scored as; strongly agree (5), agree (4), uncertain (3), disagree (2) and strongly disagree (1). A mean score in the range of 1.0-1.75 was interpreted as a very negative attitude; 1.76-2.5 (negative); 2.51-3.25 (neutral); 3.26-4.00 (positive); 4.01-5.00 (very positive).

3.13 Quality control issues for field data

The questionnaires were pre-tested among 10 individuals in Goma division found in Mukono district because it has a similar setting. This was to make sure the questions are easy to interpret and would be able to capture all the necessary information needed by the researcher in line with the study objectives. All necessary corrections depending on the pilot study results were made before the questionnaire was finally released for use in the community survey so as to ensure that accurate and reliable information was captured. The questions were individually answered by each of the youth. The researcher or her assistants would only come in to explain any questions that might have been a bit unclear as indicated by the study respondents.

Three data assistants were personally trained by the researcher so that they could help in administering the questionnaires. All questionnaires were checked for completeness before they were collected back and the information later fed into a computer system for storage by the researcher, while the hard copies were stored away safely in a locker.

3.14 Ethical issues

An introduction and clearance letter indicating the study purpose was obtained from the School of Nursing at IHSU, after which clearance was obtained from the Jinja municipal council before the study was carried out. Only the youth who willingly accepted to answer the questionnaire after the study purpose had been explained, were allowed to fill the consent form and those who were not willing to voluntarily participate in the study were allowed to freely drop out of the study. All data collection tools and the information there in contained were kept confidential by using codes so as not to reveal participants' identities. Informed consent was obtained from all the study participants before beginning of the study.

3.15. Plan for dissemination of the study results

The study results were compiled into a dissertation that will be given to the School of Nursing at IHSU. A copy of the results in report form shall be sent to Jinja municipality so that an appropriate action can be taken. The researcher will also keep a personal copy of the results. The results of the study will as well be presented in conferences, workshops and some peer reviewed journals.

CHAPTER 4: RESULTS

4.0 Introduction

This chapter contains the results from the study. The study investigated the knowledge and attitudes of the youth towards sickle cell trait testing. These youth were aged 18-30 years and had been living in Jinja west municipality. The study had three objectives and they included determining the level of uptake of sickle cell trait testing services among the youth, assessing their knowledge about sickle cell trait testing and determining their attitudes towards sickle cell trait testing. The results are presented below in accordance with the study objectives.

4.1 Social Demographic Information of the study population

The population that was surveyed in this study was the youth aged 18-30 years and the total number of people surveyed was 401. Of the 401 people, 52.9% were males and 47.1% females. Majority of these youth were within the age group of 18-21 years (40.1%) and 22-25 years (33.2%). The most dominant religion was the Anglicans (31.7%) while other religions made up only 13% of the population. About two thirds of the youth (64.1%) identified as single while only 29.4% were married. A fair percentage (43.4%) had studied up to secondary school and only 3.7% had not attained any form of formal education. In terms of employment status, 36.7% of the participants were students, with only 14% being unemployed. Close to three quarters (70.8%) had none to one child with only 2.5% having 6 or more children. More details about the social demographic information of the participants follow in Table 1 below.

Table 1: showing the socio-demographic details of the youth

Variable		Frequency (n=401)	Percentage (%)
Gender	Male	212	52.9
	Female	189	47.1
Age	18-21	161	40.1
	22-25	133	33.2
	26-30	107	26.7
Religion	Catholic	112	27.9
	Anglican	127	31.7
	Muslim	110	27.4
	Others	52	13.0
Marital status	Single	257	64.1
	Married	118	29.4
	Cohabiting	17	4.2
	Divorced	5	1.2
	Widowed	4	1.0
Education Level	No formal education	15	3.7
	Primary	56	14.0
	Secondary	174	43.4
	University/Tertiary	156	38.9
Occupation	Unemployed	56	14.0
	Student	147	36.7
	Self employed	134	33.4
	Formal employment	41	10.2
	Casual labourer	23	5.7
Number of children	0-1	284	70.8
	2-3	75	18.7
	4-5	32	8.0
	6 and above	10	2.5

4.2 Uptake of sickle cell trait testing services among the youth aged 18-30 years in Jinja west municipality.

Regarding sickle cell trait testing, only a quarter (24.7%) of the youth had tested for sickle cell trait at the time of the study while 75.3% had not tested as shown in figure 2.

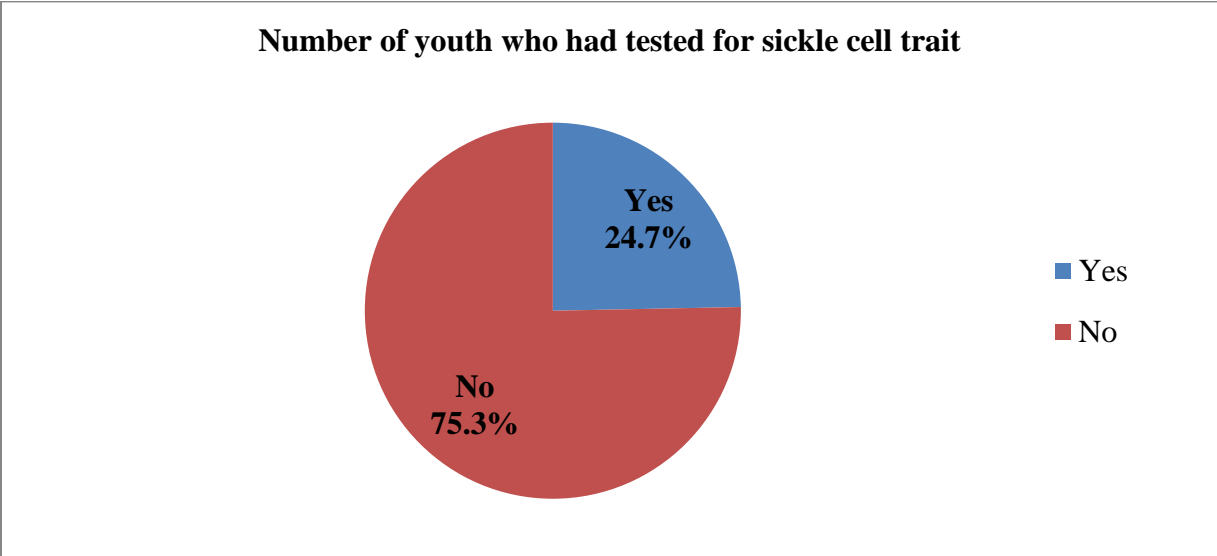


Figure 2: showing the number of youth who had ever tested for sickle cell trait.

Of the 99 youth that had tested for SCT, 79% had tested at a hospital, 12% at the clinic, 4% at schools, 2% at health camps and 2% claimed to have been tested by a traditional healer as shown in Figure 3 below.

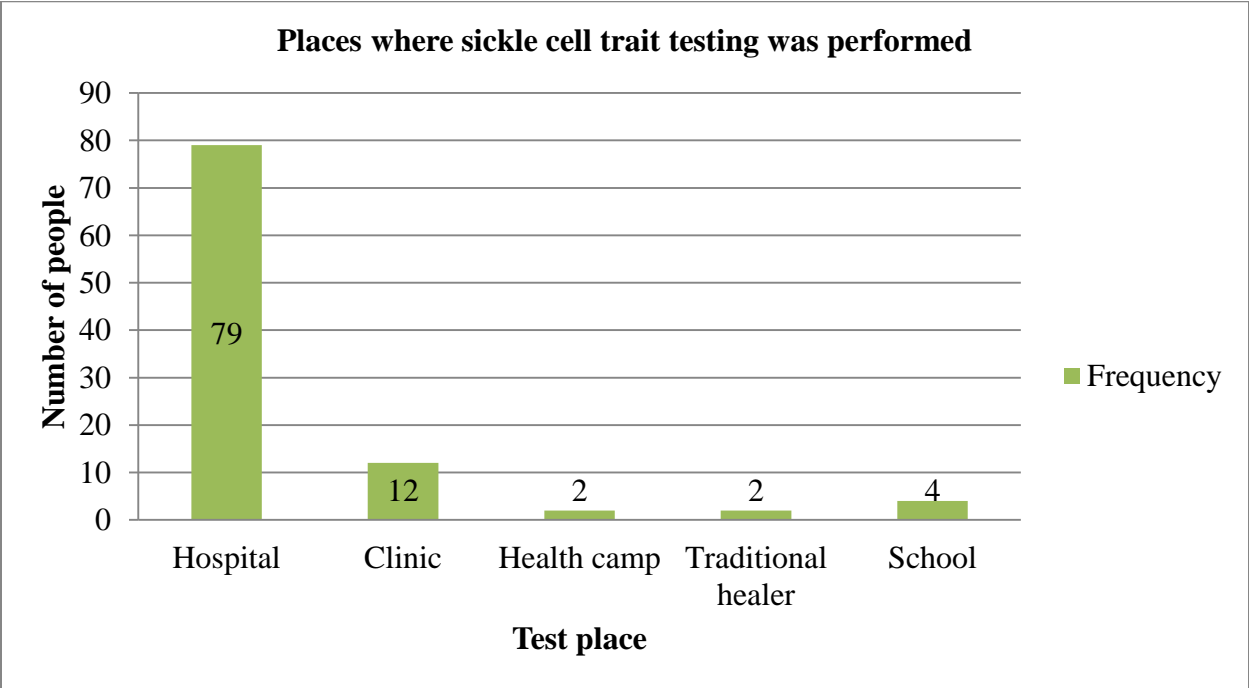


Figure 3: showing the places where the youth that had tested for SCT had tested from.

4.3 Knowledge about sickle cell trait testing among the youth aged 18-30 years in Jinja west municipality.

In this study, the youth were interviewed about their knowledge on SCD and sickle cell trait testing. This is because having knowledge about SCD would likely determine the youth's awareness about sickle cell trait testing. As shown in table 3, most of the youth (89%) had heard about SCD with 54.4% saying it is a condition that affects the RBCs. Majority (77.6%) of them knew that it is genetically transmitted with 40.4% being aware that it is common among black people and 78.3% of them stated that SCD is incurable.

Table 2: showing participants knowledge about sickle cell disease

Variable		Frequency (n=401)	Percentage (%)
Awareness about Sickle cell disease	Yes	357	89.0
	No	44	11.0
Awareness about any family member with Sickle cell disease	Yes	102	25.4
	No	299	74.6
Knowledge about Sickle cell disease	A condition that affects red blood cells	218	54.4
	Inability to walk	55	13.7
	A condition that affects the lungs	17	4.2
	Don't know	111	27.7
Knowledge about transmission of Sickle Cell Diseases	They are contagious; like cough and flue	16	4.0
	Witch craft	3	0.7
	They are inherited by the children from their parents	311	77.6
	Don't know	71	17.7
Category of people in whom sickle cell disease is most common	Boys	102	25.4
	White people	37	9.2
	Girls	100	24.9
	Black people	162	40.4
Knowledge of whether Sickle cell disease is curable	Yes	87	21.7
	No	314	78.3

The average score for knowledge about SCD among the youth was 56.62% which signifies moderate knowledge about the disease.

Knowledge was scored using the mean of the correctly answered questions and the following scale was used: 0% - 25% = poor knowledge, 26% - 50% signifies fair knowledge, 51 - 75% = moderate knowledge and 76% - 100% = good knowledge.

Regarding knowledge about sickle cell trait testing, majority of the youth (71.6%) were aware that testing for sickle cell trait existed as shown in figure 4. The major sources of information about sickle cell trait testing included the radio (42.9%), hospital (15.7%) and television (14.6%), also shown in figure 5. About a half of them (54.9%) knew that a blood sample is the specimen used in the testing. More details about their knowledge in regards to sickle cell trait testing are given in Table 3.

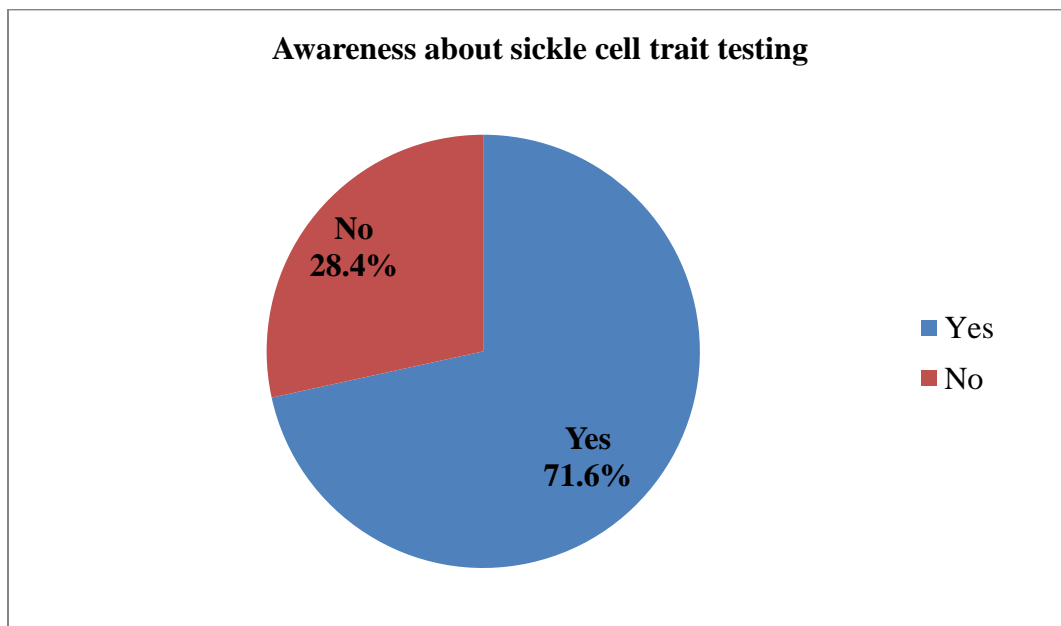


Figure 4: showing the awareness of the youth with regards to sickle cell trait testing

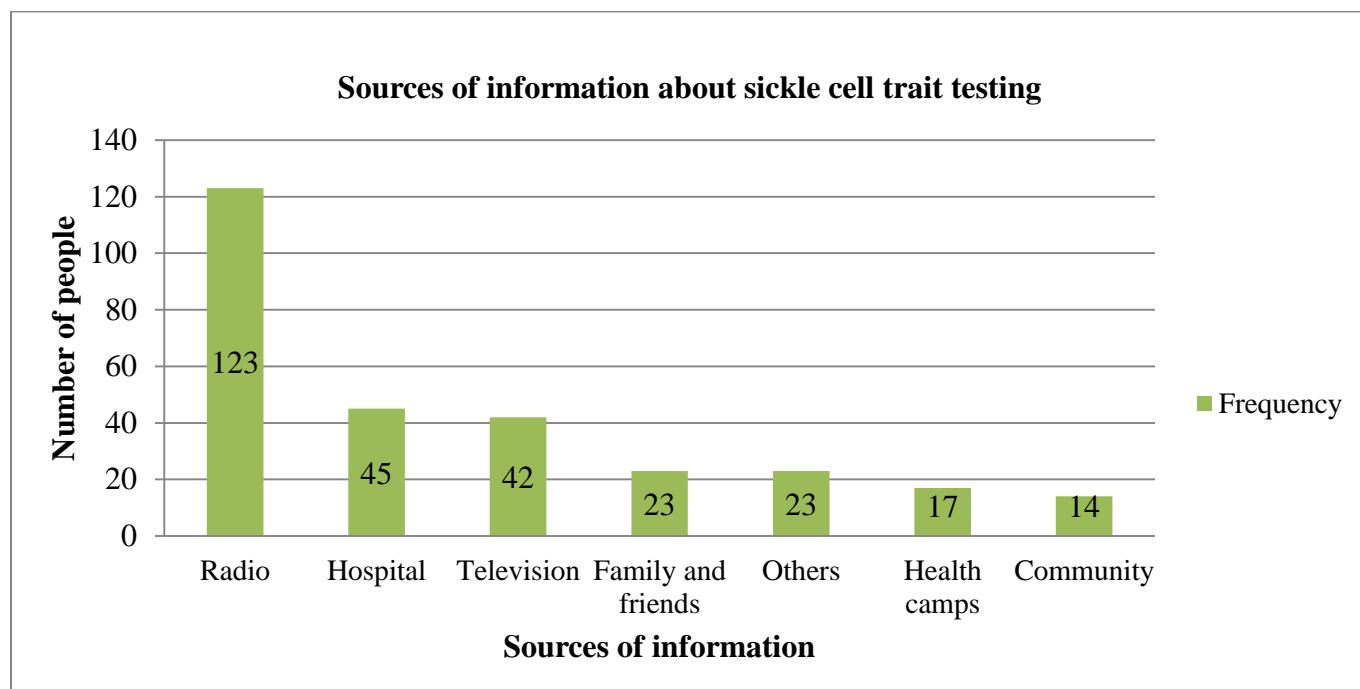


Figure 5: showing the sources of information about sickle cell trait testing.

Table 3: showing participants knowledge regarding sickle cell trait testing

Variable		Frequency (n=401)	Percentage (%)
Awareness about sickle cell trait testing	Yes	287	71.6
	No	114	28.4
Sources of information about sickle cell trait testing	Radio	123	42.9
	Television	42	14.6
	Health camps	17	5.9
	Hospital	45	15.7
	Family and friends	23	8.0
	Community	14	4.9
	Others	23	8.0
Specimen for sickle cell trait testing	Through a simple urine test	12	3.0
	One would look sick	4	1.0
	Through a simple blood test	220	54.9
	Don't know	165	41.1

The average knowledge score about sickle cell trait testing was 63.25% which signifies moderate knowledge about SCT testing.

4.4 Attitudes towards sickle cell trait testing by the youth aged 18-30 years in Jinja west municipality

The study also assessed the attitudes of the youth towards testing for the sickle cell trait. This was done through assessing their attitudes towards sickle cell trait testing as a way of prevention of SCD as well as assessing their attitudes towards the benefits of testing for SCD. The results from this assessment are given in details in table 5.

Table 4: Attitudes of the youth towards sickle cell trait testing

Variable	Frequency (percentage)					Cumulative mean score
	Strongly Disagree	Disagree	Uncertain	Agree	Strongly Agree	
Sickle cell disease can be prevented by						
Testing of both partners before marriage	21 (5.2)	5 (1.2)	12 (3.0)	234 (58.4)	129 (32.2)	4.1097
Stopping two people who both carry the sickle cell gene from having a child together	30 (7.5)	38 (9.5)	29 (7.2)	204 (50.9)	100 (24.9)	3.7631
Genetic counseling of all people who carry the sickle cell trait	14 (3.5)	10 (2.5)	23 (5.7)	238 (59.4)	116 (28.9)	4.0773
Testing in pregnancy if both parents are trait carriers	14 (3.5)	23 (5.7)	37 (9.2)	177 (44.1)	150 (37.4)	4.0623
Testing of all newly born babies	19 (4.7)	10 (2.5)	19 (4.7)	183 (45.6)	170 (42.4)	4.1845
Benefit of testing for Sickle cell trait						
It is useful to know if I have sickle cell trait	18 (4.5)	5 (1.2)	8 (2.0)	203 (50.6)	167 (41.6)	4.2369
It is useful to know if my partner has sickle cell trait	15 (3.7)	5 (1.2)	13 (3.2)	183 (45.6)	185 (46.1)	4.2918
I would encourage my partner to be tested for the sickle cell trait if I was found to be a trait carrier	17 (4.2)	10 (2.5)	24 (6.0)	177 (44.1)	173 (43.1)	4.1945
Knowing the risk of having a child with sickle cell disease would change my pregnancy plans	43 (10.7)	36 (9.0)	37 (9.2)	148 (36.9)	137 (34.2)	3.7481

More than half of the study participants agreed to testing of both partners before marriage (58.4%) and genetic counselling of all people who carry the sickle cell trait (59.4%); while about half of the youth had an opinion that two people carrying the sickle cell trait need to stopped from having a child together.

Regarding the benefits of sickle trait testing, half of the youth (50.6%) agreed that it was useful for them to know their sickle cell trait status ; but less than half (46.1%) strongly agreed to the benefit of knowing their partner's sickle cell trait status.

The attitudes of the youth towards sickle cell trait testing were scored using the following scale:

A mean score in the range of 1.0-1.75 was interpreted as a very negative attitude; 1.76-2.5 (negative); 2.51-3.25 (neutral); 3.26-4.00 (positive); 4.01-5.00 (very positive).

The overall cumulative mean score of attitude towards sickle cell trait testing as a way of prevention of SCD was very positive given a mean of 4.0394. The overall cumulative mean score of attitude towards benefits of testing was also very positive given a mean of 4.1178. This signifies that the youth had a very positive attitude towards sickle cell trait testing as a way of preventing SCD given a general overall mean attitude score of 4.0786.

This study also assessed some of the possible barriers towards sickle cell trait testing. The results are given in details in the table 6 below. From these results, an overall cumulative mean score of 3.143 was found and this suggests a neutral attitude towards the uptake of sickle cell trait testing services in general even though the youth may have a positive attitude towards sickle cell trait testing as a means of preventing SCD and appreciate its benefits. There were a number of barriers towards the actual testing for sickle cell trait that the youth identified with such as the fear that the test is painful and difficult, the fear of convincing their partners to carry out the test and stigmatization among others as shown in the Table 5.

Table 5: Perceived barriers to testing for sickle cell trait

Variable	Frequency (percentage)					Cumulative mean score
	Strongly Disagree	Disagree	Uncertain	Agree	Strongly Agree	
Testing for sickle cell trait is painful and difficult	100 (24.9)	131 (32.7)	54 (13.5)	49 (12.2)	67 (16.7)	2.6309
It will be hard to convince my partner to have the test	68 (17.0)	130 (32.4)	47 (11.7)	86 (21.4)	70 (17.5)	2.9002
I would not want to pay for sickle cell trait testing if it is not paid for by insurance or free of charge	68 (17)	79 (19.7)	62 (15.5)	129 (32.2)	63 (15.7)	3.0998
Having a sickle cell trait would make me less confident about forming relationships	45 (11.2)	50 (12.5)	72 (18.0)	148 (36.9)	86 (21.4)	3.4489
I fear being stigmatized against after the results are out	51 (12.7)	59 (14.7)	59 (14.7)	157 (39.2)	75 (18.7)	3.3641
I did not know the test for sickle cell was available	54 (13.5)	56 (14.0)	72 (18.0)	109 (27.2)	110 (27.4)	3.4115

However, this study also assessed the attitudes of the youth towards making of SCT testing widespread and found that 79.1% of them strongly agreed and were in support of SCT testing whereas only 1.2% disagreed to supporting SCT testing. Three quarters of the participants (76.6%) supported community screening of SCT with only less than one per cent (0.7%) disagreeing to community testing of SCT.

CHAPTER FIVE: DISCUSSION

5.0 Introduction

In this chapter, a discussion of the study findings in line with the study objectives and in comparison to findings from previous and related studies is presented.

5.1 Uptake of sickle cell trait testing services among the youth of Jinja west municipality

This study assessed the level of uptake of sickle cell trait testing services among the youth and found that only 24.7% of those that participated in the study had tested for SCT. Of the 99 youth that had screened, 79% had done it at hospitals, 12% at clinics, 4% at school and 2% at health camps. Interestingly, 2% claimed to have been screened for SCT at a traditional healers place. This level of uptake was low even though 71.6% of them had ever heard that testing for SCT existed with slightly more than half (54.9%) correctly knowing that a blood sample was used to carry out this testing.

Possible reasons for the low uptake could be because the youth in this study had moderate knowledge about both SCT testing and SCD with an average knowledge score of 63.25% and 56.62% respectively. The moderate knowledge levels could be why only a few had spared time to test for SCT even though 89% were aware that SCD existed and 25.4% knew of a family member that had the disease. Correspondingly, more than a quarter (28.4%) were not aware that SCT testing existed whereas 41.1% did not know that all that was needed to do the test was a blood sample.

Furthermore, 32.2% of the youth had agreed that they were not willing to pay for the test if it was not done for free while 36.9% thought that having the sickle cell trait would make them less confident about forming relationships and 39.2% feared that they would be stigmatised against if the results came back and they were found to be carriers according to the study results. It is important to note that the government provides testing free screening for SCT at all its Health Centre IVs, regional referrals and district hospitals but the private hospitals charge a fee.

Similar results were seen in a study involving adults in Oman whereby only 24.4% of these adults had screened for SCT even though screening was for free at the primary health care centres in this area and 85.1% believed that screening for SCT before marriage was valuable. Reasons for the low uptake included: more than a half (56.7%) of the participants stated they did not receive enough information about SCD from the various communication channels, 34.9% believed the testing to be painful and difficult and 40% were not aware that they simply used a blood sample to screen for SCT (Al-Azri et al., 2016).

When compared to results of a different study that was carried out in western Sudan, the current study reports slightly higher uptake of sickle cell trait testing among the youth. In the Sudanese study, only 6.1% of the parents had screened for SCD which is not astonishing given that 46.9% of the respondents had poor knowledge about SCD with only 31.3% agreeing that it was advantageous to know his/her carrier status and that of their partner (Daak et al., 2016); where as in the present study, youth had moderate knowledge about sickle cell trait testing.

Another study carried out in Uganda that involved a sample of adults from the east and west showed that only 2.54% of them had screened for SCT. Sadly, only a half of the health workers involved in the study correctly knew the available methods of screening for SCD and the district hospitals were not offering SCT screening services. It was also noted that a few of the respondents assumed SCD to be similar to HIV and thus alleged that they would have been stigmatised if they screened and the results came back as positive. It is thus not surprising that such a small number had screened for SCD with such findings (Okwi et al., 2009).

On the contrary, a high uptake of screening services was recorded in other studies for example, 72.6% of the adults in Albaha, Oman had screened for SCT and it was because a good number (68.8%) were quite knowledgeable about SCD (Alghamdi et al., 2017). Additionally, 39.1% of the university students studying at the university of Ghana had screened for SCT majorly because the screening had been provided to them for free, or because the results were needed prior them getting married or before being admitted into an institution (Boadu and Addoah, 2018).

According to the study results, since only 24.7% of the youth had screened for SCD, it means that more than three quarters are still unaware of their sickle cell status and thus there are higher

chances that these will unknowingly marry or have a child with someone who also is unaware of the status and they might unfortunately end up having a child with SCD in the case both of them were carriers of the SCT. Therefore continuous sensitization of communities about SCD and the importance of sickle cell trait testing is required in order to improve the uptake of SCT testing services in the different communities.

5.2 Knowledge about sickle cell trait testing among the youth in Jinja west municipality.

The knowledge of the youth in regards to SCD and sickle cell trait testing was assessed and the results showed that overall, the youth had moderate knowledge about SCD with an average knowledge score of 56.62%. Nearly all (89%) of the youth had ever heard of SCD prior to the study. This could have been due to the fact that 25.4% knew of a family member with SCD whereas some said they knew of a friend, classmate or someone in the community who had SCD. Plus, nowadays information about SCD is being passed onto community members via a number of channels that include radio (49.2%), television (14.6%), hospital (15.7%), family and friends (8%) and the community (4.9%) among others as shown in this study.

Having some moderate knowledge about the disease could likely explain the moderate awareness that the youth had regarding sickle cell trait testing as 72% reported knowing that SCT testing existed and more than a half (54.9%) of the youth correctly identified that a blood sample was used to test for SCT although close to a half (41.1%) admitted that they did not know and only 3% claimed it was done using a urine sample. Of those who knew how screening was done, a quarter had actually tested for SCD and the others had been well informed since they were aware that SCT exists. Of those that did not know, nearly a third (28.4%) of them had never heard of SCT testing whereas the others could have probably had less information about the testing given the moderate knowledge scores about the disease and the testing as is seen in the results.

Surprisingly, in another study carried out among secondary school students, only 2 of them were aware that a blood sample was used for the test even though in spite of the fact that 59.2% had tested for SCT. About a half (43.1%) wrongly stated that a urine sample was used to screen for SCD yet 36.5% had got their information about SCD from health workers and 18.2% from family. This was attributed to the fact that SCD screening is one of the requirements before

entering a secondary school in Nigeria and because a number of different samples are taken off at around the same time so that many tests can be done at once, the students may have failed to know which particular sample was used in the screening (Olakunle et al., 2013).

In Albaha, only 17.5% of the Saudi adults identified that a blood sample is used to identify SCD even though 51.4% had good knowledge about SCD (Alturaifi et al., 2018). Considering that fact that a good number of the study participants do not have an idea about the screening process, this could be a possible barrier to screening for SCD since it could lead to some thinking it is painful or difficult.

An assessment to find out if the youth had ever heard of SCT testing revealed that 71.6% of them said yes and these had got this information majorly from the radios (42.9%), hospital (15.7%) and television (14.6%). Lesser information sources included: health camps (5.9%), community (4.9%), family and friends (8.0%) among others. This was attributed to the fact that 32.5% of the households in the municipality use a radio as the main source of information with 56.9% of them owning radios and 49.9% owning televisions (UBOS, 2017).

However in a similar study carried out in Uganda, it showed that newspapers, television, health workers and the community provided most of the information about SCD in urban areas compared to radio and health visitors in rural areas (Okwi et al., 2009). Elsewhere in Ghana, the university students got information about SCD and its screening majorly from schools (84.6%) and 12.6% got it from radio and television (Boadu and Addoah, 2018). Basing on the study results, if any information or education about SCD needs to be passed onto the people, they should consider fully utilising radios, hospitals and television.

5.3 Attitudes towards sickle cell trait testing among the youth of Jinja municipality west

The youth had a very positive attitude towards sickle cell trait testing as a way of prevention of SCD at an overall cumulative mean of 4.0394 out of 5. More than a half (58.4%) of the youth agreed that testing of both partners before marriage is important in preventing SCD with only 1.2% disagreeing. Close to two thirds (59.4%) of the youth agreed that genetic counselling of all people that carry the SCT can prevent SCD compared to only 2.5% that disagreed. Nearly a half

(44.1%) agreed that testing of the foetus during pregnancy in the case that both the parents carry the SCT can prevent SCD however 3.5% strongly disagreed to this. About two quarters (45.6%) were in agreement that testing of all newly born babies for SCD can prevent SCD unlike the 2.5% that disagreed against it. Such a very positive attitude towards prevention of SCD was because most of the youth believed that testing for SCD empowers the person to make an informed decision basing on the results attained. Some youth said if the test results are positive, and a partner is involved, the relationship might end and if it is a child, s/he will go for treatment. A few of those not in favour of prenatal diagnosis mentioned that since the child is already formed, why go ahead and terminate the pregnancy whereas others said abortion is risky and they do not want its complications.

Similar results in regards to prevention of SCD were seen in a study carried out in Nigeria that involved secondary school students whereby 40.2% of them said genetic counselling prevents SCD and 51.9% advised couples where both partners carried the SCT to go for genetic counselling before continuing with their relationship (Olakunle et al., 2013). Whereas in Uganda, 51.6% of the respondents in a similar community study identified that SCD can be stopped if both partners are tested before marriage (Okwi et al., 2009).

Lower results were however seen in a few studies done in India. One study that involved only carriers and sicklers highlighted that only a few of these participants believed that SCD can be prevented by both pre-marital screening (19%) and pre-natal diagnosis (15.53%). They also suggested for new born screening to be widespread (Patil et al., 2017). Such low results towards prevention were surprising given that majority of these participants only carried the SCT and close to two thirds were married. Another study carried out amongst secondary school students in Nepal showed that 31% of them supported genetic screening and counselling among people of the reproductive age with 30.3% of them stating that all babies born should be screened for SCD (Ghimire, 2016).

Considering the fact that many of the youth in the current study had a positive attitude towards the prevention of SCD and many were willing to carry out premarital screening and undergo genetic counselling, these two should find a way of being incorporated into the health care

system in this area. New born screening should also be put into consideration as one of the means of eradicating SCD.

The youth had a very positive attitude towards the benefits of testing for SCD with an overall cumulative mean of 4.1178 out of 5. A half (50.6%) of the youth in this study agreed that it was beneficial to know if s/he carried the SCT while only 2% disagreed to this. Close to one half (46.1%) strongly agreed and only 1.2% disagreed that knowing their partners SCT status was useful to them. When these same youth were asked if they would encourage their partner to be tested for the sickle cell trait if they were personally found to be a trait carrier, 44.1% agreed and only 2.5% disagreed. One third (36.9%) agreed that knowing the risk of having a child with SCD would change their pregnancy plans with their partners with only 9% disagreeing to this.

Results higher than what was got in this study were seen in a study carried out in Oman where 80.7% of the adults said it was useful to find out their SCT status, and that of their partners (77.8%). About two thirds of them said the number of children they shall have will change if there is a possibility of having a child with SCD (Al-Azri et al., 2016). Lower results were seen in a Nigerian study involving nursing students in a nursing school. It showed that 16.3% of them said testing enables the person to find out their SCT status and 7.2% said it stops the person from marrying someone of an incompatible status. More than a third said that testing makes carriers of the SCT aware that they can pass on this trait to their children (Isah et al., 2016).

Since many of the youth in the current study found SCT testing to be beneficial, this means there is hope that many of them will most likely eventually screen for the disease if they are properly educated about SCD, the screening process and where these services are offered.

Whereas there was an overall positive attitude towards sickle cell trait testing as a way of preventing SCD and also the benefits of SCT testing were appreciated, the attitudes towards uptake of sickle cell trait testing were neutral, which is attributable to the different fears the youth had with regards to sickle cell trait screening. It was discovered that the youth strongly agreed to the following; that testing is painful and difficult (16.7%), 17.5% had the fear of convincing their partners to have the test, 15.7% would not want to pay for the test if it is not paid for by insurance or offered free of charge, 21.4% would be less confident about forming relationships, 27.4% didn't know that the test is available, and more than a third (39.2%) agreed

that they feared being stigmatized against after the results are out and they happened to be positive for the SCT.

African American women in a similar study in the USA did not perceive screening to be painful and difficult to screen (2.18), or it being hard to convince their partners to screen (2.10) and a good number were willing to pay for the test (2.59) (Gustafson et al., 2007). Correspondingly, only 36% of the Omani adults thought the process of screening for SCT was difficult and painful while only 37.8% stated that it would be hard to convince their partners to screen for SCT (Al-Azri et al., 2016). A study in Nigeria showed that 75.8% of the nursing students in Sokoto said the community is not aware of SCD or its screening and that is why many have not screened (Isah et al., 2016) while in a study done in Uganda, the eastern respondents supposed SCD was similar to HIV/AIDS and they thus did not want to be stigmatised against in the case of a positive screening result (Okwi et al., 2009).

If the people in the community continue living in fear of being stigmatised or losing their self-confidence because of a positive SCT testing result, many will not test for SCD. Also, since many people did not know about the test or where it is offered preferably for free, many will still not screen for SCT so community sensitisation about SCT testing is needed.

It was good to note though that the majority (79.1%) of the youth agreed and were in support of SCT testing while only 1.2% disagreed and were not in favour of it. Similarly, 76.6% of the youth were in support of community testing of SCT whereas less than one per cent (0.7%) disagreed to community testing of SCT. Similar results were seen in a study involving Jamaican adolescents in which 93% of them believed SCT testing is important for everyone and they recommended screening services be made accessible to all persons (Bhatt et al., 2011) whereas in a study carried out in western Sudan, 73.1% of the parents were of the view that all family members should be screened for SCD (Daak et al., 2016).

In view of the fact that many of the youth were in favour of both SCT testing and Community testing of the SCT, mass SCT testing within the community will most probably be successful if it is tried out and this could be a major step in preventing SCD.

5.4 Limitations of the study

This study had some limitations that need to be mentioned.

1) Recall bias.

The researcher relied solely on the information from the study participants and thus there could be a possibility that the respondents could have forgotten some information that is important in the study and could potentially influence the outcome of the study.

2) Self-report bias.

The participants were taken through and were allowed to fill the questionnaire by themselves. This may come along with the problem of having the wrong information presented simply because the participants have an idea of what is expected by the researcher. Yet it was not possible for the researcher to validate information about uptake of sickle trait testing by the youth.

CHAPTER SIX: CONCLUSIONS AND RECOMMENDATIONS

6.0 Introduction

This chapter includes the conclusion of the study and recommendations to the different stakeholders basing on the study results.

6.1 Conclusions

The level of uptake of sickle cell trait services was low with only close to a quarter of the youth having tested for SCT.

Participants had moderate knowledge about SCD with a knowledge score of 56.6%, and moderate knowledge about sickle cell trait testing with a knowledge score of 63.3%, although 72% were aware that sickle cell trait testing existed.

It was discovered that the participants had a very positive attitude towards SCT testing as a means of preventing SCD and appreciated the benefits of SCT testing, however the general attitude towards the uptake of sickle cell trait testing was neutral. However, it was good to note that majority (79%) were in support of SCT testing.

6.2 Recommendations

The researcher would like to make the following recommendations basing on the results from the study

To the district health team

More rigorous approaches of educating people about should SCD, SCT and provision of lists of the public hospitals where the testing services are provided should be considered. It is also important that emphasis is made about the availability of these services at a free cost since many youth thought that they had to pay for the services.

Premarital/ pre-conception screening of SCT should be made official after educating the people so that fewer new-borns are born with SCD.

Health workers within the municipality should be better educated about SCD and encouraged to include SCD and the importance of SCT testing among the health education they provide to their patients.

To the community leaders

They should sensitise the youth about the importance of health education.

This can be done using various mediums of communication such as radio stations, television stations and hospitals within the area as a means of passing on education about SCD and SCT testing plus the importance of screening for SCT to the community members so as to increase their knowledge levels and improve uptake of the screening services.

Education about SCD, SCT testing and the benefits of testing can be further targeted for particular groups like students in secondary schools, universities and community centres.

Recommendations for further studies

This study was done in Jinja west municipality thus the results may not be generalised to other populations in Uganda. Therefore other studies determining the knowledge and attitudes of youth towards sickle cell trait testing are recommended in other areas of Uganda.

Additionally, studies concentrating on determining knowledge about SCD, its presentation, transmission, complications and prevention should be carried out. These may address gaps related with knowledge about SCT testing.

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APPENDIX I

CONSENT FORM (English Version) KNOWLEDGE AND ATTITUDES TOWARDS SICKLE CELL TRAIT TESTING AMONG THE YOUTH AGED 18-30 YEARS IN JINJA WEST MUNICIPALITY

Warm greetings to you, I am called Nabwire Betty Lynn, a nursing student at International Health Sciences University found in Namuwongo, Kampala. Currently, I am finalising my Bachelors in Nursing Science Degree at the said university. I am kindly requesting you to participate in the above mentioned research study that is being conducted by me in partial fulfillment for the award of a Degree in Nursing.

Purpose of the study

The purpose of this study is to determine the knowledge and attitudes towards sickle cell trait testing among the youth (ages 18-30 years) of Jinja west municipality.

Procedure; this questionnaire contains a number of questions that will assess your level of knowledge and attitudes towards sickle cell trait testing. The questionnaire was designed to be brief and not take more than 10 minutes of your time.

Benefits; the information obtained from this study will be used to enhance health delivery services on sickle cell trait testing so that sickle cell disease can be prevented and the number of people affected from it reduce. The study findings will be used by relevant authorities like the Ministry of Health Uganda and the district health department in health service planning so as to improve sickle cell trait testing services. Other NGOs that are interested in sickle cell disease can also use the study findings.

Voluntary participation; you can feel free to withdraw from this study at any point in time. There are no financial rewards for participating in this study and that all information gathered from this research study will remain confidential to only the researcher because your identity will remain unknown.

You can contact me on +256703467342 in case of any concerns about the study.

PARTICIPANT INFORMED CONSENT

Signing in the space provided below shows that you have read and clearly understood the information that has been provided above and that you are freely accepting to participate in this study.

Your signature

Date.....

Signature of interviewer

Date.....

APPENDIX II

QUESTIONNAIRE (English Version)

Thank you for accepting to fill in this questionnaire. It consists of four sections. Kindly fill in all the sections appropriately as given by the instructions. Questions will be answered by either ticking the answer you choose or writing in the provided space.

Code no. _____

SECTION 1: SOCIO-DEMOGRAPHIC DATA

Please Tick The Answer Which Best Applies To You And Fill In Suitably Where Applicable.

1. Gender

Male

Female

2. How old are you?

18-21

22-25

26-30

3. What is your religion?

Catholic.

Muslim

Protestant

Others-specify

4. What is your current marital status?

Single

Cohabiting

Widowed

Married

Divorced

5. What is your highest level of education?

No formal education

Secondary.

Primary.

University/Tertiary

6. What is your current occupation?

Unemployed

Student

Self employed

Formal employment

Casual labourer

7. How many children do you have?

0-1

2-3

4-5

6 and above

SECTION 2: UPTAKE OF SICKLE CELL TRAIT TESTING

Tick only one box for every question according to what you know.

1. Have you ever tested for Sickle cell disease?

Yes

No

2. If yes, where was the test done from?

Hospital

Clinic

Health camp

Traditional healer

School

Others (specify)_____

SECTION 3: KNOWLEDGE ABOUT SICKLE CELL TRAIT TESTING.

Tick only one box for every question according to what you know.

3. Have you ever heard of Sickle cell disease?

Yes

No

4. Have you had a previous experience with a family member with Sickle cell disease?

Yes

No

5. What do you know about sickle cell trait?

A condition that affects red blood cells

A condition that affects the lungs

Don't know

Inability to walk

6. How do people get the sickle cell diseases?

They are contagious; like coughs and flue

They are inherited by the children from their parents

Witch craft

Don't know

7. Sickle Cell Disease occurs most often in

Boys

Girls

White people

Black people

8. Is sickle cell disease curable?

Yes

No

9. Have you ever heard of sickle cell trait testing?

Yes

No

10. If you said yes, what were the sources of information about sickle cell trait testing?

Radio

Magazines / newspapers

Television

School

Health camps

Family

Posters / fliers

Hospital

Friends

Community

Social media

Others (specify)_____

11. How do they test for sickle cell trait?

Through a simple urine test

Through a simple blood test

They look sick

Don't know

SECTION 4: ATTITUDES TOWARDS SICKLE CELL TRAIT TESTING

Please read each question very carefully and then tick only one of the following options; strongly disagree, disagree, uncertain, agree, and strongly agree.

Question	Strongly Disagree	Disagree	Uncertain	Agree	Strongly Agree
Sickle cell disease can be prevented by					
Testing of both partners before marriage					
stopping two people who both carry the sickle cell gene from having a child together					
Genetic counseling of all people who carry the sickle cell trait					
Testing in pregnancy if both parents are trait carriers					
Testing of all newly born babies					
Benefit of testing for Sickle cell trait					
It is useful to know if I have sickle cell trait					
It is useful to know if my partner has sickle cell trait					
I would encourage my partner to be tested for the sickle cell trait if I was found to be a trait carrier					
Knowing the risk of having a child with sickle cell disease would change my pregnancy plans					

Barriers to testing for sickle cell trait					
Testing for sickle cell trait is painful and difficult					
It will be hard to convince my partner to have the test					
I would not want to pay for sickle cell trait testing if it is not paid for by insurance or free of charge					
Having a sickle cell trait would make me less confident about forming relationships					
I fear being stigmatized against after the results are out					
I did not know the test for sickle cell was available					
Should screening for sickle cell trait be made widespread					
I support sickle cell disease carrier testing					
I support sickle cell disease carrier testing for all communities					

Thank you so much for participating in this study

APPENDIX III : CONSENT FORM (LUSOGA VERSION)

OKWIKANA

ENTEGETELA NENDOWOZA ERY OKWEKEBEZA OBULWAILE BWA SIKOSELO MUBAVUBUKA ABALINA EMYAKA 18-30 MU MINISIPALITIY OBUGWANDUBA BWA IDHINDA

Mbalamwisaiino amainagange ninze Nabwire Betty Lynn inga ndimusomi mwitendekelo lyabasawo enaamuwongo, ekampala. Mukaseela kano ndikumaliliza okusoma kwange era ndi mumwaka gwange ogusembayo. Ndikusaba bamwenhigilemu okunoneleza kwendikwenda omalilize okusoma kwange.

Ensonga yo kunoneleza kuno

Ensonga yo kunoneleza kuno elinti twenda kubona entegera nendowoza yabavubuka wagati wemwaka 18 na30 mu bugwanduba bwa idhinda munisipaliti eri okwekebeza obulwaile bwa sikoselo

Emitendera; Olupapula luno lulimu ebibuzo ebijjo'tuyamba ku kuzula woli mukutegela nendowozayo eli okwekebeza obulwaile bwa sikoselo. Kida kutwala dakika ntono inho nga ikumi donka.

Emigaso; ebinava mukunoneleza kuno bidakuyamba okutumbula ebyobulamu ilala okwekebeza obulwaile bwa sikoselo kiziyize obulwaile buno era kikendeze nomuwendo gwabo ababulina. Ebinava mukunoneleza bidakuba bikozezebwa abakungu mu minisitule yebyobulamu mu Uganda nebitongoole ebeli mu disitilikiti muntekateka yayo nadala okwekebeza obulwaile bwa sikoselo. Nebitongole ebitali bya govumenti byona bidakwetaga okukozesa ebinava mu kunoneleza kuno.

Voluntary participation; Oliwa i'dembe okuva mu kunoneleza kuno mukiseela kyonakyona. Era idukila inti ezila kusasulwa sente olwo kwenigira mu kunoneleza kuno. Ela ebinava mukunoneleza kuno bida kusigalanga byakyama wagati wange niwe.

Bwoba ngolina okwemulugunya osobola onkufuna kwi'simu eno 0703467342

PARTICIPANT INFORMED CONSENT (LUSOGA VERSION)

Bwotaku omukono wansi wano kitegeeza nti osomye bulungi wategela obubaka obuli mu. Ela mwene wakiliza okweginila mukunonyeleza kuno

Omukono gwo..... Enaku domwezi.....

Omukono gwomubuzi enaku domwezi.....

APPENDIX IV: QUESTIONNAIRE (LUSOGA VERSION)

EBIBUZOO

Webale iino okwikiliza okwiduuzamu ebibuzo biino. Ebibuzo bili mumitendela ehna era nkusaba okwiduzamu emitendera gyoona nga wekyeitagisa mumirembe. Ebibuzo bidakwilibwamu ngo okozesa tiiki ku ansa enttufu oba okuwandika ansa enttufu mwibanga elikuweleebwa.

Code no. _____

AWASOOKA: EBIKWOGHEELAKU

Taku tiiki ku ansayo jowulila nti ntufu oba wandika wekyetagiisa.

1. Oli muulenzi oba muwaala?

mulenzi

muwala

2. Olina emyaka emeka?

18-21

22-25

26-30

3. Oliwa idini ki?

Mukatuliki

Musilamu

Mukulisitayo

Eidini elindi.....

4. Oli mufumbo?

Tili mufumbo

Nketegeleza

Ndinamwandu
/ssemwandu

Ndi mufumbo

Twayawukana

5. Wasooma kutuka wa?

Tiwasooma ku

Siniya

Nasoma paka kyamusanvu.

Yunivasiti

6. Okola mulimu ki?

Tiikoola

Nsooma

Nkoola byenasomelera

Nekozeza

Mpakasa

7. Olina bana bameeka?

0-1

2-3

4-5

Mukaaga nokwambuka

OMUTENDELO GWOKUBILI : OKWEKEBEZA OBULWAILE BWA SIKOSELO.

Taku Tikii Okusinzila Kyo'idi.

1. Wekebezanga ku obulwaile bwa sikoselo?

Eeh

Mbee

2. Bwobanga wekebeza , wakikolelawa?

Mwidwaliro einene

Kubayiwa

Mukalwaliro akatono

Kwisoomero

Mukungana de byobulamu

Awandi wa _____

OMUTENDELO GWOKUSATU : ENTEGELAYO KU KWEKEBEZA OBULWAILE BWA SIKOSELO.

Taku Tikii Okusinzila Kyo'idi.

3. Owulilanga ku obulwaile bwa sikoselo?

Eeeh

Mbee

4. Muboluganda, waliwo eya lwala ku obulwaile bwa sikoselo?

Eeeh

Mbee

5. Kiki kyo'idi ku bulwaile bwa sikoselo?

Obulwaile obukosa abasilikale
bomumusayi

Obulwaile obukossa amawuwe

Obutasobalaa kutambula

Tiidi

6. Abantu bafuuna batya obulwaile bwa sikoselo?

Mumpewo okugezanga okukolola ne
niila

Abaana babutoola kubazaile

Eilogo

Tiidi

7. Sikoselo atela kugema bantu kika ki?

Balenzi

Bawaala

Bazungu

Bailugavu

8. Sikoselo awoona?

Eee

Mbee

9. Owulilanga ku inti bakebela obulwaile bwa sikoselo?

Eeh

Mbee

10. Bwekiba nti wawulilaku, amawulire wagafuna otya?

Kuladiyo

Mubawaka

Ku Telefayina

Mwi dwaliro

Ku nkungana de byobulamu

Mubemikwano

Ku Bitimbe

Kumikutu

Mpapula damawulile

Mubatyame bekitundu

Kwisomero

Awandi wa _____

11. Bakebeza batya obulwaile bwa sikoselo?

Bakozeza maine

Bakebeza musayi

Baboneka nga abalwaile

Tiidi

OMUTENDELA GWOKUNA: ENDOWOOZA YO ELI OKWEKEBEZA OBULWAILE BWA SIKOSELO

Sooma bulungi buli kibuzo era oteku tiiki kubino wansi; tiikiliza walewale, tikiliza, tidiwengwa, kituffu, era kituffu innho.

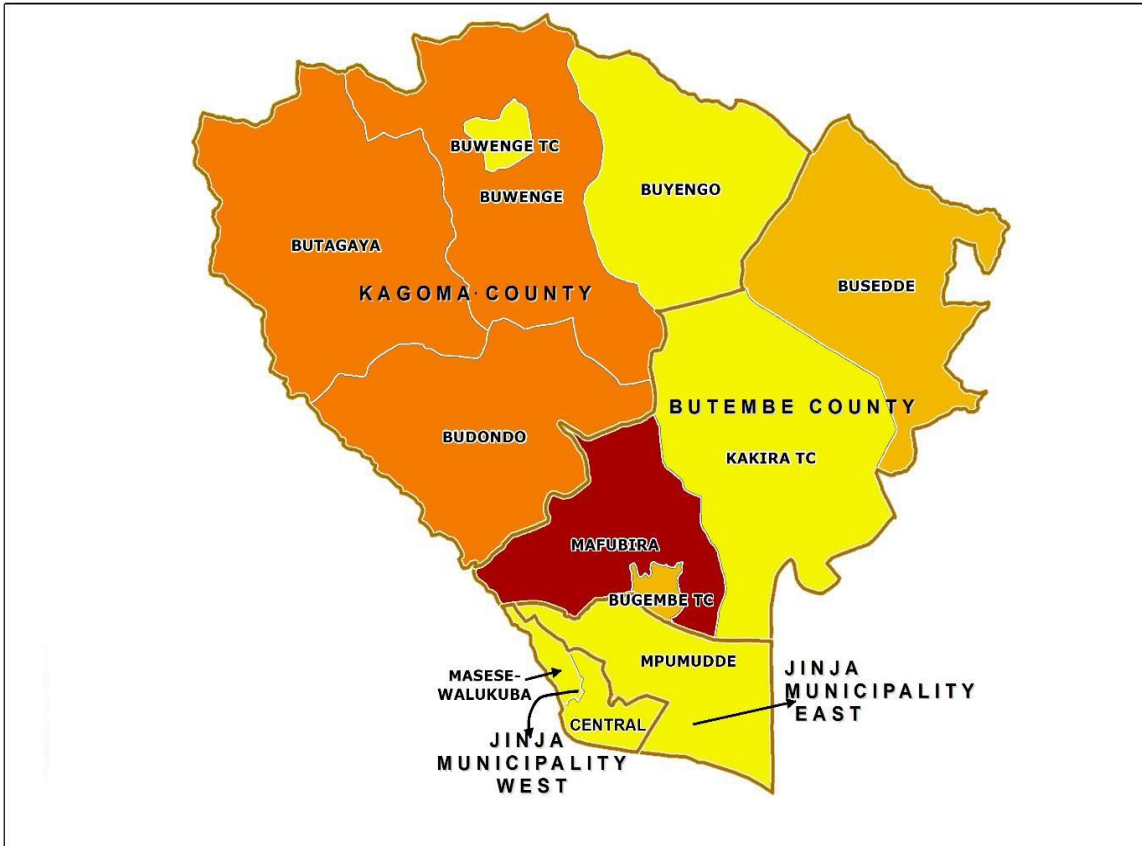
Ekibuzo	Tiikiliza walewale	Tikiliza	Tidiwengwa	Kitufu	Kituffu innho
Sikoselo bamuziyiiza batya					
okweekebezaa okwa bafuumbo nga bakaali kwewasa					
Kukoba bantu ababili abalina obulwaile buno, obutailamu okuzaala omwana bombi					
Okubudabuda ino abantu abalina obulwaile buno					
Okukebeza omukyala ngali lubuto okuzula nti abazaile bombi balina obulwaile bwa sikoselo.					
Okukebeza abaana abato abakazalibwa					
Omugaso gwokwekebeza obulwaile bwa sikoselo					
Kilungi ntegere oba ndina obulwaile bwa sikoselo oba be					
Kilungi okutegela oba omuganzi wange alina obulwaile bwa sikoselo					
Nandikubiliza musada wange okwekebeza obulwaile bwa sikoselo singa mba nekebeiza nga mbulina.					
Okutegera obuzibu obuli mukuba nomwana ngalina sikoselo kida kukyusa entekateka yange yokwilamu okufuuna olubuto.					
Ebiziyiza abantu okwekebeza obulwaile bwa sikoselo					
Okwekebeza obulwaile bwa sikoselo kiluma ate kizibu					
Kida kuba kizibu okumatiza musadawange oba mukazi wange okwekebeza.					

Tyandyenze okusasulila okwekebeza obulwaile bwa sikoselo singa kibaile tikisasulibwa bitongole oba singa tibya bwerere.					
Okuba no bulwaile bwa sikoselo, kyandibaile kiinafuuya mu kukola emikwano					
Ntya okwekebeza olwo kufuna okutya eino ngebivilemu mukukebeza bifulwuime					
Mbaile tidii nti okukebeza obulwaile bwa sikoselo kubangawo					
Tukoole ekyokwekebeza obulwaile bwa sikoselo kibe kya uganda yonayona					
Mpagila ekyokwekebza obulwaile bwa sikoselo					
Mpagila ekyo kwekebeza obulwaile bwa sikoselo mubitundu byonabyona					

Neyanziza innho okwenigila mu kunoneleza kuno

APPENDIX V: MAP

A MAP OF JINJA DISTRICT SHOWING THE LOCATION OF JINJA WEST MUNICIPALITY AND OTHER SUBCOUNTIES



APPENDIX VI: INTRODUCTORY LETTER



making a difference in health care

Office of the Dean, School of Nursing

Kampala, 25th May 2018

To THE
TOWN CLERK JINJA MUNICIPAL COUNCIL

Dear Sir/Madam,

RE: ASSISTANCE FOR RESEARCH

Greetings from International Health Sciences University.

This is to introduce to you **Nabwire Betty Lynn** Reg. No. **2014-BNS-FT-024** who is a student of our University. As part of the requirements for the award of a Bachelors degree in Nursing of our University, the student is required to carry out research.

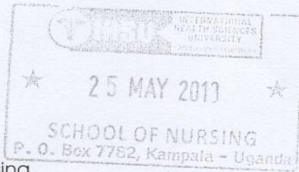
The topic of research is: **Knowledge and attitudes towards sickle cell trait testing among the youth of Jinja Municipality West, Jinja district.**

This therefore is to kindly request you to render the student assistance as may be necessary for the research.

I, and indeed the entire University are grateful in advance for all assistance that will be accorded to our student.

Sincerely Yours,

Ms. Agwang Agnes
Dean, School of Nursing



The International Health Sciences University
P.O. Box 7782 Kampala – Uganda
(+256) 0312 307400 email: aagwang@ihsu.ac.ug
web: www.ihsu.ac.ug

APPENDIX VII: APPROVAL LETTER



Telephone: 256(0)782842962
075 2647215
Fax: 256 43 123002E-mail: jmc
@source.co.ug

JINJA MUNICIPAL COUNCIL

TOWN CLERKS DEPARTMENT
P. O. BOX 720
JINJA

31th May, 2018

CR/164/3

To: **Nabwire Betty Lynn,**
International Health University,
P o box 7782,
Kampala – Uganda.

Thru: **Ms. Agwang Agnes,**
Dean, School of Nursing

RE: RESEARCH FOR NABWIRE BETTY LYNN.

This is in reference to yours dated 28th May, 2018 requesting for permission to conduct a research in Jinja Municipal Council.

I am happy to inform you that permission is hereby granted to undertake a research on the topic **“Knowledge and attitudes towards sickle cell trait testing among the youths of Jinja Municipality West, Jinja District.”** for a period of one week with effect from 02nd June, 2018 up to 09th June, 2018.

You will be expected to abide by section f-f 4, 5 & 6 of standing orders relating to divulging any information acquired or accessed during research to unauthorized person verbally, in writing or otherwise and not to publish such information without lawful authority.

Wampande Aisha
HUMAN RESOURCE OFFICER

Cc; Municipal Officer of Health.