KNOWLEDGE, BELIEFS, AND ATTITUDE OF STUDENTS AT KAMPALA INTERNATIONAL UNIVERSITY TOWARDS SICKLE CELL DISEASE.

BY

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A RESEARCH REPORT SUBMITTED TO THE FACULTY OF CLINICAL MEDICINE AND DENTISTRY IN PARTIAL FULFILMENT OF THE REQUIREMENTS FOR THE AWARD OF DEGREE OF BACHELOR OF MEDICINE AND SURGERY AT KAMPALA INTERNATIONAL UNIVERSITY.

APRIL, 2019

DECLARATION

I, **SHUAIBU MUKHTAR SHUAIBU** declare that this research is my original work and it has never been presented to any other institution for an award.

....

Signature Date

APPROVAL

This is to certify that this research work titled, '**Knowledge, beliefs, and attitude of students at international university towards sickle cell disease**' was done under my supervision and do approve the student for submission.

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…… **……..**

SIGNATURE **DATE**

DEDICATION

This work is dedicated to my parents; my father Alhaji Muhammad Mukhtar Shuaibu and my mother Malama Zainab Sani Galadima and my late sister; Samira Mukhtar Shuaibu. (May her soul continue to rest in peace, Amen)

ACKNOWLEDGEMENT

All praise is due to ALLAH, The Beneficent, The most merciful who spare our lives to this moment, I will like to express my forever ascending gratitude to my parents; Alhaji MUHAMMAD M. SHUAIBU and MAL. ZAINAB SANI GALADIMA, for, they have been the constant source of my inspiration and gave me the discipline and all necessary support to face any task with determination and enthusiasm, without them nothing could have been possible.

Indeed, this time is an emotional moment for me, knowing my beautiful time in this wonderful country is almost expiring, I will like to express my heartiest gratitude to all the people in Uganda.

I am grateful to my supervisor DR ODONG RICHARD JUSTIN for his guidance, constructive advices, valuable suggestions and patient correction of this research report.

I will like to pay my gratitude to all my teachers for their academic and administrative support.

Finally, I will like mention all my family members and friends for their unending encouragement and believe in me.

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LIST OF ABBREVIATIONS

CDC Centers for Disease Control and Prevention

KIU Kampala International University

SCD Sickle cell disease

SCT Sickle Cell Trait

WHO World Health Organization

DEFINITION OF TERMS

Sickle cell disease: group of inherited hemoglobin disorders characterized by predominance of abnormal sickle hemoglobin in erythrocytes

Hemoglobin: iron containing oxygen transport protein of the red blood cells

ABSTRACT

Background: Sickle cell disease (SCD) is among the most widespread genetic disorders among the African descents. SCD is associated with increased morbidity and mortality with may misconceptions about how people get the disease, as such there are shred of evidences on the need to increase knowledge and change on bad attitudes and beliefs about the disease to help reduce its incidence. This study aimed to describe the knowledge, beliefs, and attitude of students at Kampala International University, Uganda.

Method: A descriptive cross-sectional study design was used. With 384 students of Kampala International university participating in the study. Semi-structured questionnaire was employed to collect data from participants on demographic characteristics, general knowledge of SCD, beliefs, and attitudes of students at the university towards SCD.

Results: Nearly all the students were aware of SCD (99.2%). The Knowledge level of participants on SCD according to their scores discovered a mean score of 9.7± 4.5 with 65%, 30%, and 5% for poor, moderate and excellent respectively. The Majority of the respondents strongly agreed that they feel concerned (52.9%) and have sympathy (51.3%) for people affected with SCD. Participants had the belief that it is an inherited disease acquired from parents (48.2%) but not a punishment from God (76.3%) or disease of bad luck and the majority of the students agreed to higher institutions screening their students before admission.

Conclusion: Majority of the students were aware of SCD although they have poor comprehensive knowledge about the pattern of inheritance, Majority of the respondents demonstrated positive attitude towards SCD and had the belief that it is an inherited disease acquired from parents, but not a punishment from God or disease of bad luck, and close to one third are ready to end their relationship if they found out their genotypes could predispose them to have children with SCD. Generally, there was a poor understanding of SCD pattern of inheritance with the majority of the students not knowing they might be SCD carriers themselves.

CHAPTER ONE: INTRODUCTION

1.0 Background

Sickle cell disease (SCD) refers to a group of inherited hemoglobin disorders characterized by a predominance of abnormal sickle-hemoglobin in erythrocytes (Johnson, 2016). This genetic disorder (SCD) is as a result of an abnormality in the synthesis of B-globin chain of hemoglobin molecule that results from the substitution of polar amino acid, glutamic acid, with a non-polar amino acid, valine, in the 6th position of on chromosome 11 (Ribeil *et al*., 2017). Sickle cell anemia, which results from homozygous inheritance of sickle-hemoglobin from both parents, is the most common and severest form of sickle cell diseases which on deoxygenation, sickle hemoglobin undergoes a conformational change that promotes intracellular polymerization, which leads to distortion of the normal biconcave erythrocyte disc into the distinctive and pathological crescent shape (WHO 2016). The resulting hemolytic anemia manifests as recurrent vasoocclusion and organ damage that together cause substantial morbidity and early mortality (Centers for Disease Control and Prevention, 2016).

Worldwide, it is estimated that about 400,000 children with SCD are born each year including 300,000 with sickle cell anemia (WHO, 2017). The greatest burden is seen in sub-Saharan Africa, where more than 75% of all sickle cell disease occurs, with this proportion projected to increase by 2050 (WHO, 2016). In Africa, sickle cell disease contributes substantially to mortality in children younger than 5 years, and, therefore, limits progress towards achieving United Nations (UN) Sustainable Development Goal (SDG), Good Health and Well-Being, which includes the reduction of childhood mortality (UN, 2017).

In Uganda, a substantial difference in the prevalence of sickle cell trait exists between different Ugandan tribes and regions (Uganda Ministry of Health 2017). For instance, a study by Okwi and colleagues on an up-date on the prevalence of sickle cell trait in Eastern and Western Uganda reported that, the prevalence of the SCT (As) in Eastern Uganda was 17.5% compared to 13.4% and 3% in Bundibugyo and Mbarara/Ntungamo respectively (Okwi *et al*., 2010). A recent nationwide study, however, reported values of 13·3% and 0·7% for sickle cell trait and SCD respectively (Ndeezi *et al.*, 2016).

The impact of SCD is threatening to the life of people suffering from its effects, it results in an average lifespan of around mid to late 40's (Johnson, 2016). For instance, SCD results in anemia that may present with symptoms of fatigue, jaundice, and shortness of breath; continuous tissue and organ damage; pulmonary disease; and stroke (Weatherall, 2013).

Pain crises, caused by vasoocclusion, are the trademark of SCD and affect most people with the disease (Novelli & Gladwin, 2016). Vasoocclusion occurs when the sickled red blood cells (RBC) obstruct the other blood cells resulting in an inadequate supply of blood to the organs (Fujita *et al.*, 2016). The initial pain episode generally occurs as swelling in the hands and feet (hand-foot syndrome or dactylitis) resulting from diminished oxygen caused by obstructed/impassable blood vessels. Moreover, nearly 50% of children with SCD get dactylitis by the age of two, with approximately 50 to 60% of all emergency room visits and 60 to 80% of hospitalizations are due to pain crises (Ribeil *et a*l., 2017). Additionally, studies indicate that acute pain is the main cause of hospitalization for people with SCD of all ages; however, it occurs more often in teens and young adults (Dorsey & Murdaugh, 2003; Elander, 2006; Jenerette, Funk, & Murdaugh, 2005; NHLBI, 2010). Furthermore, frequent reoccurrences of acute pain are related to premature death in SCD patients over 20 years old (Rees *et al.*, 2010). Several factors including dehydration, extreme temperatures, infection, and low oxygen levels (high altitudes) can trigger SCD crises (Damanhouri *et al*., 2015).

Another severe complication of SCD is Acute chest syndrome (ACS). ACS results from infiltrates in the lungs or can also result from infections. Besides, ACS may also result in fever, chest pain, wheezing and cough symptoms following or accompanied by other acute symptoms (Kato, Steinberg, & Gladwin, 2017). There are numerous causes for ACS including infection, sickling, fluid overload and atelectasis caused by hypoventilation from over sedation or inadequate pain control (Azar & Wong, 2017). ACS is the second most common reason for hospital admissions among people with SCD (Hussein, Weng, Kai, Kleijnen, & Qureshi, 2018) with admissions lasting an average of 10 days. There are several factors related to the longer length of admission including, older age, fever, pain, transfusion, and respiratory failure. ACS results in about 25% of deaths in people with SCD (Robinson & Fuchs, 2016). The effects of ACS are worst on adults with SCD in comparison to children with SCD. For instance, patients older than 20 years old with SCD (9%) have a higher fatality rate than patients younger than 20

years old with SCD (2%) (Maeschia *et al.*, 2014). Therefore, immediate treatment of ACS is necessary to prevent the progression of the condition resulting in respiratory failure and death (Chakravorty & Williams, 2015).

SCD is also considered to be one of the most widespread reasons for strokes in children (Novelli & Gladwin, 2016). About 10 % of individuals with SCD experience a stroke during some point in their lives with the highest prevalence found in children between 4 and 6 years old. Strokes develop following a vasoocclusion in the blood vessels within the brain, restricting oxygen delivery and often results in headache, partial paralysis, cranial nerve palsy, and difficulty or inability to swallow (Ribeil *et al*., 2017).

Splenic sequestration refers to the enlargement of the spleen resulting in a reduction in hemoglobin creation and a higher risk of infection and if left untreated, splenic sequestration can result in death (Gladwin & Sachdev, 2012). Splenic sequestration develops in about 30% of SCD patients younger than six years old (Damanhouri et al., 2015). The manifestations of splenic sequestration increase the risk of infection for children with SCD compared to their healthy counterparts. Children with SS generally experience auto-infarction of the spleen by the time they are 5 years old; however, those with SC and ST are at risk for splenic sequestration throughout their lifetime. For instance, the oldest patient with SC found to have splenic sequestration was 44 years old (DeBaun & Telfair, 2012).

Marriage is a lifelong contract between persons aiming to provide support to each other and procreation, but the course of selecting a spouse is inarguably challenging particularly when considering health status. (Kwame Ameade, Mohammed,Kofi Helegbe & Yakubu 2015). Giving birth to younger ones brings tremendous happiness and joy to most couples, but also a great responsibility that demands time and finances especially if the child has a chronic disease such as SCD. (Kwame Ameade, Mohammed,Kofi Helegbe & Yakubu 2015)

Studies by Jenerette, Brewer, Silva, & Tanabe, 2016 have reported that a great number of married people got married unaware of their SCD genotypes, this can account for the reported 2% annual incidence of SCD in developing countries. Knowledge of SCD before marriage/dating is crucial especially in higher institutions where numerous youths are in their reproductive age, and the campus provides an excellent environment for choosing their life partners. (Daak *et al*., 2016)

The attitude and beliefs of students towards SCD is an important contributing factor that is vital in planning educational program as well as finding out the degree of stigmatization towards people affected with SCD. This study, therefore, determined the knowledge, beliefs, and attitude of students at Kampala International University (KIU), Western campus, Uganda.

1.1: Problem statement

SCD is considered to be a major Hemoglobin Disorder, and has recently been declared a global health problem by the World Health Organization (WHO, 2017). Despite SCD becoming a global health issue, in Uganda, more focus is paid on treatment and management of the disease rather than prevention. This emphasis on treatment and management of the physical effects chiefly led to ignorance or little attention to the psychosocial bearing of the disease on the person affected and their family. A major Key to prevention is an understanding of how SCD is inherited from parents, and making people to know it's in the same way any physical traits and blood type are acquired. Since it is inherited genetically, a major approach to prevention should be education about the reproductive implications of the disease. The literature on informed reproductive decisions among people with SCD is limited. And the current literature suggests that there is inadequate knowledge about SCD, carrier status (includes both Sickle Cell Trait (SCT) and reproductive implications of the disease among high-risk populations. The gaps in knowledge indicate the need for adequate education of at-risk individuals; particularly, prevention needs to be aimed at young people who are about to start planning for long-term relationships and marriage. Prevention and intervention programs should be geared towards increasing knowledge, changing false beliefs, and attitudes about the disease as well as its reproductive implications.

Galadanci *et al*., (2014),carried out a study of this nature in Nigeria and recommended that tertiary level students should be an emphasis for the prevention of SCD because they are engaged in dating and relationships, therefore SCD trait screening and increase in education, as well as awareness among students is crucial to reduce on the incidence of the disease. However, no study of this nature has been carried out in Kampala International University, Uganda, hence this study described the knowledge, beliefs, and attitude of students at Kampala International University towards sickle cell disease.

1.2: Study objective

1.2.1: Main objective

The main objective of this study was to describe the knowledge, beliefs and attitude of students at Kampala International University towards sickle cell disease.

1.2.2: Specific objectives

1. To describe knowledge of sickle cell disease of students in Kampala International University, Western campus.
2. To describe the beliefs of students in Kampala international university regarding sickle cell disease
3. To describe the attitude of students towards sickle cell disease in Kampala International University, Western campus.

1.3: Research questions

1. What is the knowledge regarding sickle cell disease among students at Kampala International University, Western campus?
2. Which beliefs regarding sickle cell disease do students at Kampala International University, Western campus have?
3. What is the attitude towards sickle cell disease among students at Kampala International University, Western campus?

1.4: Justification of the study

Most studies focus on patient education and disease management (Hershberger *et al*., 2016, Daak *et al*., 2016, Asnani, Quimby, Bennett, & Francis, 2014). However, there was a gap in the literature regarding education efforts to increase knowledge, change bad health beliefs among individuals (non-patients) at risk especially young couples.

Attitudes about chronic conditions like SCD are important in influencing preventive behaviors such as seeking screening for SCD trait. Furthermore, attitudes about the disease, form preventive behaviors among individuals not affected by the disease and among those who are at different levels of risk. If most individuals who perceive SCD as a “dark” disease are also more inclined to support unfavorable perspectives about the disease, then those racial views are harmful and may cause individuals from other race/ethnicity to misjudge their predisposition of

being SCD carrier, these views form a significant problem requiring greater research focus (Haywood *et al.*, 2014).

Finally, Uganda is one of the countries whose population has been affected by sickle cell disease and it (Uganda) being a developing nation, resources to support the increased in awareness and decrease incidence of the disease are not readily available thereby increasing the need for innovative ways of preventing complications that may arise secondary to the disease. One of the ways in which the complications can be prevented is by finding out how knowledgeable individuals are, in regards to sickle cell disease, and address the misconceptions about the disease (which are form of secondary prevention). Thus, this study described the knowledge, beliefs and attitude of students at Kampala International University towards sickle cell disease.

1.5: Study scope

1.5.1: Geographical scope

The study was done at KIU western campus in Bushenyi Ishaka municipality, south western Uganda.

1.5.2: Content scope

This study assessed knowledge, beliefs, and attitude of Kampala international university students towards sickle cell disease.

1.5.3: Time scope

This study took place in March 2019.

CHAPTER TWO: LITERATURE REVIEW

2.0: Introduction

This chapter begins by providing the reader with an overview of SCD in terms of background of the disease, and provides an overview of the literature related to SCD knowledge, health beliefs, attitudes, and screening behaviors. The gaps in the literature are addressed.

2.1Knowledge about SCD among university students

Several studies assessing knowledge about SCD have been conducted among college students globally. In a cross-sectional study of University students in Nigeria found that more than half (76.6%) of the students did not know their carrier status (Olakunle, Kenneth, Olakekan, & Adenike, 2016). This shows that the students had little knowledge about SCD. In another cross-sectional study of university students in Nepal by Ghimire, (2016) found that 46.2% had average knowledge regarding Sickle-cell disease and around one third (35.9%) of respondents had low knowledge, the same study showed that family history was associated with knowledge about SCD. For instance, students who had a relative with SCD had better knowledge compared to those without an affected relative. However, the study found no relationship between students' knowledge of their own carrier status and having a relative affected by the disease. A recent study among undergraduate students of a Nigerian tertiary educational institution showed that although only (1.8%) reported that they had never heard of SCD, some students believed SCD was caused by evil spirits (19%) or bad food (27%) and could be cured by spiritual healers (27%). Females had better knowledge about SCD compared to males (Ugwu, 2016). In the United States (US), studies assessing the knowledge about SCD among college students are limited, but in a mixed method study of African American college students, Long, Thomas, Grubs, Gettig, & Krishnamurti, (2011) found that the students seemed to have a good knowledge about the transmission of the disease. However, 40% of the students incorrectly indicated that SCD was contracted through blood transfusions. Approximately 58.2% of the students provided correct responses to at least six out of ten questions. Participants had basic knowledge about SCD. For example, participants were aware that SCD was a blood disorder but they could not provide specific characteristics about the disease. Participants knew that SCD was inherited; however, they did not have a good understanding of the SCD inheritance pattern. Carriers were not clear about the reproductive implications of having children with another carrier and non-carriers were unclear about the reproductive implications of having children with a carrier. Long

et al., (2011) also found significant gender differences in knowledge about SCD. Females had a higher level of knowledge about SCD compared to males.

2.2 Health Beliefs about SCD and Screening

Health beliefs are important factors to consider in addressing the issue of SCD. According to the health belief model, individuals must perceive SCD to be a serious condition for which they are at high risk and must perceive high benefits and low barriers to carrier screening (Abraham & Sheeran, 2014). Therefore, assessing college students' health beliefs about SCD and screening will provide important information for prevention and intervention programs addressing SCD particularly, the severity, risk and benefits of knowing one's own and partner's carrier status as well as addressing barriers.

In a study of factors that contribute to the knowledge, health beliefs, attitudes, and behaviors regarding sickle cell disease among college students, Marcella, (2015) found that participants believed that SCD was a serious disease. The study also found a positive correlation between the average level of knowledge and perceived severity of SCD. Perceived severity was positively correlated with knowledge of SCD inheritance, severity of symptoms, and carrier status. Perceived severity was significantly related to knowledge about SCD. Participants with greater knowledge about SCD believed SCD to be more serious than those with less knowledge (Marcella, 2015). Similarly, another study showed that perceived severity of SCD increased by 18.2% after a health education intervention (Olaton, 2012).

In a qualitative study including SCD patients, parents of children with SCD and individuals from the community with SCT, Gallo et al., (2010) found that participants had a high-perceived severity of SCD. Many participants showed that SCD involved serious complications for them and their children, or anyone with the disease. Participants described SCD as "suffering" and "struggle" when referring to pain crisis and frequent hospital admissions. Study participants were "grateful" their children did not have SCD and did not want their children or grandchildren to ever experience SCD. One of the participants with SCT indicated, "Most people don't know how horrible SCD is, or can be".

2.3 Attitudes Towards Carrier Screening

Genetic testing is an unbiased approach for providing important information that may be useful in order to prepare for a genetic condition and/or to make informed reproductive choices (Ndeezi

et al., 2016). Given the limited research and the importance of carrier screening and knowing one's carrier status, it is important to understand the attitudes towards carrier screening for SCD in order to plan for SCD prevention programming.

Several studies indicate that overall, people have positive attitudes about carrier screening (Al-Farsi *et al.*, 2014, Oludarei & Ogili, 2013, Adewoyin, Alagbe, Adedokun, & Idubor, 2015). In a study including 50% African Americans and 50% Caucasians, Ogunsiji, Wilkes, Peters, & Jackson, (2013) found that the majority (> 90%) of the participants believed that genetic screening was a good thing with the most significant benefit of prevention of or preparation for the disease. African Americans were more likely to believe that genetic screening would lead to racial discrimination compared to Caucasians. However, African Americans were more likely to think that all pregnant women should have genetic screening compared to Caucasians.

Most of the African American participants (85.3%) in Long *et al*., (2011) study had positive attitudes regarding carrier screening for SCD. The study also found a significant difference between age and attitudes toward carrier testing for SCD. Younger participants had a less favorable attitude towards screening compared to older participants. There was a significant difference between age and attitudes about SCD and SCT. Younger participants felt less comfortable talking about carrier status with others compared to older participants. The study also found a relationship between family history of SCD. Students with a family history of SCD or SCT were more likely to have positive attitudes about talking about SCD carrier status compared to those without a family history. Students with a family history were also more likely to have positive attitudes regarding the possibility of testing positive for SCD or SCT. Participants with no family history had neither positive nor negative attitudes (Long et al., 2011). Ross *et al.*, (2011) conducted a study assessing the attitudes of Ghanaian women toward genetic screening. The sample included both SCD carriers and non-carriers. Women who had undergone screening (88.6%) were more likely than women who had not been screened (69.4%) to agree that knowledge of their SCT status would aid them in making important life decisions. A greater number of women in the screening group believed that knowledge of SCT status was important. The study also found that a greater number of women (70.8%) who had not undergone screening reported that they would feel less healthy if they were aware that they were SCD carriers.

Moreover, women who had not been screened also had greater concern that they may feel singled out if their screening was positive (Ross et al., 2011).

Studies also found favorable attitudes towards carrier screening before marriage. For instance, a study of multi-racial Malaysians, Wong, George, & Tan, (2011) found that most of the participants (90.6%) believed that premarital screening for thalassemia was needed for everyone. Almost 35% of the participants believed that couples should not get married if they were both carriers of thalassemia. Some participants had never been screened because they felt they were not at risk (Wong *et al.*, 2011). In a recent study of Omani adults aged 20–35 who attended primary healthcare institutions at the South Batinah Governorate in Oman, Al-Farsi et al. (2014) found that most of the participants (84.5%) agreed that premarital carrier screening was essential. Most of the participants also indicated that they would advise their partners to do premarital carrier screening. Furthermore, more than 60% indicated that they would think about the premarital carrier screening results carefully before marrying their partners. However, 30.5% of the participants indicated that they did not agree with premarital carrier screening regardless of marital status. Lack of knowledge (36%) was the most common reason reported by married participants who did not get screening. Other participants reported a lack of screening locations (13%), no interest (10%), lack of family history (9%), not important (7%), no partner (6%) as reasons for not seeking screening (Al-Farsi *et al.*, 2014).

Positive attitudes about premarital screening were also found among college students, in a study of unmarried, Omani, undergraduate students, Al Kindi, Al Rujaibi, & Al Kendi, (2012) found that students had favorable attitudes towards premarital screening. Most of the students (92%) believed premarital screening was important and said they would get screened in the future. Students that agreed with premarital screening believed it would prevent transmission of the disease to future children, ensuring their partners were healthy, and ensuring fitness for marriage. Students who refused to do screening, had a fear of unfavorable test results, perceived the test results as an insult, felt it interfered with God's will, and that it would prevent marriage (Al Kindi *et al.,* 2012). Similarly, in another study of university students in Nigeria, (94.2%) of the student had positive attitudes regarding premarital screening for SCD (Omuemu, Obarisiagbon, & Ogboghodo, 2013).

CHAPTER THREE: METHODOLOGY

3.0: Introduction

This chapter discusses the methodology used in the study.

3.1: Study design

The study was a descriptive cross-sectional study involving students at Kampala International University - western campus, to describe their knowledge, belief, and attitude towards sickle cell diseases.

3.2: Study site

The study took place at KIU-WC. The campus is located along Ishaka-Mbarara high way in Basaja town of Bushenyi-Ishaka municipality. It has different faculties including, faculty of clinical medicine and dentistry, faculty of nursing, faculty of humanities, faculty of business administration and faculty of allied health sciences among others.

3.4: Study population

The study involved all KIU students at western campus.

3.4.1: Inclusion criteria

All students in KIU western campus were included in the study.

3.4.2: Exclusion criteria

Students who refuse to give consent for the study were not be included, and students who were on holidays/vacation were not included in the study.

3.5: Sample size determination

The sample size was determined by using Kish's formula (Rutterford, Copas, & Eldridge, 2015) which states that,

$$\mathbf{N} = \frac{\boldsymbol{Z^2(p(1-p))}}{\boldsymbol{\varepsilon^2}}$$

Where;

N = the required sample size

p= Proportion of students with knowledge about sickle cell disease. For unknown population, 50% is taken (Elashoff & Lemeshow, 2014).

ε = margin of error on p (set at 5%)

z= standard normal deviate corresponding to 95% confidence level (=1.96)

$$\mathbf{N = \frac{1.96^2(0.5(1-0.5))}{0.05^2} = 384.}$$

3.6: Sampling Procedures

The researcher used consecutive sampling to get the 384 students needed for the study.

3.7: Data collection methods and management

A structured questionnaire was used in getting the information on participants, their brief demography, screening of SCD genotype, and awareness. 5-point Likert scale with a range from 'strongly agree to strongly disagree' was employed to assess the participant's attitudes, and beliefs of SCT/SCD.10 questions were asked in total for participant's to ascertain, and as such assessing their general knowledge of SCD (including pattern of inheritance) while 5 questions each were asked to find out the participants beliefs and attitudes toward SCD.

3.8: Data Analysis

Data was entered and analyzed using IBM SPSS version 25. To sort the knowledge of respondents, score of 1 and 2 was respectively assigned to agree and strongly agree on agreeing questions on the 5-point Likert scale whereas a score of 0 was assigned to otherwise. On the other hand, if the correct answer was negative, a score of 2 was awarded for strongly disagree and 1 for disagree with 0 for other response (wrong answer). The maximum score of knowledge assessment was 20, and a score below 10.0 or 50% was categorized as poor, scores between 10.0 and 16.6 (50% to 80%) were moderate and above 16.6 or 80% was considered excellent. The Demographics and other SCD information were summarized in frequencies and proportions.

3.9: Quality control

The questionnaire was pretested on 10 students to check for relevance and ambiguity. The questions were modified accordingly. Results from pretest were not included in the final results. In addition, questionnaires were filled in the presence of the researcher to avoid any external source of information such as the internet.

3.10: Ethical consideration.

Ethical approval was sought from the faculty of clinical medicine and dentistry. Permission to collect data was sought from the dean student affairs. Participants participated upon informed consent and they were allowed the freedom to withdraw from the study at any time they wanted.

3.11: Limitations of the study

This study was liable to several limitations.

The data was self-reported, which creates vulnerability to response bias. To lessen response bias, participants were informed that responses would remain anonymous and no identifying information would be collected.

Another limitation was the study design was due to the cross-sectional research design, causality could not be assumed.

Another limitation includes the sampling and recruitment method. Since the current study used a convenience nonprobability sample, it was not possible to generalize to the university population beyond the participants in this study. Replication using random sampling would increase generalizability.

CHAPTER FOUR

PRESENTATION AND INTERPRETATION OF RESULTS

4.1 Demographic characteristics of participants

The study involved 384 participants, half (50.5%) of the participants were within the age range of 21-29 years and were mostly male 269 students (70%), (98.9%) 380 were undergraduates. Most of the participants were single (95.1%) and (88.1%) are Christians. Almost all the participants (99.2%) were aware of SCD but most (96.1%) had not ever tested for the genetic disorder (SCD).

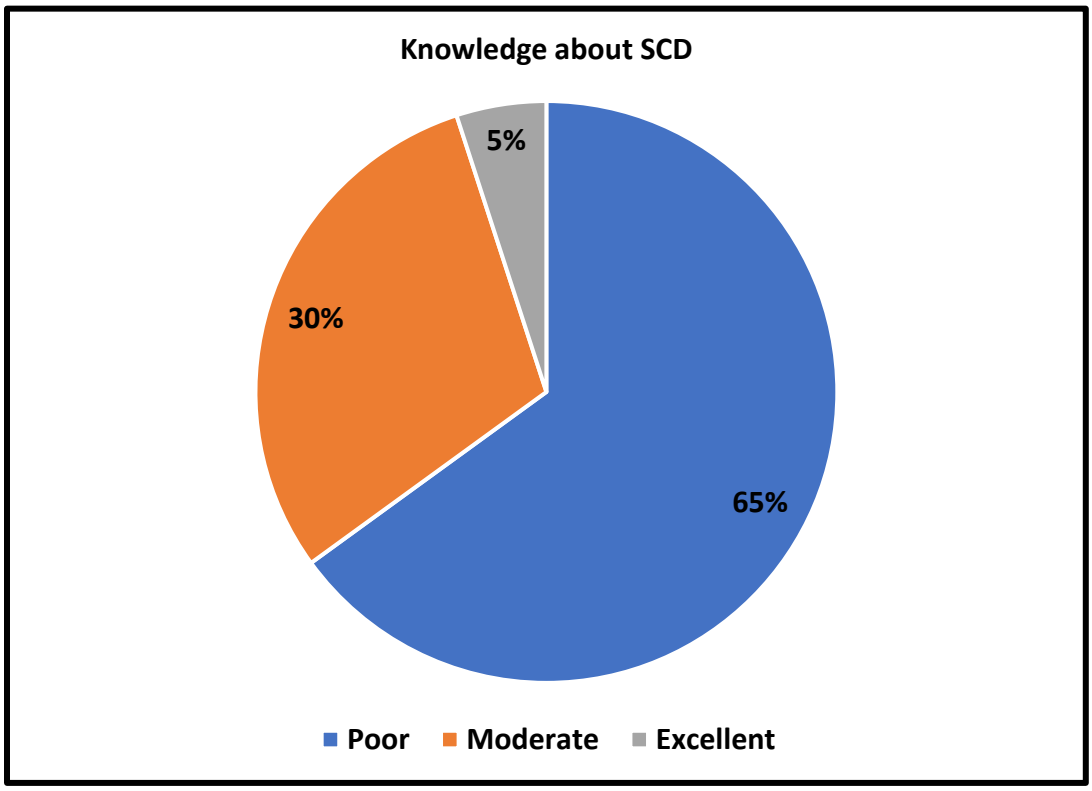
Table 1: Demographic characteristics and sickle cell information of participants

Characteristics	Frequency	Percentage (%)
Age (years)		
≤20	133	34.6
21-29	194	50.5
≥30	57	14.9
Gender		
Male	269	70.0
Female	115	30.0
Educational level		
Undergraduate	380	98.9
Postgraduate	4	1.1
Marital status		
Single	365	95.1
Married	19	4.9
Religion		
Muslim	45	11.7
Christian	339	88.3
Aware of SCD		
Yes	381	99.2
No	3	0.8
Tested for SCD genotype		
Yes	15	3.9
No	369	96.1

4.2 Knowledge of SCD among participants

A total score of 20 was awarded to knowledge. A knowledge levels of (score<10) were grouped as poor, a score 10-16 moderate, and excellent (score>16) depending on the total score of participants (Figure 1). The mean knowledge score was 9.7 ± 4.5 SD indicating a poor general knowledge of participants. And of the 384 participants, majority (65%) had poor while the rest 30% and 5% respectively had moderate and excellent knowledge of SCD.

Figure 1: Knowledge of SCD among participants



4.3 Beliefs and attitudes about SCD

Nearly half of the students (48.2%) strongly believed that SCD is a hereditary disease, and not disease of evil or punishment from God or disease of bad luck. Majority of the students who participated (7%) believed that genetic counseling before to marriage does not indicate lack of faith in God and also believed SCD can affect families that believe in God. Most of the students showed positive attitudes in terms of care and being sympathetic towards people with SCD. And more than one-third (35.7%) of the students strongly agreed to end their relationships if they discover their genotypes and that of their partners predispose them to have children with SCD, and about one-third of the students that participated (33.3%) could not decide on rather having no child than a child with SCD. Majority of the participants 204 (53.1%) strongly agree with 80 (20.8%) agrees tertiary institutions should test/screen students for the SCD genotype before being admitted in these institutions.

Table 2: Beliefs and attitudes about SCD

Beliefs	**Strongly agree**	**Agree**	**Neither agree or disagree**	**Disagree**	**Strongly disagree**
SCD is a disease of evil	0	3	21	89	271
SCD is a genetic disease acquired from parents	185	147	20	16	16
SCD is a punishment from God or disease of bad luck.	0	0	19	72	293
SCD cannot affect families that believe in God	13	9	29	87	246
genetic counseling before marriage indicate lack of faith in God	0	3	20	105	256
Attitudes					
We should worry less towards people with SCD since they may die soon	15	10	21	135	203
I feel sympathy towards people with SCD	197	133	26	21	7
Regardless of my genotype I will not marry someone with SCT/SCD	109	108	98	53	16
If I discover the genotypes of me and my partner predispose us to having children with SCD, I will end my relationship.	137	89	97	36	25
I rather not to have a child than	68	61	128	67	60

to give birth to a child with SCD					
Tertiary institution should require students tested for their SCD genotype before being admitted to the institution	204	80	65	19	16

CHAPTER FIVE

DISCUSSION

SCD, a chronic hereditary blood disease that is associated with recurrent painful periods on affected individuals, and moreover placing economic and emotional issues on families affected. It is important for potential couples to be aware of SCD and their possibility of producing children with the disease before getting into marriage.

In this study, majority of the students (99.2%) were aware of Sickle Cell Disease (SCD) which could be due to the fact that the study was carried out in a tertiary institution, moreover involving medical students with access to medical information. However, it was shocking that even though almost all the participants were aware of SCD, only about half had ever screened/tested for Sickle Cell Disease. This could be because medical screenings of tertiary institutions in Uganda does not include SCD test/screening. In Uganda and of course many African countries, knowing one's SCD genotype is mainly through free medical screening/testing, compulsory medical screening/testing prior to admission into an institution or before marriage. The above findings were similar to reports from Ugwu, (2016), where he found out that over half of the students interviewed in a Nigerian tertiary educational institution don't know their SCD genotype. Another finding by Hershberger et al., (2016) and Ndeezi et al., (2016) showed that majority (95.1%) and more than half (76.4%) of university students do not know their SCD genotypes.

It is significant that those with the SCT become aware and knowledgeable of their carrier status, and potentiality of passing the trait or disease on to their offspring. In all, we can deduce that the students had insufficient knowledge of SCD, although almost all students 381 (99.2%) were aware of Sickle Cell, almost half (65%) of the participants had poor comprehensive knowledge, moderate knowledge (30%) and excellent knowledge (5%) of the disease. This is in agreement with a similar poor knowledge about SCD (31%) in a study carried out in Eastern Uganda by (Okwi et al., 2015). Another study by Kato et al.,(2017), reported 25% of the participants answer questions of the pattern of Sickle Cell inheritance correctly, which shows that individuals are unaware that they may be having sickle cell trait and therefore at risk of producing children with SCD or SCT.

Despite poor comprehensive knowledge of Sickle Cell Disease among the participants, majority (66.7%) agreed to consider genetic screening/testing before marriage which indicates the potential of the realization of the importance of genetic testing/screening as a good measure to reduce the incidence of SCD. This finding is in agreement with findings by Olakunle et al., (2016) where most of the participants agreed with genetic testing/screening as a preventive strategy of genetic disorder (SCD). More so, the remaining students who have disagreed to genetic testing/screening before marriage could be because they fear of losing a potential life partner by knowing their Sickle Cell status.

Most of the participants strongly believe that SCD is not a disease of evil or bad luck (70.6%) rather an inherited disease (48.2%) and not as punishment by God (76.3%). This is similar to the findings of Ugwu, (2016) who reported majority of the participants (78.4) believed that SCD is an inherited disease.

In general, most of the participants demonstrated good positive attitudes towards people affected with Sickle Cell Disease (SCD). About half of the students (52.9%) strongly agreed to worry and felt sympathetic (51.3%) towards people with Sickle cell (SCD). Similar, positive attitude (66.7%) were reported by Ndeezi et al., (2016) among his participants. Close to one third of the students strongly agreed (35.7%) and agreed (23.1%) not to marry anyone with SCT/SCD if their genotype risks them produce children with Sickle Cell Disease and that they will end their relationship should they find out.

CHAPTER SIX

CONCLUSION AND RECOMMENDATIONS

6.1 Conclusion

Majority of the students were aware of SCD although they have poor comprehensive knowledge about the pattern of inheritance, majority of the respondents demonstrated positive attitude towards SCD and had the belief that it is an inherited disease acquired from parents but not a punishment from God or disease of bad luck, and, close to one third are ready to end their relationship if they found out their genotypes could predispose them to having children with SCD. Generally, there was poor understanding of SCD pattern of inheritance with majority of the students not knowing they might be SCD carriers themselves.

6.2 Recommendations

To reduce the incidence of SCD, this study suggests more education on SCD and particularly SCT, especially in tertiary institutions and secondary schools where many youths have the potential of meeting their life partners, health centers and churches and other strategic places can also help address misconceptions as well as increasing knowledge of SCD and sensitize people on risks of having a child with the disease.

Moreover, this study suggests Tertiary institutions should require students on their admission into the institution to test/screen for their sickle cell genotype so that they know their own genotype before being enrolled into these institutions, so that they can make informed choice before they meet a potential life partner.

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Appendix

Appendix i: informed consent

The study has been described to me in a language that I understand, and I freely and voluntarily agree to participate in this study. I understand that my identity will not be disclosed and that I may withdraw from the study without giving a reason at any time and this will not negatively affect me in any way.

Participant's name: …….

Participant's signature: ……..

Date: …… ……

Witness……

Appendix ii: questionnaire

Section A: demographic characteristics

1. Age (years) ……..

2. Sex

Males ☐ Female ☐

3. Educational level

Undergraduate ☐ postgraduate ☐

4. Marital status

Single ☐

Married ☐

separated ☐

5. Religion

Christian ☐

Moslem ☐

Section B: Sickle cell information

6. Aware of SCD

Yes ☐

No ☐

7. Test for SCD

Yes ☐

No ☐

8. Knows genotype

Yes ☐

No ☐

9. If yes in 8, Genotype

AA ☐

AS ☐

SC ☐

Section C: Knowledge about SCD

10. base on your understanding of sickle cell disease, which definition best defines it?

a) An inherited blood disorder
b) Sickle cell trait usually turns into sickle cell disease
c) It is an infectious disease
d) A genetic disease only affecting Africans

11. Are there different types of traits that can lead to sickle cell disease

a) Yes
b) No

12. Which of the following are true of sickle cell disease

a) It is a blood disease there are many types of SCD
b) SCD can be identified by blood test
c) blood transfusions are sometimes used to treat the disease
d) all of the above

13. Do you know your sickle cell trait status

Yes ☐

No ☐

14. do you know your partner's sickle cell trait status

Yes ☐

No ☐

15. do you think you yourself may be a carrier of SCD

Yes ☐

No ☐

16. do you think your partner may be a carrier of SCD

Yes ☐ No ☐

17. sickle cell disease can be got from
    a) Dirty needles
    b) Bad blood transfusion
    c) From both your biological parents
    d) hanging around with a person who has it
    e) sexual intercourse with someone who has it

18. which gender do you think is more likely to catch the disease
    a) Male
    b) female
    c) equal chances
    d) don’t know