SCHOOL OF PUBLIC HEALTH

COLLEGE OF HEALTH SCIENCES

UNIVERSITY OF GHANA

KNOWLEDGE, PERCEPTION AND PRACTICES OF YOUNG ADULTS IN TEMA TOWARDS SICKLE CELL DISEASE.

BY

ADWOA AYEWA AYIMADU

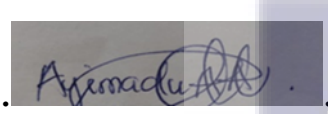
(10938700)

THIS DISSERTATION IS SUBMITTED TO THE UNIVERSITY OF GHANA, LEGON IN PARTIAL FULFILMENT OF THE REQUIREMENTS FOR THE AWARD OF MASTER OF PUBLIC HEALTH (MPH) DEGREE.

JANUARY, 2023

DECLARATION

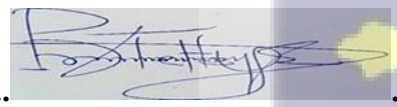
I, ADWOA AYEWA AYIMADU hereby declare that apart from specific references made to other people's work which have been duly acknowledged, this dissertation is my own independent work undertaken under the supervision of Dr. PRUDENCE TETTEY. I also declare that no part of this thesis has been submitted for the award of any degree in this University or any University or Institution elsewhere.



… **……** **……28/04/23……..**

ADWOA AYEWA AYIMADU **DATE**

Student



.. **…** **…….28/04/23……**

Dr. PRUDENCE TETTEY **DATE**

Academic Supervisor

DEDICATION

This thesis is dedicated to my uncle, Mr. Jonathan Amankwah for sponsoring my master's degree in Public Health.

ACKNOWLEDGEMENTS

I would like to express my foremost and immense gratitude to God for how far He has brought me. Putting together this thesis has not been by my human strength but by His grace and mercies and I am so thankful for His goodness and faithfulness toward me.

To my supervisor, Dr Prudence Tettey, who patiently guided me into doing an excellent work, I would like to say a big thank you. God richly bless you Dr Tettey.

I would also like to thank the lecturers and staff of the School of Public Health, especially those in the Department of Biological, Environmental, and Occupational Health Sciences for their help and encouragements throughout my MPH journey.

I would also like to say a big thank you to my parents, Mr and Mrs Ayimadu Amankwah and siblings, Mrs Akosua Otiwaa Ampofo and Mr Kwabena Nuamah Ayimadu for their prayers and support throughout this journey.

A special thanks goes to my friends who stood by me through difficult times and encouraged me with their support into finishing strong. I appreciate you all so much.

My final acknowledgement goes to my course mates who in their own special ways, have contributed to my success story. God bless you all immensely.

ABSTRACT

Background: Globally, about 25 million people live with sickle cell disease. In sub-Saharan Africa, there are 240,000 children affected by the disease and 50% - 80% of them die before the age of 5. Out of the total number of babies born each year in Ghana, 15,000 (2%) are born with sickle cell disease. Sickle cell disease (SCD) is an inherited blood disorder that affects red blood cells. Unlike normal red blood cells, which have an average life span of about 120 days, are smooth, round, flexible, and can easily move through blood vessels, sickle-shaped red blood cells are stiff and sticky and live up to about 10 to 20 days. Due to the increased rates of morbidity and mortality associated with the disease, The UN has declared SCD as a global public health concern hence the need to decrease the number of infants born annually with sickle cell disease in Ghana through advocacy and increased education of the general public especially young people who are of childbearing age.

Aim of Study: The aim of this study was to determine the knowledge, perception, and practices of young adults in Tema toward sickle cell disease.

Methodology: This study was carried out using a quantitative research approach, with a cross-sectional survey of young adults in Tema. The study population for this research comprised 400 young adults between the ages of 18 to 40. The data collection tool which was a structured questionnaire was divided into 5 sections; socio-demographic characteristics and prevalence of sickle cell disease among young adults in Tema, their knowledge, perception attitude and practices towards sickle cell disease. Scores between 0 and 0.5 were considered as poor knowledge, attitude, perception, and practices, while scores between 0.6 and 1 were considered as good knowledge, attitude, perception, and practices. All of the "Yes" responses were the appropriate answers to the questions posed, which were scored as either 1 for "Yes" responses or 0 for "No/I don't know" responses. The data collected were stored in excel and

analyzed using logistic regression models with the STATA software and presented in frequency tables, graphs and summary statistics.

Results: Findings show that there was a 9% prevalence rate of SCD among young adults in Tema, 73.5% of respondents had good SCD knowledge, 86.8% and 60.7% had poor attitude and poor perceptions respectively and an overall good practice toward the disease. There was a significant association between educational level of participants and knowledge of SCD.

Conclusion: In conclusion, there should be effective education on SCD to improve the knowledge, attitudes, perceptions and particularly, practices toward SCD to help reduce its prevalence in Ghana.

TABLE OF CONTENTS

LIST OF ABBREVIATIONS

GHS – Ghana Health Service

PGD – Preimplantation Genetic Diagnosis

PGT – Preimplantation Genetic Testing

PND – Prenatal (Genetic) Diagnosis

SCD – Sickle Cell Disease

UN – United Nations

WHO – World Health Organisation

LIST OF TABLES

LIST OF FIGURES

CHAPTER 1
INTRODUCTION

1.1 Background

Sickle cell disease is an inherited blood disorder that affects hemoglobin, an oxygen-carrying protein in red blood cells (Sedrak & Kondamudi, 2021). Unlike normal red blood cells which are smooth, round, flexible with an average life span of about 120 days and can easily move through blood vessels, sickle-shaped red blood cells are stiff and sticky and live up to about 10 to 20 days (Shiel, 2021). Because of their nature, they are not able to move freely through blood vessels thereby blocking the flow of blood and oxygen from getting to all parts of the body (CDC, 2022). This action causes affected persons to experience mild to severe pain as well as other health complications like avascular necrosis, stroke, pulmonary hypertension, kidney failure, acute chest syndrome, priapism, and organ damage, among others (Tanabe et al, 2019).

Sickle cell disease is the most common inherited genetic disease in the world and it is most prevalent in Africa. It is caused by inheriting two abnormal hemoglobins, which include hemoglobin S (HbS) and one other which may be hemoglobin C, D, E, or O from each parent (Asare et al, 2018). These abnormal hemoglobins are structural variants arising from a mutation in the hemoglobin beta (HBB) gene (Chakravorty & Williams, 2014). One can have the sickle cell trait by inheriting one abnormal hemoglobin from one parent and normal hemoglobin A (HbA) from the other parent. People with the trait may in rare cases, also experience mild to severe forms of pain crises and complications and can pass on the trait to their children. There is a 1 out of 2 chance (50%) that a child will inherit the sickle cell trait and a 25% (1 out of 4) chance of inheriting the disease if both parents have the trait (CDC, 2022). Globally, about 20 to 25 million people are living with the disease and in sub-Saharan Africa, 240,000 children are born every year with it and 50 - 80% of these children die before age 5 (Mulumba & Wilson, 2015). Fifteen thousand (15,000) babies, which is 2% of children born each year in Ghana are

born with the disease (Sims et al, 2021). Sickle cell disease has therefore been recognized as a global public health concern by the United Nations due to the increased rates of morbidity and mortality associated with it (Mulumba & Wilson, 2015).

With the introduction of various interventions like newborn screening (although restricted), genetic diagnosis, use of antibiotics particularly penicillin to treat and avoid infections (Mulumba & Wilson, 2015), there has been a tremendous improvement in the quality of life and life expectancy of people living with sickle cell disease over the past few years (Alghamdi et al, 2018). However, to further decrease morbidity and mortality rates with its associated complications and the psychosocial and economic burden that comes with it (Lubeck et al, 2019), more awareness through advocacy and education needs to be created to sensitize the general public, especially young adults (20-35 years) with the right knowledge on the disease (Aygun & Odame, 2012).

1.2 Problem Statement

Sickle cell disease (SCD) does not only affect individuals living with the disease but also caregivers and the nation as a whole (Buser et al., 2021). There is a recognized economic burden on the healthcare system, direct and indirect costs on caregivers and sickle cell patients coupled with excruciating pain episodes as a result of the disease (Holford et al., 2021). People living with SCD are often stigmatized and discriminated against by other individuals who for lack of knowledge, assume that the disease is either a curse or punishment for sins committed by families of affected persons. This results in decreased social activities and increased psychological traumas which affect the quality of life of persons with the disease. Sickle cell disease also affects the productivity of patients due to repeated pain crises which in the long run, affects the overall productivity of the nation (Holford et al., 2021).

There is a need to decrease the number of infants born annually with sickle cell disease in Ghana through advocacy and increased education of the general public especially young people who are of childbearing age (Boadu & Addoah, 2018).

1.3 Justification of Study

Tema is a big urban city in the Greater Accra Region of Ghana which houses a population of about 196,224 people. In 2013, Tema was ranked the 11th most populous settlement in Ghana (Ghana Statistical Service, 2021). Although a few studies have been conducted on sickle cell disease among inhabitants of Tema in the past (Ephraim et al., 2015; Ephraim et al., 2016; Nimako, 2012), this study is however, the first to consider the topic of knowledge, perception, and practices of SCD among young adults in Tema. Also, all research conducted on the stated topic over the last few years in Ghana have only covered students in the second cycle and tertiary institutions but not communities (Boadu & Addoah, 2018; Djan & Mensah, 2020). The study population which comprises young adults between the ages of 18 to 40 is said to be the age at which most people consider the possibility of dating, marrying, or having children. Being well-informed about sickle cell disease is a key component in its prevention since it enables people between the ages of 18 to 40 to make smart decisions regarding marriage and having children. Therefore, assessing the knowledge of unmarried individuals about sickle cell disease can aid in creating pertinent public health initiatives to raise awareness and knowledge of the problem (Adigwe, 2022).

1.4Research Questions

1. How prevalent is SCD among young adults in Tema?
2. What is the knowledge level of young adults in Tema concerning sickle cell disease?
3. What is the attitude of young adults in Tema towards sickle cell disease and people living with it?
4. What perception do young adults in Tema have of SCD and people living with SCD?
5. What practices regarding SCD do young adults in Tema carry out?
6. What is the association between the socio-demographic characteristics of participants and knowledge, perception, attitude, and practices of young adults in Tema)?
7. What is the association between SCD status and the socio-demographic characteristics of participants?

1.5 Objectives

1.5.1 General Objectives

The general objective was to determine the knowledge, perception, and practices of young adults in Tema toward sickle cell disease.

1.5.2 Specific Objectives

The specific objectives of the study were to:

1. determine the prevalence of SCD among young adults in Tema.
2. assess the knowledge level of young adults in Tema regarding sickle cell disease.
3. assess the attitude of young adults in Tema towards sickle cell disease and people living with it.

4. assess the perception young adults in Tema have of SCD and people living with the disease.
5. assess the practices of young adults in Tema regarding sickle cell disease.
6. measure the association between the socio-demographic characteristics of participants and knowledge, perception, attitude of young adults in Tema.
7. measure the association between SCD status and the Socio-demographic characteristics of participants.

1.6 Conceptual Framework showing Factors affecting the Knowledge, Perception and Practices of Young Adults toward Sickle Cell Disease

The conceptual framework in figure 1.1 assesses the factors that can affect the knowledge, perception, and practices of young adults toward sickle cell disease.

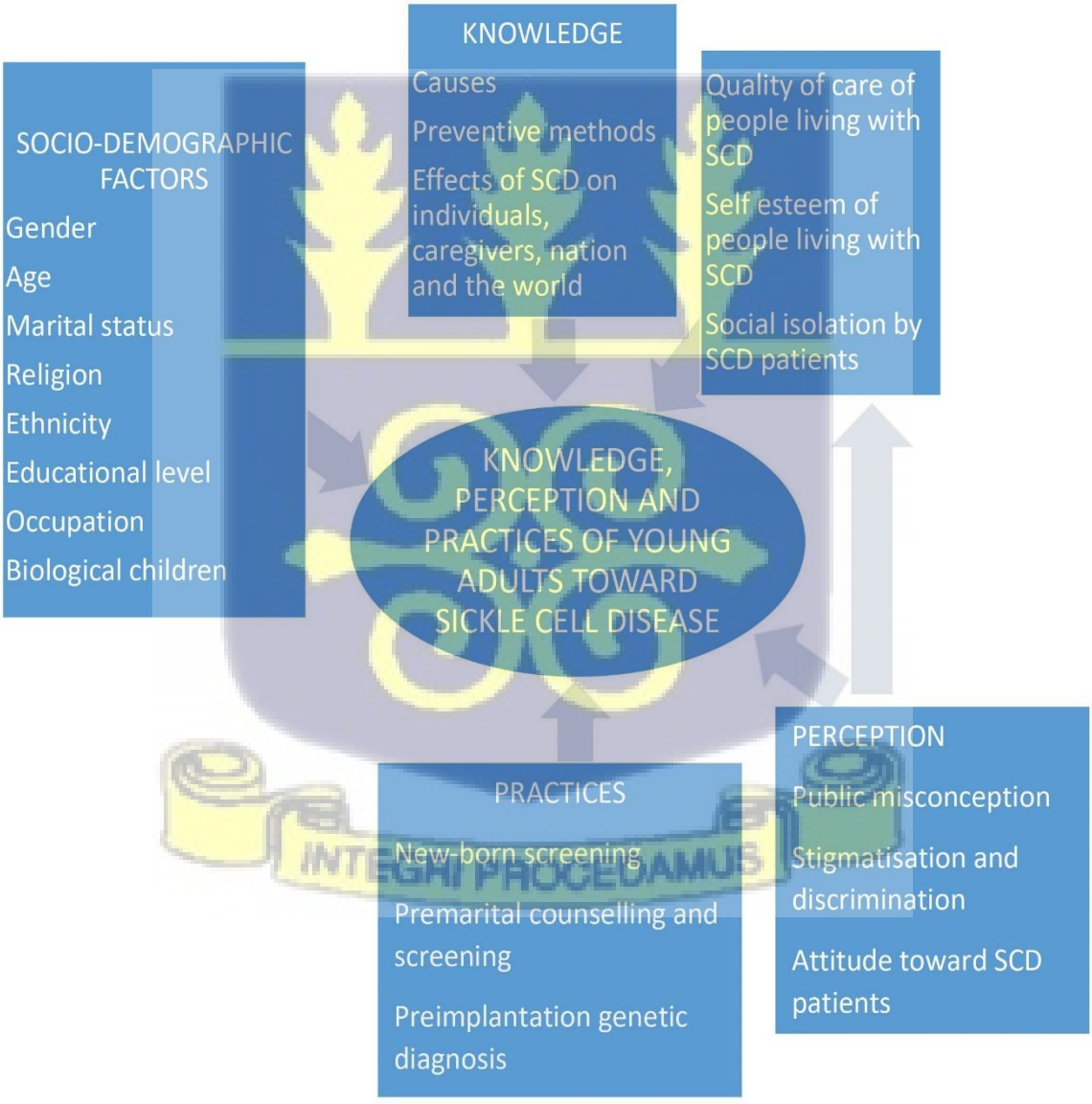


Figure 1.1 Conceptual framework showing Factors affecting the Knowledge, Perception, and Practices of young adults toward Sickle Cell Disease.

Socio-demographic factors like age, gender, marital status, religion, ethnicity, educational level, occupation and whether or not one has children can influence an individual's level of knowledge on sickle cell disease i.e. whether the individual knows how the disease is inherited, what causes the disease, how to prevent the disease, among others (Boadu & Addoah, 2018). The knowledge level of the disease can also influence a person's perception positively or negatively. A person can have a right or wrong attitude toward an SCD patient based on either the knowledge obtained or the lack of it. This can determine whether a person living with SCD will be discriminated against, or stigmatized by other individuals, based on a belief or disbelief in misconceptions about sickle cell disease which will affect the overall quality of life of people living with the disease (Buser et al., 2021). Again, one's level of knowledge can affect the practices of an individual toward sickle cell disease. If people have the right knowledge of SCD before marriage, they will ensure that they know their genotype or sickling status and that of their soon-to-be spouses by engaging in pre-marital screening (Edwin et al., 2011). In the case where the right knowledge is obtained after marriage, people can also engage in pre-natal diagnosis when it comes to childbirth if the genotypes are incompatible and also early diagnosis in the situation where the couple has had a child already. These practices, whether they are done or not, can either contribute to the increase or decrease in prevalence of sickle cell disease and its related morbidity and mortality (Edwin, Edwin & Etwire, 2011).

CHAPTER 2
LITERATURE REVIEW

2.1 Introduction

This chapter provides a detailed analysis of sickle cell disease, its prevalence globally, in Africa, and Ghana, as well as knowledge, perception, and practices of young adults in Tema towards SCD. Recent and existing literature on these topics were critically scrutinized to complete this chapter and to find answers to the research questions while fulfilling the purpose of this study. The first section talks about the prevalence of SCD globally, in Africa and in Ghana, section two talks about the knowledge of SCD and highlights on the causes, symptoms, diagnosis, morbidities associated with the disease and its management. Section three discusses the perception of sickle cell disease with reference to studies carried out in some parts of Africa and in Ghana. Section four deals with the practices toward SCD and the last section talks about the association between SCD status and the socio-demographic factors considered in this study.

2.2Prevalence of Sickle Cell Disease

Sickle cell disease is the most common inherited hematological disease and affects about 300,000 babies every year in the world. Although there is a high prevalence of the disease in sub-Saharan Africa, South Asia, the Middle East, and the Mediterranean region (David et al., 2018), SCD is most prevalent in sub-Saharan Africa, where public health initiatives to reduce mortality and morbidity are not always available. Close to 90% of the total global population of SCD comes from Nigeria, India, and the Democratic Republic of Congo (DeBaun & Galadanci, 2022).

SCD has been identified as a global public health issue by the World Health Organization and the United Nations. In Ghana, there is an approximation of 15,000 babies which is 2% of babies born annually, diagnosed with SCD (Asare et al, 2018). Out of these 15,000 babies born, it is estimated that 7000 to 12,000 of them die as the disease is unknown to their parents (Ohene-Frempong, 2018). Developed nations like the United States have however seen tremendous

improvements in their mortality rates for children living with SCD due to interventions like neonatal screening programs, preventive and management therapies, and other comprehensive treatment programs like bone marrow transplant and hydroxyurea therapy (Mulumba & Wilson, 2015). Many of these therapies can assist SCD patients in Africa and Ghana in the same ways.

Homozygous SCD, indicated by the presence of two copies of globin S mutation is the most prevalent subtype of SCD in the world and codes for sickle cell hemoglobin (Hb S). Sickle cell anemia, Hb SS, SS disease, and sickle cell disease-SS are names used to describe homozygous SCD (Piel et al., 2010) although sickle cell disease and sickle cell anemia (Hb SS) are not the same, as sickle cell anemia is a form of SCD. In low-altitude equatorial parts of Africa, SS is most frequent, followed by SC as the second SCD subtype frequently found in Africa. People of West African descent almost exclusively carry the "C" allele, which is most prevalent in Burkina Faso and northern Ghana (Grosse et al., 2011). Another form or subtype of SCD is beta thalassemia ($S\beta^{+}$-thalassemia) which is very rare in most parts of sub-Saharan Africa (Modell & Darlison, 2008). About 60,000 of the babies born globally with sickle cell disease each year have beta thalassemia with 1500 of them coming from Africa (Fattoum, 2009).

The incidence rate of SCD in a population is determined by the proportion of carriers present in that population (Weatherall & Clegg, 2001). According to Anie et al. in 2010, the proportion of healthy carriers i.e. people living with sickle cell trait ranges between 10% to 40% across Equatorial Africa and declines to about 1% to 2% in Northern Africa and below one percent in Southern Africa (Anie et al., 2010). In West African countries like Ghana and Nigeria, carriers are 15% to 30% more frequent than they are in countries like Uganda and Tanzania in Eastern Africa (World Health Organisation, 2006). As carriers tend to be protected against malaria-related mortality and hence have increased survival and consequently continuous transmission

of the HbS gene, it is believed that this distribution in Ghana and Nigeria reflects present or historical exposure to plasmodium malaria infection (Anie et al., 2010).

2.3Knowledge of Sickle Cell Disease

2.3.1 Causes of SCD

Sickle hemoglobin (HbS) is an abnormal form of adult hemoglobin that results from a mutation in the HBB gene and is passed down through an autosomal recessive Mendelian gene (Piel et al, 2013). Unlike normal hemoglobin-containing red blood cells which are round in shape, smooth, and flexible, red blood cells with sickle hemoglobin are very stiff and sticky in nature and take the form of a crescent moon or sickle when they run out of oxygen thereby obstructing blood arteries and causing pain as a result (John Hopkins medicine, 2022). The disease is passed on when one inherits two sickle cell genes, one from each parent. If a person inherits just one gene from a parent, that person is known as a carrier or someone with the sickle cell trait (SCT) and has a 1 in 4 chance of giving birth to a child with the disease if he or she has that child with another carrier (Mulumba & Wilson, 2015). In a study conducted in 2018 in Ghana by Boadu and Addoah, almost all 350 respondents who took part in the study were aware of the disease with 48% of them believing that the disease was obtained by inheriting the SCD genes from both parents. It was also established by the authors through the responses gathered that a high level of education was significantly associated with higher knowledge levels of SCD (Aboagye & Aboagye, 2019). A similar study by Orish et al., 2014 with the title "Evaluating the knowledge of sickle cell disease and hemoglobin electrophoretic patterns among people living in Sekondi-Takoradi Metropolis, Ghana" indicated that males, married couples especially those with children, and older individuals were more likely to have good knowledge on SCD as compared to females, singles and younger individuals. With the general knowledge levels of individuals toward SCD, studies by Uche et al, (2017) and Boadu & Addoah, (2018) reported an overall fair knowledge and a poor knowledge of students toward SCD respectively.

2.3.2 Symptoms of SCD

Symptoms of SCD include anemia which occurs as a result of the short-lived nature of sickle-shaped cells which causes a shortage of red blood cells in the body and leads to exhaustion, dizziness, and shortness of breath. Another symptom that can be fatal is acute chest syndrome. It arises mainly when sickle cells stick together and block the flow of oxygen to the lungs (Rees et al., 2010). Due to the shorter lifespan of sickle cells than typical red blood cells, they degenerate faster than the liver can remove them from the body. These disintegrated cells produce bilirubin, which accumulates in the body and gives these broken-down cells their yellow hue and causes jaundice. The most prevalent clinical symptom of this illness, however, is pain, which causes excruciating misery. SCD produces serious lifetime morbidity that necessitates frequent, extended hospital stays (Isah et al., 2016). Other symptoms include priapism, splenic sequestration, etc. (Chakravorty & Williams, 2015). In a study on the knowledge and home management strategies among caregivers in Northern Ghana, caregivers noted fever, difficulty in breathing, pain, swelling of the limbs, jaundiced eyes, and yellowish urine as some of the symptoms of SCD (Ajinkpang et al., 2022).

2.3.3 Diagnosis of SCD

Sickle cell disease can be diagnosed with the aid of clinical laboratory tests. Both biochemical and molecular tests are run on blood samples for the detection of hemoglobin S, and diagnosis of SCD or SCT (Wajcman & Moradkhani, 2011). The full blood cell count, Hb electrophoresis, and high-performance liquid chromatography, regarded as the best for SCD diagnosis are the most commonly used biochemical and molecular tests (Fonseca et al., 2015).

Newborn screening (NBS) is a successful, early diagnosis approach for enabling the start of penicillin prophylaxis, which guards against invasive, life-threatening pneumococcal infections (Rankine-Mullings & Owusu-Ofori, 2021). Additionally, NBS offers access to

evidence-based clinical care, prompt enrollment of newborns in comprehensive care clinics, and effective healthcare education and counseling for families (Kato et al., 2018).

Late diagnosis, which is more prevalent in sub-Saharan Africa (SSA), where the burden of SCD is the largest, results in severe morbidity and extremely high childhood mortality rates of up to 50–90% (Wastnedge et al., 2018). There continues to be potential for early SCD detection as part of a thorough, all-encompassing strategy, commencing with diagnosis and complication prevention in the newborn period and extending across the lifespan to prevent premature death.

2.3.4 Morbidities associated with SCD

SCD is a chronic disease with several complications associated with it. These complications include musculoskeletal disorders, stroke, pulmonary hypertension, septicemia, and chronic pain. These complications frequently coexist, reducing the quality of life of patients and, if left untreated, increasing the risk of death (Mulumba & Wilson, 2015) with Stroke being the most critical complication due to vascular occlusion. In developed countries, people living with SCD have a 250-fold increased chance of having a stroke compared to people without the condition. An example is the United States where 24% of people who have SCD suffer a stroke at 45 years of age (Kolapo & Vento, 2011). Again, in the United States, about 30% of SCD patients suffer from pulmonary hypertension caused by chronic hemolysis which kills most patients after 3 years of diagnosis (Battersby et al., 2010). In a study conducted by Balogun et al. in 2010, out of 318 children with SCD in Nigeria, most of them who were below the age of 10 experienced multiple musculoskeletal disorders with 7.2% of them having avascular necrosis with femoral head, 63.3% with osteomyelitis and 95% of them having septic arthritis. Of those between the ages of 11 and 20, 5% had septic arthritis, 30.6% had osteomyelitis and 46.4% had avascular necrosis of the femoral head (Balogun et al., 2010).

According to research found in articles published between 2005 and 2010, bacterial infections that induce septicemia are a major cause of morbidity and mortality for children with SCD in Africa, especially those under the age of two (Battersby et al., 2010; Booth et al., 2010, Williams et al., 2009).

2.3.5 Management of SCD

The past 20-50 years have seen tremendous improvements in the management of SCD globally, in Africa, and Ghana (Campbell et al., 2022). The average life expectancy which was 14 years in the 1970s, is now 47 years (Lubeck et al., 2019; Campbell et al., 2022) as a result of the improvements in management practices. These practices have included drinking lots of water, the use of pain medication, intravenous infusions, folic acid, blood transfusions, and antibiotics (John Hopkins Medicine, 2022). Since the 1980s, novel approaches to sickle cell disease treatment have also included the implementation of penicillin prophylaxis for sickle cell children, the establishment of newborn screening programs, and the use of transcranial Doppler screening for the detection of cerebral vasculopathy and stroke prevention (Gardner, 2018).

In the 1980s, hydroxyurea, the only medication that was found to effectively lower the frequency of unpleasant episodes was introduced into clinical practice for adults. It was designed as a cancer-fighting medication and has been used in the management of cancers like leukemia and ovarian cancer (McGann & Ware, 2015). In 1984, hydroxyurea was tested in sickle cell disease and was found to increase the hemoglobin level of sickle cell patients and their fetal hemoglobin (HbF), reduce their pain episodes by 50% as well as lower blood transfusion rates in adults by 50% (Agrawal et al., 2014). With increasing evidence of hydroxyurea's safety and efficacy in both adults and 50% of children, its use is increasing in both high- and low-income countries, but it remains underutilized (Piel et al., 2017).

In November 2019, the government of Ghana partnered with Novartis, a Swiss-American multinational pharmaceutical company to improve and speed up treatment for SCD patients

with the use of hydroxyurea (Novartis, 2019). On World Sickle Cell Day (June 19th) in 2021, Ghana's government announced the provision of hydroxyurea for SCD patients through the National Health Insurance Scheme (Ohene-Frempong et al., 2022).

The management of SCD includes disease prevention as a key component. One of the ways to prevent SCD is through premarital screening. Premarital screening, which forms a part of genetic counseling is a series of tests that are conducted for engaged couples in order to rule out any genetic or infectious ailments that might be passed to their offspring or each other throughout their marriage and also for them to have the right information to influence decision making where health is concerned (Rahman et al., 2014). In Ile-Ife (Nigeria), a study by Abioye-Kuteyi et al. (2009) found that one-fourth of married and soon-to-marry respondents were unaware of their partner's sickling status. According to one-third to two-thirds of the study participants, they would keep dating their partner regardless of the outcome of any premarital screening. Another study was conducted by Memish and Saeedi (2011) in Saudi Arabia on the effect of premarital and genetic counseling on SCD and B-thalassaemia throughout a six-year period (2004 to 2009) and at the end of the period, the results showed a reduction in the number of marriages that were at risk for producing SCD and B-thalassaemia offspring which meant that there will be less genetic diseases in the country in the coming years. Additionally, it was deduced that premarital screening has a greater advantage over newborn screening since it is a method for primary prevention (Memish & Saeedi, 2011).

2.4Perception and Attitude toward SCD

Being well-informed about sickle cell disease is a key component in its prevention and in treating people with the disease better. Although a study conducted in Nigeria among unmarried people indicated a high level of awareness of the disease, the majority of respondents lacked sufficient information about the illness (Adigwe, 2022). A study in Jos revealed that

one-fourth of 137 students sampled mistakenly thought that sickle cell disease was brought on by evil spirits (Olakunle et al. 2013). Among the Igbo communities in Nigeria, the disease is believed to be the outcome of evil reincarnation (Anie, 2010).

Another study in the Republic of Benin highlighted that the majority of the survey participants were aware that sickle cell disease is a blood disorder. However, there were some misconceptions, as a sizable portion incorrectly associated bacterial and viral infections with the condition. Other myths debunked by the study and other studies include the claims that sickle cell illness is contagious and that more than 80% of those who have it die before the age of 20 (Zounon et al., 2012; Lanzkron et al., 2013). The prevalence of these beliefs was higher among people who knew they had SCD or carried the gene than among people who did not. Again in Benin, people think that the illness is brought on by an evil spirit nibbling on their child's bones and seeking the assistance of a traditional healer for a cure (Rahimy et al., 2012).

In Ghana, a qualitative study was conducted on caregivers to find out their perception of the disease. Results from this study showed that majority of the caregivers either didn't know the source of the ailment or believed that it was brought on by stomach worms that rendered individuals weak, in line with local superstitions and beliefs (Ajinkpang et al., 2022). Tusuubira et al. (2018) noted a generally negative perception displayed by participants in a study they conducted on SCD. In a similar research conducted by Boadu & Addoah (2018), most of the participants had a positive attitude toward SCD where 52.9% of the participants worried strongly about people with SCD. Other researches by Uche et al, (2017), Ameade et al, (2015) and Olatona et al, (2012) also reported that more than half of the participants were unwilling to continue relationships that would put them at risk of having children with SCD.

2.5Practices towards SCD

Newborn screening is a low-cost intervention that decreases the rates of morbidity and mortality associated with sickle cell disease through early detection. In sub-Saharan Africa, there are no universal screening programs, and only a few hospitals and organizations are capable of carrying out screening for newborns despite the fact that the disease burden is high (Segbefia et al, 2021). In Africa, seven countries—Ghana, Kenya, Liberia, Nigeria, Uganda, Tanzania, and Zambia—participating institutions will receive standard-of-care screening and early intervention therapies made possible by a partnership between Novartis and ASH's Consortium on Newborn Screening in Africa (CONSA). CONSA conducts clinical follow-ups for infants with SCD and screens 10,000–16,000 newborns annually in each nation (Novartis, 2022).

Preimplantation genetic diagnosis (PGD) identifies defective embryos early in the prenatal genetic diagnosis process so that only genetically healthy embryos are used for implantation (Parikh et al., 2018). Preimplantation genetic diagnosis (PGD) is now a viable option for couples who want to avoid pregnancy termination but are concerned about passing a known genetic disorder to their unborn child. Prenatal genetic diagnosis (PND) is not always acceptable due to moral and religious considerations; therefore, PGD may be a suitable substitute and can also be an effective method to increase the success rate of in vitro fertilization (Keshvar et al., 2022). In a study conducted on parents with SCD to find out their knowledge and awareness of PGD, only 16 (24%) of the 67 parents who responded to the survey had heard of preimplantation genetic testing (PGT) for SCD, 65 out of 67 parents (97%) said it was crucial or extremely crucial for parents of children with SCD to be aware of PGT and 29 out of 32 parents who are considering having more kids (91%) mentioned they would personally use PGT if it was covered by insurance (Attia et al., 2020).

A more practical way which has been found to be more effective in decreasing the incidence of SCD than newborn screening and PGD (Memish & Saeedi, 2011) is by avoiding marriages or childbirth with partners whose genotypes puts one at risk of having SCD children. A research by Uche et al. (2017) reported that 79% of participants decided against marrying their partners if they were going to be put at risk of having SCD babies. Likewise, another study conducted by Olatona et al. (2012) on the effects of health education on knowledge and attitude toward SCD found a significant decrease in the proportion of participants who had agreed to marry their partners if they were both carriers and be childless after they had gained more insight on the disease.

2.6Association between SCD status and Socio-demographic factors

The clinical course and fate of SCD are strongly predicted by the sociodemographic characteristics of those who have the condition (Nwabuko et al., 2022). In evaluating the knowledge of sickle cell disease and hemoglobin electrophoretic pattern among people living in Sekondi-Takoradi Metropolis, Ghana by Orish et al, age, education, and marital status were associated with a better awareness of sickle cell disease status and genotype in this study. Older participants, as well as those who had tertiary education and married participants who had children of their own, knew their SCD status. The study also established that people's knowledge of SCD had a significant impact on them knowing their SCD status (Orish et al., 2014). Ameade et al, 2015 also found a significant association between gender and knowledge of SCD status. In the study, more females were aware of their SCD status than males which was linked to the fact that women who visited antenatal clinics during their pregnancies were tested for SCD and given information about it, which may have also had an impact on their knowledge of the condition.

CHAPTER 3
METHODOLOGY

3.1 Introduction

This chapter gives a detailed description of the methods used in successfully carrying out this study. Section one provides information on the study design used, section two describes the study area, section three talks about the study population, with its inclusion and exclusion criteria. The fourth section highlights the dependent and independent variables used in this study. Section five gives an overview of the sample size used and how it was calculated for the study and section six discusses the sampling technique used. Sections seven, eight and nine highlights how data were collected, the tools used in collection and where and how the pilot study for this research was conducted. Section ten entails information regarding the data analysis for this study, section eleven talks about quality control measures, section twelve about inform consent and section thirteen about voluntary participation. Section fourteen talks about confidentiality/privacy, section fifteen discusses Data storage and use and section sixteen talks about the plan for dissemination of results. The last sections, which are sections seventeen, eighteen and nineteen talks about ethical considerations, cost/compensations and conflict of interest respectively.

3.2 Study Design

A descriptive cross-sectional study with a quantitative approach was adopted in this study to seek information on knowledge, perception, and practices regarding sickle cell disease among young adults living in Tema. This study design was used because it will help in analyzing information about a population at a specific time. This study is a social/behavioral research.

3.3 Study Area

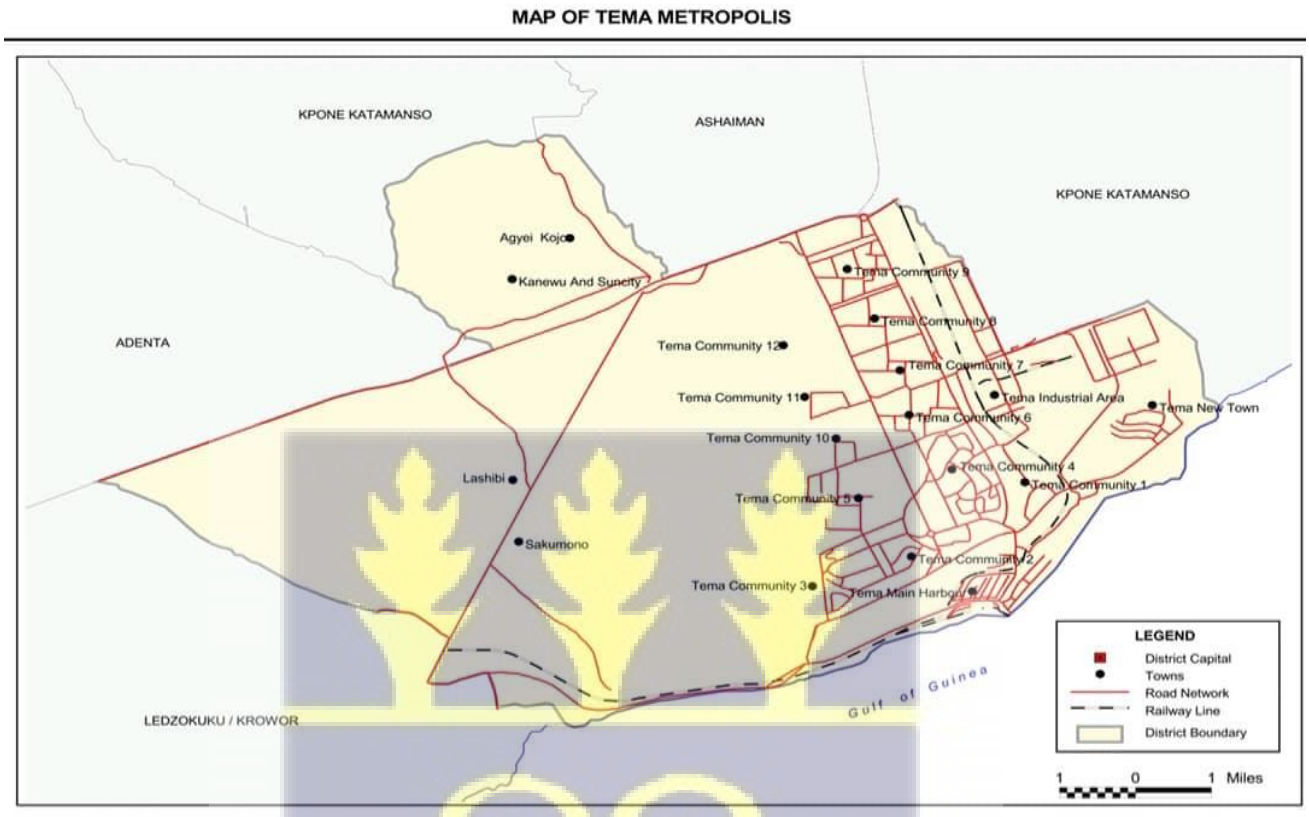


Figure 3.1 A map of Tema Metropolis showing the communities where the study was carried out.

Source: https://www.ghanadistricts.com/Home/LinkDataDistrict/5243

Tema is a city located in the Greater Accra region and the southeastern part of Ghana. It is located 25 kilometers east of Ghana's capital, Accra. It is the capital of the Tema Metropolitan District and has a total population of about 196, 224 people with 96,846 males and 99,378 females based on 2021 statistics (Ghana Statistical Service, 2021). In 2013, Tema was ranked the eleventh most populous city in Ghana. It covers an area of 50.90km^2 with a population density of about 3,855/km^2 and has 25 communities.

It is one of the major industrial hubs and it also houses the largest port in Ghana hence the nickname, "the harbor city". Tema was built on a small fishing site where a local calabash plant named "Tor" was cultivated (Jackson & Oppong, 2014). It was initially named "Torman" after

which the name Tema was adopted. The city was commissioned by Osagyefo Dr. Kwame Nkrumah in 1961 by Ghana's first president and expanded quickly after the harbor was built. Major industries in Tema include Ghana Textile Print (GTP), Tema Oil Refinery (TOR), Valco Aluminium Company (VALCO), Pioneer food company, Nestle Ghana Ltd, etc. Tema has a polyclinic and a general hospital among other health facilities. There are also several primary, junior and secondary schools as well as a few university campuses (Tema Metropolitan Assembly, 2021).

Tema metropolitan forms part of the metropolis and municipal districts in the Greater Accra Region and shares boundaries with other municipal districts like Ledzokuku-Krowor, Ashaiman, Kpone Katamanso, and Adenta (Jackson & Oppong, 2014).

3.4 Study Population

The population for this study consisted of young adults aged 18-40 years who were either local indigenes of Tema or had migrated to the city as a result of school, work, etc. The total number of young adults aged 18 to 40 years according to the 2021 population census is about 80,000 (City Population, 2021).

3.4.1 Inclusion Criteria

All males and females who were 18 to 40 years old and live, school, or work in Tema and gave consent to participate in the study.

3.4.2 Exclusion Criteria

All males and females who school, work, or reside in Tema but do not fall within the ages of 18 to 40 and all those who were unwilling to take part in the study even though they fell within the age bracket were excluded.

3.5 Variables

Dependent variables – Knowledge, attitude, perception, practices, and sickle cell disease.

Independent variables – Socio-demographic factors like gender, age, marital status, religion, and cultural/ ethnic beliefs.

3.6 Sample Size Calculation

A sample size is a fraction of a given population that serves as a representation of the entire populace, selected to partake in a study (Andrade, 2020). The sample size for this study was determined based on the Yamane, 1967 criterion (Umar & Wachiko, 2021):

$$n = \frac{N}{1+N(e)^2}$$

Where:

n = completed sample size needed

N = size of the young adult population in Tema

e = the level of precision. Therefore

$$n = \frac{80000}{1+80000(0.05)^2}$$

$$n = \frac{80000}{201}$$

$$n = 398.0099 = 399 = 400$$

Therefore, a sample of 400 people were selected as participants for the study.

3.7 Sampling method

A homogenous purposive sampling technique which is a non-probability quantitative sampling method was adopted in this study. This method was employed to find 16 volunteers each in the 25 communities in Tema who were 18 to 40 years and were willing and comfortable to participate in the study. 400 out of the 80,000 young adult population in Tema were sampled from churches, schools, marketplaces, hospitals, households, etc. in the various communities to take part in this study.

3.8 Data Collection

A structured questionnaire was used as a means to gather data from young adults in Tema who fell within the inclusion criteria. The questionnaire was designed with clear response instructions and made easy to answer. The structured questionnaire was pre-tested in Ashaiman, a municipal district that shares boundaries with Tema to ensure the questions' appropriateness, directions, and arrangement, as well as the content's comprehensiveness, technological feasibility, and clarity.

The questionnaire required participants to anonymously complete questions related to their socio-demographics, knowledge, perception, attitude, and practices on Sickle cell disease. Participants were educated on the concept of the research and the potential benefits to the individuals and the metropolis as a whole if the study is successful. All participants' consent was sought before issuing questionnaires for them to fill out.

3.9 Data Collection Tool

The data collection instrument used for this study was a structured questionnaire. Previously published open-access studies with similar titles and objectives/ research questions served as a guide in constructing the data collection instrument which was used for this study and all adopted questions were duly cited. The structured questionnaire was divided into 5 sections.

The first section examined the socio-demographic characteristics (sex, age, marital status, religion, occupation, etc) of young adults in Tema and also examined the prevalence of sickle cell disease among them. Section two examined the knowledge young adults in Tema have regarding SCD, section three looked at the perception of the study population toward SCD, the fourth section examined their attitude and the last section examined practices towards sickle cell disease. Scores between 0 and 0.5 were considered as poor knowledge, attitude, perception, and practices, while scores between 0.6 and 1 were considered as good knowledge, attitude, perception, and practices. All of the "Yes" responses were the appropriate answers to the questions posed, which were scored as either 1 for "Yes" responses or 0 for "No/I don't know" responses. The questionnaire can be found in appendix C.

3.10 Data Analysis

The data obtained was analyzed for discussion using STATA-IC version 16.1 statistical software.

Descriptive statistics on the independent variables (socio-demographic characteristics of participants) were presented in frequency tables, graphs, and summary statistics. The prevalence of SCD among young adults in Tema was calculated using proportions. Also, Logistic regression analysis was used to compute associations between the socio-demographic characteristics of participants and the knowledge of SCD, perception, attitude, and practices among young adults in Tema. The association between SCD status and socio-demographic characteristics of participants was also analysed using logistic regression.

3.11 Quality Control Measures

The data collection tool which is the questionnaire was pretested in the Ashaiman community to ensure the quality of the data. This helped in the determination of how clear the questions

were to the participants and also helped in identifying inconsistencies that arose during the collection of data. Data was checked for errors after every data collection session. Two research assistants were recruited and trained to assist in the data collection process as well.

3.12 Ethical Considerations

Approval for this study was sought from the Institutional Review Board of the Noguchi Memorial Institute for Medical Research. All participants received a detailed explanation that included the purpose of the study and its methods. Written informed consent was taken from each participant. The study conserved participants' privacy and maintained the confidentiality of the data. Permission was also sought from the authorities of selected schools, health facilities and churches before sampling of participants and administering of questionnaires.

3.12.1 Inform consent

Prior to the collection of data, informed consent was sought from each participant. All participants were expected to select the Yes box to confirm consent before filling out both the e-questionnaires and hard copies.

3.12.2 Voluntary participation

Participants were informed about their option to withdraw from the study even after providing their initial consent. Participants were also in33formed that their withdrawal from the study had no negative consequences.

3.12.3 Confidentiality and privacy

Confidentiality and privacy was assured to the participants. All data gathered were made anonymous. Both the identity of the research participants and the confidentiality of the research data were guaranteed.

3.12.4 Data storage and use

Responses to online surveys were automatically saved in the Google Forms response folder. With the help of the two research assistants recruited, data from the in-person surveys on the other hand, were entered into the google forms response folder generated. The data was saved in Excel and stored on the laptop with a password only the researcher had access to and transferred to STATA version 16 for analysis.

3.13 Dissemination of Results Plan

Findings from this study will be published as an article and also disseminated to the Ghana Health Service, Tema General Hospital, Ghana Institute of Clinical Genetics at the Korle Bu Teaching Hospital, and the University of Ghana, School of Public Health.

3.14 Cost /compensation

This study was self-funded and there were no compensations or payments to participants.

3.15 Conflict of interest

There were no potential conflicts of interest in the study.

CHAPTER 4
RESULTS

4.1Introduction

This chapter presents the results according to the objectives of the research conducted on the knowledge, perception and practices of young adults in Tema toward sickle cell disease. The findings on the prevalence of SCD, awareness of sickle cell trait and disease, sources of information about SCD, knowledge of SCD, attitude toward SCD, perception and practices toward SCD as well as the association between socio-demographic characteristics and SCD status and knowledge of SCD have been represented in graphs and tables to give a clear overview of what this study sought to achieve.

4.2Socio-demographic characteristics of participants

Females were the majority of participants (56%) in the study. With participants' ages ranging from 18 to 40 years, most of them were found to be within the 21 – 30 age group with the mean age being 27 years (standard deviation (SD) ±6). The majority of the participants were single (77%), and a greater percentage of them were Christians as well (78.8%). A higher proportion was of the Akan ethnicity (49.3%), followed by those belonging to the Ga ethnic group (18.5%). The majority of participants had also attained tertiary education (71%) and most of them were employed (80.5%). The majority of the participants (77.3%) had no biological children as shown in Table 4.1 below.

Table 0.1 Socio-demographic characteristics of participants

Variable	Frequency	Percentage (%)
Gender		
Male	176	44
Female	224	56
Age (in years)		
Below 21	55	13.75
21 – 30	242	60.5
31 – 40	103	25.75
Marital status		
Single	308	77
Married	92	23
Religion		
Christian	315	78.75
Muslim	64	16
Other	21	5.25
Ethnicity		
Akan	197	49.25
Ewe	54	13.5
Ga	74	18.5
Mole-Dagbon	33	8.25
Other	42	10.5
Educational level		
No formal education	27	6.75
JHS	14	3.5
SHS	75	18.75
Tertiary	284	71
Occupation		
Employed	322	80.5
Unemployed	78	19.5
Biological child		
Has biological children	91	22.75
Has no biological children	309	77.25
Total	**400**	**100**

4.3Prevalence of SCD

As shown in Figure 4.1 below, the prevalence of Sickle Cell Disease among participants was 9%.

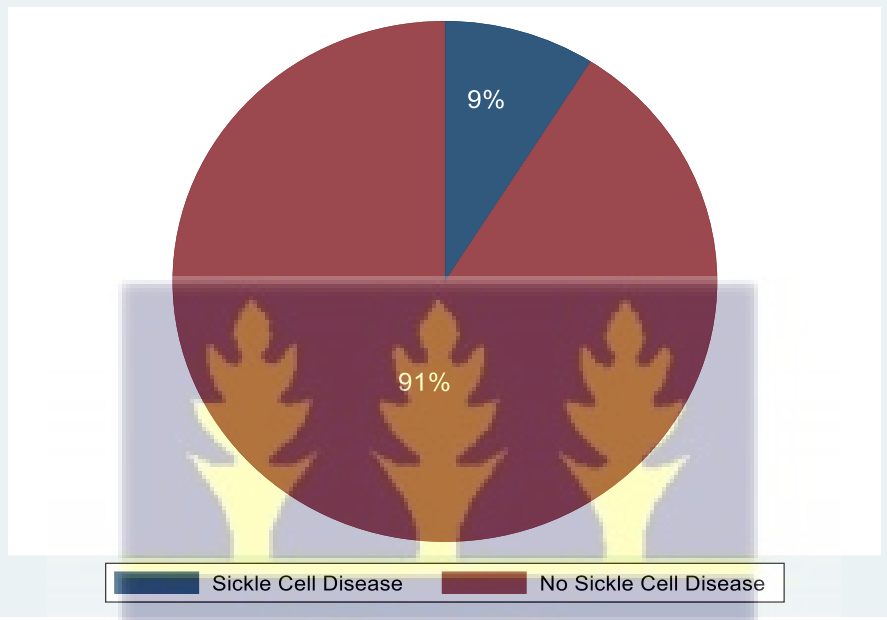


Figure 0.1 Prevalence of Sickle Cell Disease among participants

4.3 Awareness of Sickle Cell Disease and Sickle Cell Trait

Majority of the participants (94.8%) had heard of SCD and hence were aware of the disease as shown in figure 4.2 below.

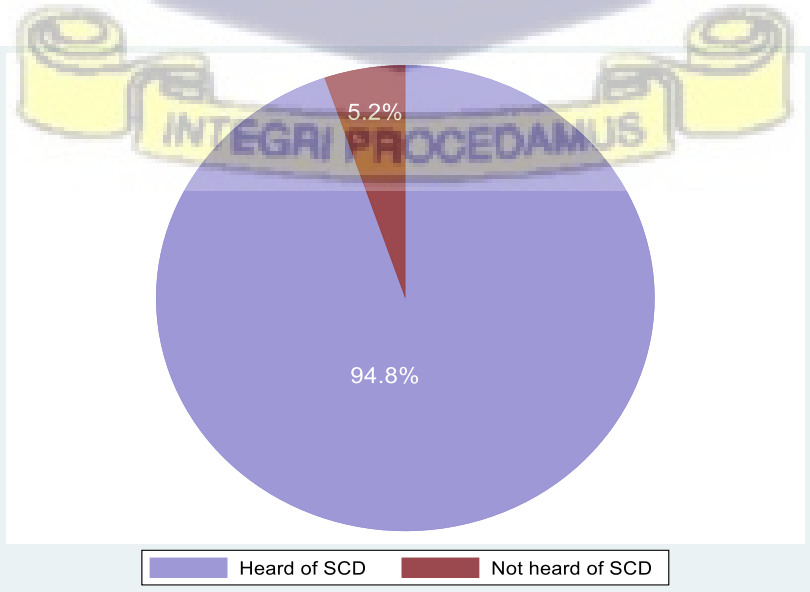


Figure 0.2 Participants' awareness of Sickle Cell Disease.

As shown in figure 4.3, a higher proportion of the participants (69.8%) indicated that they have heard of Sickle Cell trait.

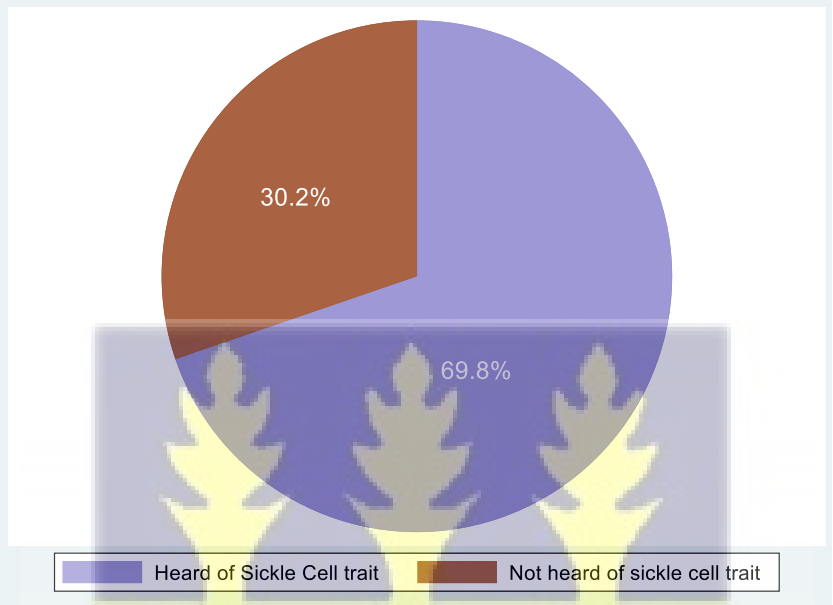


Figure 0.3 Sickle Cell trait awareness of participants

4.4Sources of Information about Sickle Cell Disease

Health professionals serve as source of information of SCD for half of the participants (50%), followed by internet (44.8%) and then friends/family (39.5%) as shown in Table 4.2.

Table 0.2 Sources of information about SCD

Variable	Frequency	Percentage (%)Ψ
Source of information about SCD		
TV/radio	114	28.5
Internet	179	44.8
Friends/family	158	39.5
Health professionals	200	50.0
Other	82	20.5

Ψ **Multiple responses, percentages represent percentage of cases**

4.5Knowledge of Sickle Cell Disease

Majority of the participants (72.5%) correctly indicated the cause of SCD as being genetically inherited. In addition, majority (75.5%) correctly indicated the use of blood test as a way of diagnosing SCD, while most (69.5%) correctly indicated that, SCD is preventable. 73.8% of the participants correctly indicated genetic counselling/pre-marital screening as a way of prevention. 134 participants (33.5%) correctly predicted that, there will be no chance of having healthy children by parents who both have SCD as shown in table 4.3 below.

Table 0.3 Knowledge of SCD

Variable	Frequency	Percentage (%)
Cause of SCD		
Acquired	45	11.25
Family curse	7	1.75
Spiritual attack	6	1.5
Genetically inherited	290	72.5
Don't know	52	13
How SCD is diagnosed		
Blood test	302	75.5
Urine test	18	4.5
Don't know	80	20
Preventability of SCD		
Preventable	278	69.5
Not preventable	40	10
Don't know	82	20.5
Way of SCD prevention		
Genetic counselling/Pre-marital screening	295	73.75
Abortion	15	3.75
Don't know	90	22.5
Chance of having healthy baby with SCD parents		
100%	37	9.25
50%	27	6.75
25%	84	21
No chance	134	33.5
Don't know	118	29.5
Total	**400**	**100**

Frequent sickness was known to majority of the participants (77.3%) as a sign/symptom of Sickle Cell Disease, followed by skinny body (28.0%) as shown in table 4.4 below.

Table 0.4 Knowledge of Signs/ Symptoms of SCD

Variable	Frequency	Percentage (%)Ψ
Signs/ Symptoms of SCD		
Skinny body	112	28.0
Frequent sickness	309	77.3
Yellow eyes	109	27.3
Don't know	56	14.0

Ψ Multiple responses, percentages represent percentage of cases

Majority of the participants (73.5%) had good knowledge of SCD as shown in figure 4.4 below.

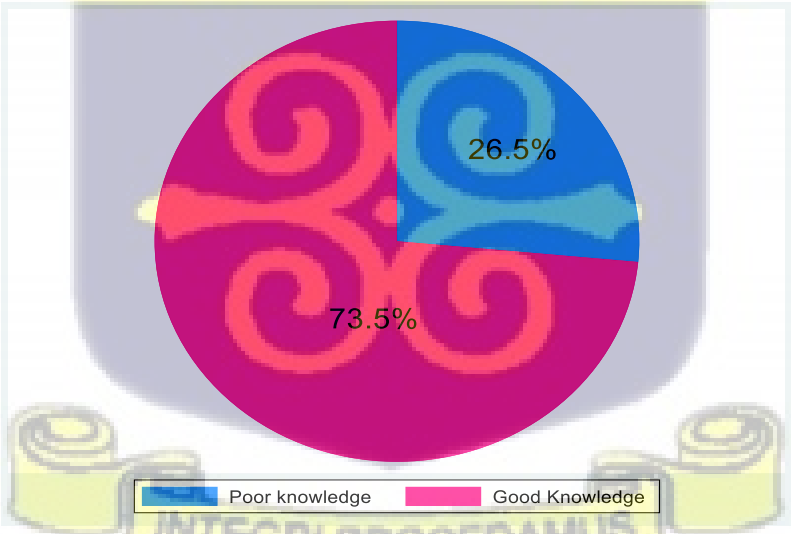


Figure 0.4 Overall knowledge of Sickle Cell Disease of participants

4.6Attitude towards Sickle Cell Disease

About half of the participants (50.2%) agreed that, there should be a feeling of sympathy for people with SCD, while few of the participants (37.8%) disagreed saying that, people should worry less about those living with SCD since they may die soon. Exactly half of the participants (50%) agreed that, a relationship should be ended if partner's genotype will risk having a child

with Sickle Cell Disease. Very few of the participants (6.5%) agreed that, they would choose not to have a child than to have a baby with SCD as shown in table 4.5 below.

Table 0.5 Attitude towards Sickle Cell Disease

Variable	Frequency	Percentage (%)
Feel sympathetic for people with SCD		
Agree	201	50.25
Disagree	199	49.75
Worry less about people with SCD since they may die soon		
Agree	249	62.25
Disagree	151	37.75
End relationship if partner's genotype risks having SCD child		
Agree	200	50
Disagree	200	50
Choose not to have a child than have SCD baby		
Agree	26	6.5
Disagree	374	93.5
Total	**400**	**100**

Overall, majority of participants (86.3%) have poor attitude towards SCD as shown in figure 4.5 below.

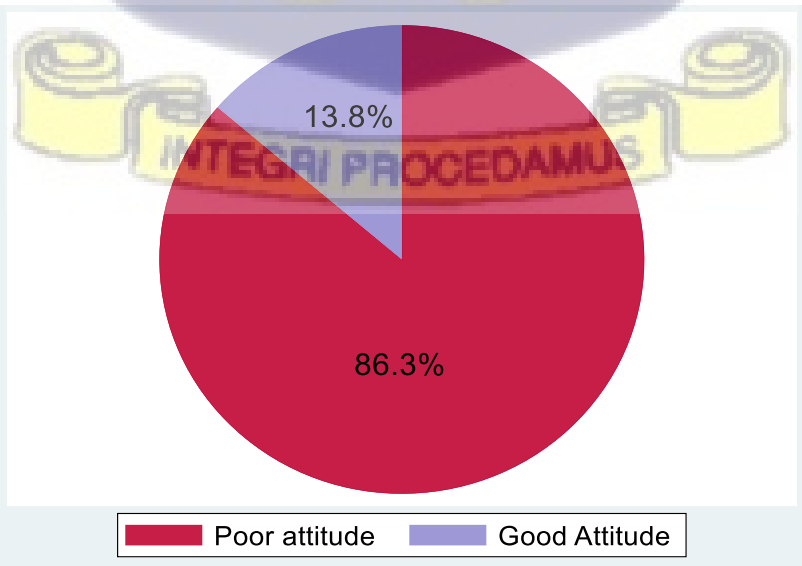


Figure 0.5 Overall Attitude of participants towards Sickle Cell Disease

4.7Perception about Sickle Cell Disease

A higher proportion of participants (56.3%) agreed that, a person with SCD can work, while 52.5% also agreed that, a person with SCD can school. Most participants (54%) agreed that, a person with SCD can live a normal life, while few (23.3%) disagreed that, a person with SCD cannot live long. Less than half of the participants (47.8%) disagreed that, people with SCD are disabled, while also only 42% disagreed that, people with SCD are abnormal. About one-third of the participants (30.8%) disagreed that, people with SCD are not to be treated as normal people as shown in table 4.6 below.

Table 0.6 Perception about Sickle Cell Disease

Variable	Frequency	Percentage (%)
One with SCD can work		
Agree	225	56.25
Disagree	175	43.75
One with SCD can school		
Agree	210	52.5
Disagree	190	47.5
One with SCD can live normal life		
Agree	216	54
Disagree	184	46
One with SCD cannot live long		
Agree	307	76.75
Disagree	93	23.25
People living with SCD are disabled		
Agree	209	52.25
Disagree	191	47.75
People living with SCD are abnormal		
Agree	232	58
Disagree	168	42
SCD patients are not to be treated as normal people		
Agree	277	69.25
Disagree	123	30.75
Total	**400**	**100**

Overall, majority of participants (60.7%) had poor perception about SCD as shown in figure 4.6.

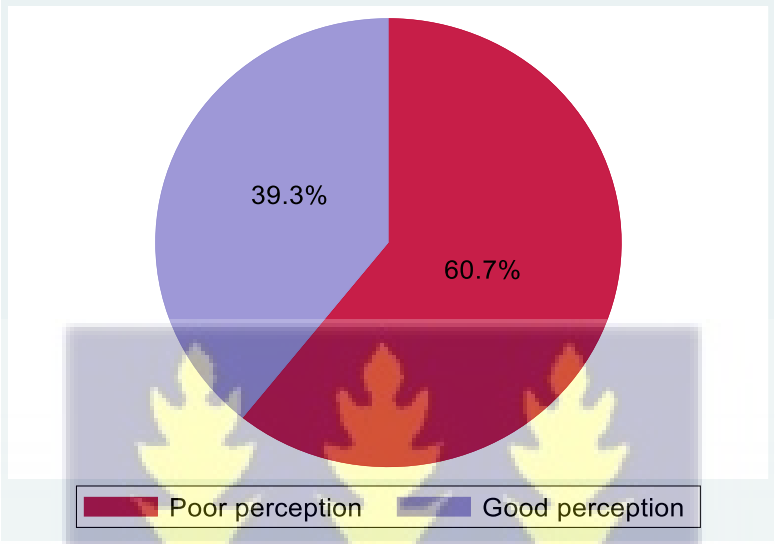


Figure 0.6 Overall Perception of Participants about SCD

4.8Practices towards Sickle Cell Disease

A higher proportion of participants (54.5%) had tested for SCD. Majority of participants (76%) indicated that, knowledge of partners' genotype influenced or will influence their decision to marry said partner. Majority (72.8%) were not willing to continue a relationship if it poses a risk of having SCD baby as shown in Table 4.7.

Table 0.7 Practices towards SCD

Variables	Frequency	Percentage (%)
Ever tested for SCD		
Ever tested	218	54.5
Never tested	182	45.5
Knowledge of partner's genotype influence marriage decision		
Knowledge influenced/will influence decision	304	76
Knowledge didn't/wont influence decision	96	24
Willing to continue relationship despite risk of having SCD baby		
Willing	109	27.25
Not willing	291	72.75
Total	**400**	**100**

Figure 4.7 below shows that, of those who have ever tested for SCD, 28.4% were influenced by health issues, followed by curiosity (27.5%).

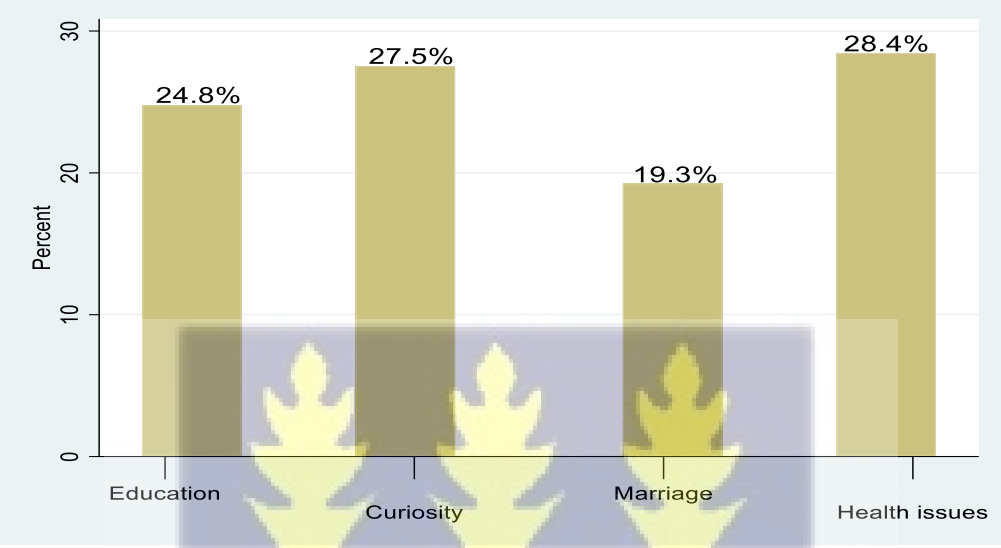


Figure 0.7 Factors influencing participants' decision to test for SCD

4.9Bivariate association between overall knowledge of Sickle Cell Disease and Socio-demographic characteristics

There was significant difference between participants who had poor knowledge and those who had good knowledge of SCD based on age (χ^2= 18.10, p<0.0001), religion (χ^2= 36.51, p<0.0001), ethnicity (χ^2= 32.72, p<0.0001), educational level (χ^2= 82.83, p<0.0001) and occupation (χ^2= 4.39, p=0.036). There was however, no significant difference among participants based on gender (χ^2= 0.01, p=0.935), marital status (χ^2= 0.50, p=0.481) and whether or not parent has biological child (χ^2= 0.33, p=0.568) as indicated below in Table 4.8.

Table 0.8 Bivariate association between overall knowledge of SCD and Socio-demographic characteristics

Variable	Level of knowledge of SCD						χ2	p-value
	Poor knowledge N (%)		Good knowledge N (%)		Total N (%)			
Gender							0.01	0.935
Male	47	(44.3)	129	(43.9)	176	(44)		
Female	59	(55.7)	165	56.1)	224	(56)		
Age (in years)							18.10	**<0.0001***
Below 21	8	(7.5)	47	(16)	55	(14)		
21 – 30	55	(51.9)	187	(63.6)	242	(61)		
31 – 40	43	(40.6)	60	(20.4)	103	(26)		
Marital status							0.50	0.481
Single	79	(74.5)	229	(77.9)	308	(77)		
Married	27	(25.5)	65	(22.1)	92	(23)		
Religion							36.51	**<0.0001***
Christian	62	(58.5)	253	(86.1)	315	(79)		
Muslim	35	(33)	29	(9.9)	64	(16)		
Other	9	(8.5)	12	(4.1)	21	(5.3)		
Ethnicity								
Akan	34	(32.1)	163	(55.4)	197	(49)	32.72	**<0.0001***
Ewe	18	(17)	36	(12.2)	54	(14)		
Ga	18	(17)	56	(19)	74	(19)		
Mole-Dagbon	20	(18.9)	13	(4.4)	33	(8.3)		
Other	16	(15.1)	26	(8.8)	42	(11)		
Educational Level							82.83	**<0.0001***
No formal education	8	(7.5)	19	(6.5)	27	(6.8)		
JHS	11	(10.4)	3	(1)	14	(3.5)		
SHS	45	(42.5)	30	(10.2)	75	(19)		
Tertiary	42	(39.6)	242	(82.3)	284	(71)		
Occupation							4.39	**0.036***
Employed	78	(73.6)	244	(83)	322	(81)		
Unemployed	28	(26.4)	50	(17)	78	(20)		
Biological child							0.33	0.568
Has biological children	22	(20.8)	69	(23.5)	91	(23)		
Has no biological children	84	(79.2)	225	(76.5)	309	(77)		

*Statistical significance, p<0.05

4.10 Multiple logistic regression analysis of the association between socio-demographic factors and knowledge of Sickle Cell Disease

Table 4.9 shows multiple logistic regression analysis of the association between socio-demographic factors (gender, age, religion, ethnicity, educational level, and occupation) and knowledge of SCD. From the crude analysis, age, religion, ethnicity, educational level, and occupation were significantly associated with overall knowledge of SCD. However, after adjusting for gender, age, religion, ethnicity and occupation, participants who had acquired tertiary education were 3.35 times more likely to have good knowledge about SCD compared with those who had no formal education [AOR=3.35, CI= (1.32- 8.50), p value=0.011)].

Table 0.9 Multiple logistic regression analysis of the association between socio-demographic factors and knowledge of Sickle Cell Disease

Variable	OR (95% CI) p-value	AOR (95% CI)	p-value
Gender	0.935		
Male	reference	reference	
Female	1.02 (0.65-1.59)	0.87 (0.51-1.49)	0.615
Age (in years):	**<0.001***		
Below 21	reference	reference	
21 - 30	0.58 (0.26-1.30)	0.73 (0.28- 1.93)	0.525
31 - 40	0.23 (0.10-0.55)	0.38 (0.13-1.14)	0.083
Religion	**<0.0001***		
Christian	reference	reference	
Muslim	0.20 (0.12-0.36)	0.52(0.23-1.19)	0.121
Other	0.32 (0.13-0.81)	0.92 (0.31-2.76)	0.879
Ethnicity	**<0.0001***		
Akan	reference	reference	
Ewe	0.42 (0.21-0.82)	0.63 (0.28-1.42)	0.265
Ga	0.65 (0.34-1.24)	0.83 (0.38-1.85)	0.655
Mole-Dagbon	0.14 (0.06-0.30)	0.50 (0.16-1.55)	0.230
Other	0.34 (0.16-070)	0.74 (0.29-1.91)	0.539
Educational level	**<0.0001***		
No formal education	reference	reference	
JHS	0.11 (0.03-0.53)	0.25 (0.05-1.22)	0.087
SHS	0.28 (0.11-0.72)	0.44 (0.16- 1.20)	0.109
Tertiary	2.43 (1.00-5.90)	3.35 (1.32- 8.50)	**0.011***
Occupation	**0.038***		
Employed	reference	reference	
Unemployed	0.57 (0.34-0.97)	0.62 (0.32-1.18)	0.147

*Statistical significance, p<0.05, OR=Crude Odds Ratio, AOR=Adjusted Odds Ratio

4.11 Bivariate association between overall attitude towards Sickle Cell Disease and Socio-demographic characteristics

From the results (Table 4.10), there was no significant difference between participants who had poor attitude and those who had good attitude towards SCD based on sociodemographic characteristics such as; gender (χ^2= 0.28, p=0.599), age (χ^2= 2.43, p=0.297), marital status (χ^2= 0.66, p=0.417), religion (χ^2=0.51, p=0.775), ethnicity (χ^2= 1.27, p=0.867), educational level (χ^2=1.25, p=0.74) occupation (χ^2= 0.07, p=0.79), and whether or not parent has biological child (χ^2= 0.27, p=0.606).

Table 0.10 Bivariate association between overall attitude towards SCD and Socio-demographic characteristics

Variable	Attitude towards SCD						χ2	p-value
	Poor attitude N (%)		Good attitude N (%)		Total N (%)			
Gender							0.28	0.599
Male	150	(43.5)	26	(47.3)	176	(44)		
Female	195	(56.5)	29	(52.7)	224	(56)		
Age (in years)							2.43	0.297
Below 21	51	(14.8)	4	(7.3)	55	(13.8)		
21 – 30	205	(59.4)	37	(67.3)	242	(60.5)		
31 – 40	89	(25.8)	14	(25.5)	103	(25.8)		
Marital status							0.66	0.417
Single	268	(77.7)	40	(72.7)	308	(77)		
Married	77	(22.3)	15	(27.3)	92	(23)		
Religion							0.51	0.775
Christian	272	(78.8)	43	(78.2)	315	(78.8)		
Muslim	54	(15.7)	10	(18.2)	64	(16)		
Other	19	(5.5)	2	(3.6)	21	(5.3)		
Ethnicity							1.27	0.867
Akan	172	(49.9)	25	(45.5)	197	(49.3)		
Ewe	47	(13.6)	7	(12.7)	54	(13.5)		
Ga	64	(18.6)	10	(18.2)	74	(18.5)		
Mole-Dagbon	28	(8.1)	5	(9.1)	33	(8.3)		
Other	34	(9.9)	8	(14.5)	42	(10.5)		
Educational level							1.25	0.74
No formal education	22	(6.4)	5	(9.1)	27	(6.8)		

JHS	13	(3.8)	1	(1.8)	14	(3.5)		
SHS	66	(19.1)	9	(16.4)	75	(18.8)		
Tertiary	244	(70.7)	40	(72.7)	284	(71)		
Occupation							0.07	0.79
Employed	277	(80.3)	45	(81.8)	322	(80.5)		
Unemployed	68	(19.7)	10	(18.2)	78	(19.5)		
Biological child							0.27	0.606
Has biological children	77	(22.3)	14	(25.5)	91	(22.8)		
Has no biological children	268	(77.7)	41	(74.5)	309	(77.3)		

*Statistical significance, p<0.05

4.12 Multiple logistic regression analysis of the association between socio-demographic factors associated with attitude towards Sickle Cell Disease

Table 4.11 shows multiple logistic regression analysis of the association between socio-demographic factors (Gender, age, marital status, religion, ethnicity, educational level, occupation and biological child) and attitude towards SCD. From both the crude and adjusted analysis there was no significant association between overall attitude towards SCD and sociodemographic factors (i.e., Gender, age, marital status, religion, ethnicity, educational level, occupation and biological child).

Table 0.11 Multiple logistic regression analysis of the association between socio-demographic factors and attitude towards Sickle Cell Disease

Variable	OR (95% CI)	p-value	AOR (95% CI)	p-value
Gender		0.599		
Male	reference		reference	
Female	0.85(0.48-1.52)		0.92(0.51- 1.66)	0.782
Age (in years):		0.312		
Below 21	reference		reference	
21 - 30	2.30(0.78-6.75)		2.10(0.67- 6.58)	0.204
31 - 40	2.01(0.63-6.42)		1.71(0.46-6.44)	0.425
Marital status		0.419		
Single	reference		reference	
Married	1.31(0.68- 2.49)		1.31(.44- 3.93)	0.630
Religion		0.7777		
Christian	reference		reference	
Muslim	1.17(0.55-2.47)		0.98(0.36-2.72)	0.984
Other	0.67 (0.14-2.96)		0.55 (0.11-2.80)	0.474
Ethnicity		0.870		

Akan	reference	reference	
Ewe	1.02(0.42-2.52)	0.91(0.35-2.39)	0.862
Ga	1.08(0.49-2.36)	0.97(0.41-2.30)	0.950
Mole-Dagbon	1.23(0.43-3.48)	1.35(0.34-5.38)	0.668
Other	1.62(0.67-3.89)	1.74(0.61-4.96)	0.296
Educational level	0.748		
No formal education	reference	reference	
JHS	0.33(0.04-3.22)	0.34(0.03-3.45)	0.359
SHS	0.6(0.18-1.98)	0.64(0.18-2.26)	0.487
Tertiary	0.72(0.25-2.01)	0.81(0.27-2.38)	0.707
Occupation	0.791		
Employed	reference	reference	
Unemployed	0.91(0.43-1.89)	1.00(0.44-2.24)	0.996
Biological child	0.607		
Has biological children	reference	reference	
Has no biological children	1.19(0.62-2.29)	0.97(0.32- 2.93)	0.963

OR=Crude Odds Ratio, AOR=Adjusted Odds Ratio

4.13 Bivariate association between overall perception about SCD and Socio-demographic characteristics

Results in Table 4.12 shows that, there was significant difference between participants who had poor perception and those who had good perception about SCD based on marital status (χ^2= 7.02, p=0.008) and whether or not parent had biological child (χ^2= 6.31, p=0.012). There was however, no significant difference between participants who had poor perception and those who had good perception about SCD based on gender (χ^2= 0.04, p=0.849), age (χ^2= 1.15, p=0.562), religion (χ^2=2.49, p=0.289), ethnicity (χ^2= 1.01, p=0.908), educational level (χ^2=4.11, p=0.25) and occupation (χ^2=0.38, p=0.538).

Table 0.12 Bivariate association between overall perception about SCD and Socio-demographic characteristics

Variable	Perception about SCD				Total N (%)		χ2	p-value
	Poor perception N (%)		Good perception N (%)					
Gender							0.04	0.849
Male	106	(43.6)	70	(44.6)	176	(44)		
Female	137	(56.4)	87	(55.4)	224	(56)		

Age (in years)							1.15	0.562
Below 21	34	(14)	21	(13.4)	55	(13.8)		
21 – 30	151	(62.1)	91	(58)	242	(60.5)		
31 – 40	58	(23.9)	45	(28.7)	103	(25.8)		
Marital status							7.02	**0.008***
Single	198	(81.5)	110	(70.1)	308	(77)		
Married	45	(18.5)	47	(29.9)	92	(23)		
Religion							2.49	0.289
Christian	188	(77.4)	127	(80.9)	315	(78.8)		
Muslim	44	(18.1)	20	(12.7)	64	(16)		
Other	11	(4.5)	10	(6.4)	21	(5.3)		
Ethnicity							1.01	0.908
Akan	119	(49)	78	(49.7)	197	(49.3)		
Ewe	32	(13.2)	22	(14)	54	(13.5)		
Ga	43	(17.7)	31	(19.7)	74	(18.5)		
Mole-Dagbon	21	(8.6)	12	(7.6)	33	(8.3)		
Other	28	(11.5)	14	(8.9)	42	(10.5)		
Educational level							4.11	0.25
No formal education	15	(6.2)	12	(7.6)	27	(6.8)		
JHS	12	(4.9)	2	(1.3)	14	(3.5)		
SHS	44	(18.1)	31	(19.7)	75	(18.8)		
Tertiary	172	(70.8)	112	(71.3)	284	(71)		
Occupation							0.38	0.538
Employed	198	(81.5)	124	(79)	322	(80.5)		
Unemployed	45	(18.5)	33	(21)	78	(19.5)		
Biological child							6.31	**0.012***
Has biological children	45	(18.5)	46	(29.3)	91	(22.8)		
Has no biological children	198	(81.5)	111	(70.7)	309	(77.3)		

4.14 Multiple logistic regression analysis of the association between socio-demographic factors and perception about SCD

Results in Table 4.13 shows multiple logistic regression analysis of socio-demographic factors (marital status, biological children, gender, age and educational level) and perception about SCD. The analysis showed that, there was no significant association between marital status, biological child, gender, age and educational level and overall perception of participants about SCD.

Table 0.13 Multiple logistic regression analysis of the association between socio-demographic factors and perception about SCD

Variable	OR (95% CI) p-value	AOR (95% CI)	p-value
Marital status	**< 0.009***		
Single	reference	reference	
Married	1.88(1.17- 3.01)	1.59 (0.75- 3.37)	0.230
Biological children	**0.013***		
Has biological children	reference	reference	
Has no biological children	0.55(0.34-0.88)	1.28(0.61-2.69)	0.521
Gender	0.850		
Male	reference	reference	
Female	0.96(0.64-1.44)	0.98(0.65-1.49)	0.941
Age (in years)	0.563		
Below 21	reference	reference	
21 – 30	0.98(0.53-1.78)	0.86(0.47-1.60)	0.645
31 – 40	1.26(0.64-2.45)	1.08(0.53- 2.19)	0.825
Educational level	0.311		
No formal education	reference	reference	
JHS	0.21(0.04-1.12)	0.20(0.04-1.09)	0.062
SHS	0.88(0.36-2.14)	0.92(0.37-2.28)	0.853
Tertiary	0.81(0.37-1.80)	0.92(0.41-2.11)	0.861

*Statistical significance, p<0.05, OR=Crude Odds Ratio, AOR=Adjusted Odds Ratio

4.15 Bivariate association between Sickle Cell Disease status of participants and Socio-demographic factors

Results in Table 4.14 shows that, there was a significant difference between participants who had Sickle Cell Disease and those who had no Sickle Cell Disease based on ethnicity (p=0.010), educational level (p=0.013) and whether or not parent had a biological child (χ^2= 8.06, p=0.005). There was however, no significant difference among participants based on gender (χ^2= 1.00, p=0.318), age (χ^2= 4.07, p=0.131), marital status (χ^2= 0.51, p=0.475), religion (p=0.204) and occupation (χ^2= 0.79, p=0.373).

Table 0.14 Bivariate association between Sickle Cell Disease status and Socio-demographic factors

Variable	Sickle Cell Disease						χ2	p-value
	SCD		No SCD		Total			
	N (%)		N (%)		N (%)			
Gender							1.00	0.318
Male	13	(36.1)	163	(44.8)	176	(44)		
Female	23	(63.9)	201	(55.2)	224	(56)		
Age (in years)							4.07	0.131
Below 21	1	(2.8)	54	(14.8)	55	(13.8)		
21 – 30	24	(66.7)	218	(59.9)	242	(60.5)		
31 – 40	11	(30.6)	92	(25.3)	103	(25.8)		
Marital status							0.51	0.475
Single	26	(72.2)	282	(77.5)	308	(77)		
Married	10	(27.8)	82	(22.5)	92	(23)		
Religion								0.204[a]
Christian	26	(72.2)	289	(79.4)	315	(78.8)		
Muslim	6	(16.7)	58	(15.9)	64	(16)		
Other	4	(11.1)	17	(4.7)	21	(5.3)		
Ethnicity								**0.010[a]***
Akan	11	(30.6)	186	(51.1)	197	(49.3)		
Ewe	4	(11.1)	50	(13.7)	54	(13.5)		
Ga	7	(19.4)	67	(18.4)	74	(18.5)		
Mole-Dagbon	4	(11.1)	29	(8)	33	(8.3)		
Other	10	(27.8)	32	(8.8)	42	(10.5)		
Educational level								**0.013[a]***
No formal education	3	(8.3)	24	(6.6)	27	(6.8)		
JHS	5	(13.9)	9	(2.5)	14	(3.5)		
SHS	7	(19.4)	68	(18.7)	75	(18.8)		
Tertiary	21	(58.3)	263	(72.3)	284	(71)		
Occupation							0.79	0.373
Employed	31	(86.1)	291	(79.9)	322	(80.5)		
Unemployed	5	(13.9)	73	(20.1)	78	(19.5)		
Biological child							8.06	**0.005***
Has no biological children	21	(58.3)	288	(79.1)	309	(77.3)		
Has biological children	15	(41.7)	76	(20.9)	91	(22.8)		

*Statistical significance, p<0.05; [a]Fisher's exact test (expected cell count<5)

4.16 Multiple logistic regression analysis of the association between socio-demographic factors and Sickle Cell Disease status of participants

Results in Table 4.15 shows multiple logistic regression analysis of the association between socio-demographic factors (ethnicity, educational level, biological children, gender and age)

and Sickle Cell Disease status of participants. From the adjusted analysis, ethnicity and biological children were significantly associated with Sickle Cell Disease status of participants. After adjusting for educational level, biological children, gender and age, participants who belonged to other ethnic groups (other than the four listed), were 5.58 times more likely to have SCD compared to those who belonged to Akan ethnicity [AOR=5.58, CI= (1.90- 16.30), p value=0.002)]. Also, after adjusting for ethnicity, educational level, gender and age, participants who had biological children were 2.99 times more likely to have SCD compared to those who had no biological children [AOR=2.99, CI= (1.35-6.59), p value=0.007)].

Table 0.15 Multiple logistic regression analysis of the association between socio-demographic factors and Sickle Cell Disease status of participants

Variable	OR (95% CI) p-value	AOR (95% CI)	p-value
Ethnicity	**0.012***		
Akan	reference	reference	
Ewe	1.35 (0.41- 4.43)	0.92(0.26-3.24)	0.895
Ga	1.77 (0.66-4.74)	1.54(0.54-4.39)	0.419
Mole-Dagbon	2.33 (0.70-7.82)	1.74(0.44-6.86)	0.431
Other	5.28 (2.07-13.46)	5.58(1.90- 16.30)	**0.002***
Educational level	**0.015***		
No formal education	reference	reference	
JHS	4.44(0.88-22.54)	5.42(0.86-34.26)	0.072
SHS	0.82(0.20- 3.44)	0.79(0.17-3.74)	0.771
Tertiary	0.63(0.18- 2.30)	0 .80(0.20-3.15)	0.745
Biological children	**0.006***		
Has no biological children	reference	reference	
Has biological children	2.71(1.33- 5.50)	2.99 (1.35-6.59)	**0.007***
Gender	0.320		
Male	reference	reference	
Female	1.43(0.70-2.92)	2.04(0.93-4.46)	0.074
Age (in years)	0.206		
Below 21	reference	reference	
21 – 30	5.94(0.79- 44.92)	3.22(0.39-26.64)	0.278
31 – 40	6.46(0.81- 51.40)	2.03(0.22-19.02)	0.534

*Statistical significance, p<0.05, OR=Crude Odds Ratio, AOR=Adjusted Odds Ratio

CHAPTER 5
DISCUSSION

5.1 INTRODUCTION

This chapter discusses the results obtained on the prevalence of SCD, awareness of sickle cell trait and disease, sources of information about SCD, knowledge of SCD, attitude, perception and practices toward SCD. The chapter also investigated the association between the socio-demographic characteristics of participants and the SCD status, knowledge, attitude, perception and practices of participants toward SCD and compared them to existing literature on similar studies.

5.2 Prevalence of Sickle Cell Disease

According to the study's findings, 9% of the individuals who participated in this study were known to have sickle cell disease. The prevalence rate discovered in this study is higher than the one reported in a recent study (6%) carried out among children in Asutsuare, a town in the Greater Accra region (Oppong et al., 2020). A pilot study conducted in the Ashanti region also revealed a 1.8% prevalence rate among all newborns who were screened (Asare et al., 2018). Despite the efforts made by health professionals to inform young adults in Tema about the disease, as reported in the findings, there was still a high prevalence rate found among study participants. This could be attributed to the fact that more children with SCD now survive into adulthood as the average life expectancy which was 7 years in the 1970s is now 47 years, due to the tremendous improvements seen over the years in the management practices of SCD (Asare et al., 2018; Lubeck et al., 2019; Campbell et al., 2022). Another contributing factor could be the low level of public education on the disease by the media as reported in the study. With the Television and radio being two of the main platforms for dissemination of information, it is important for the Ghana Health Service to collaborate with the media to increase the awareness about SCD and the positive practices that will help in its decline. Since majority of the study participants identified as Christians, the church can help reduce the

incidence of SCD by requiring premarital screening as part of the premarital counselling process for individuals who decide on marriage. Given that most young adults in Tema have a good practice of discontinuing relationships that increase the chance of having SCD children based on the findings of this study, this will guide couples decide whether to proceed with or abandon their intention to get married. According to research (Memish & Saeedi, 2011), premarital counselling and screening, which is more effective than new-born screening, is the best way to reduce the occurrence of the disease. Therefore, efforts must be made to continually implement such effective prevention measures in order keep the prevalence of the disease low.

5.3 Knowledge of Sickle Cell Disease

Unlike studies conducted by Uche et al. (2017) on the assessment of knowledge, awareness, and attitude of undergraduates toward sickle cell disease in Lagos, Nigeria which reported an overall fair knowledge of students toward SCD and another study by Boadu & Addoah, 2018 which indicated a poor general knowledge among university students toward SCD, this study found that majority of the participants (73.5%) have a good overall knowledge of SCD, with majority knowing that SCD is a genetic disorder diagnosed using a blood test and prevented through genetic counselling/ pre-marital screening. Again, the study found that majority of the participants correctly predicted that there will be no chance of having healthy children for parents with sickle cell disease, and also identified frequent sickness as a sign or symptom of the disease.

According to prior research (Mulumba & Wilson, 2015; Piel et al, 2013), which is consistent with the knowledge of SCD held by the majority of the participants in this study, the disease is genetically inherited, is diagnosed through a lab test using blood samples (Fonseca et al., 2015; Wajcman & Moradkhani, 2011), and can be prevented through genetic counseling and pre-marital screening (Rahman et al., 2014; Memish & Saeedi, 2011). Participants in this study

mentioned frequent sickness and yellow eyes as some of the signs and symptoms of the condition, which are also mentioned in other studies (Ajinkpang et al., 2022; Isah et al., 2016).

The finding of this study gives a good indication that young adults of Tema have good knowledge of SCD which is very encouraging. Once accurate knowledge about the disease is disseminated with them, young adults can make the right decisions and employ the appropriate preventive measures to avert any rise in the incidence of the disease, which has been identified by the United Nations as a global public health issue (Mulumba & Wilson, 2015). If the older generation that gave birth to the study's participants had the same high degree of disease awareness as was observed among the study's participants, it may have helped in reducing the high prevalence of SCD identified among the study population.

It is important to note that since the majority of research participants learned about SCD via healthcare providers, followed by the internet and then friends and family, it is crucial to have policies in place to support the continual flow of information regarding the disease from these numerous sources. Encouraging health professionals in particular to maintain and expand education on the disease will be beneficial in this regard to increase knowledge of SCD among residents of Tema and the nation at large.

5.4 Attitude towards Sickle Cell Disease

This study found that the majority of participants (86.3%) had an overall poor attitude towards SCD. As found in this study, 62.3%, which is the majority of the participants agreed that, people should worry less about those living with SCD since they may die soon, whereas only a few (6.5%) agree that, they will choose not to have a child than to have a baby with SCD. These findings are contrary to that of studies conducted by Boadu & Addoah (2018), where most participants demonstrated a positive attitude toward SCD with 52.9% of the participants worrying strongly about people with SCD. In studies by Uche et al, 2017, Ameade et al. (2015)

and Olatona et al. (2012) where more than half of the participants were unwilling to continue relationships that will put them at risk of having children with SCD.

Some of these poor attitudes which emanate from wrong perceptions about the disease (for example; that SCD children may die soon) have been debunked by some studies (Lubeck et al., 2019; Campbell et al., 2022). The kind of attitude people portray toward the disease and those with the disease tends to have an impact on approaches aimed at managing people with the disease or strategies aimed at curbing the incidence of the disease in that poor attitude will make the management of those who have already acquired the disease quite difficult. For instance, if the attitude of many people, as discovered in this study, is that they should worry less about those with SCD because they may die soon, then it follows that those with such an attitude may not express strong sympathy or provide the necessary support to such patients, which could lead to a worsening of the condition of SCD patients as most of them will begin to socially isolate themselves and develop low self-esteem, which affects their quality of life, thereby making their management challenging as found in a study conducted in 2022 by Kilonzi et al.

It is interesting to note that although the majority of study participants were found to have good knowledge about the disease, that knowledge did not translate into having a positive attitude toward the disease. It is necessary to adopt a targeted approach to educating young people about particular issues that cause them to portray a poor attitude toward the disease in order to support efforts aimed at curbing any possible increase in the prevalence of the disease and any difficulties that are likely to be encountered with managing those who already have the disease.

5.5 Perception about Sickle Cell Disease

Most participants in this study (60.7%) had a negative overall perception of the condition. This inference is comparable to that made by Tusuubira et al. (2018), who similarly noted a generally negative perception displayed by study participants. The misconceptions that the

majority of study participants had about SCD included the following: 1) SCD patients cannot live long; 2) SCD patients are disabled; and 3) SCD patients are abnormal. These false perceptions have been disproved by research by Lanzkron et al. (2013), who found that even though SCD patients' lives are marked by frequent hospitalization, they are still able to live normally and mature into adulthood. Likewise, other studies (Ajinkpang et al., 2022; Anie et al, 2010; Olakunle et al., 2013; Zounon et al., 2012) have also debunked similar myths and misconceptions associated with SCD.

The distinct problems with incorrect perception that were discovered in this study as opposed to other studies may be the result of the disparities in the study population, as well as in the customary values and cultural practices of the people at the various study locations. The incorrect perceptions study participants held about the disease were less about the disease itself and more about attitudes toward people with the disease, which, if not addressed, could affect how the disease is managed and how much support and cooperation people with SCD can expect from family and friends. For instance, the incorrect perception found in this study that people with SCD cannot live long, has been challenged by recent findings by Campbell et al., 2022; Lubeck et al., 2019 which shows that, life expectancy among those with SCD has increased significantly over the years through improved management of the disease. The fact that most participants of this study have a poor perception about SCD indicates that, having good knowledge about the disease does not guarantee that one will not develop poor perceptions about the disease. Therefore, it is necessary to start targeted education that takes into account the belief system of the populace and their level of literacy in order to help erase any erroneous perceptions about the disease that may be peculiar to them, which if left unaddressed, could jeopardize efforts aimed at reducing prevalence and successfully managing the disease.

5.6 Practices towards Sickle Cell Disease

A great deal of individuals (54%), according to this study, had had SCD tests and aware of their SCD status. Research conducted by Aboagye & Aboagye in 2019 showed that out of the 65.8% of respondents who were aware of SCD, only 34.2% of them had taken tests and knew their status which is relatively lower than that reported in this study. This demonstrates the positive impact continuous education on SCD has had on the youth as most of them are now interested in knowing their status, in comparison to four years ago when that research (Aboagye & Aboagye, 2019) was carried out. For the vast majority (76%) of participants, learning about their partner's genotype influenced or would influence their decision to get married. 72.8% of participants also expressed their unwillingness to stay in a relationship if it increases the chance of having children with SCD. As a means of preventing individuals with SCD from being born, the activities mentioned above toward SCD that were discovered in this study are regarded as good practices that are beneficial in lowering the occurrence of the disease (Memish & Saeedi, 2011).

The practices found among young adults of Tema in this study which are considered good practices towards SCD, are similar to the outcome of the research by Uche et al. (2017) where 79% of participants indicated that they will not marry their partners if marrying them will put them at risk of having SCD babies. Another study conducted by Olatona et al. (2012) on the effects of health education on knowledge and attitude toward SCD found a significant decrease (2.46%) in the proportion of participants who were initially determined to marry their partners if they were both carriers and be childless after they had been educated and had gained more knowledge about SCD. This goes to show the importance of educating the general public about the disease. The prevention of SCD has been found to be more successful with practices that avoid marriages that could potentially increase the chance of having SCD children (Memish & Saeedi, 2011). These practices have also been recognized to have a greater advantage over

newborn screening. It will be beneficial for all parties involved to keep promoting the kinds of practices reported among the participants of this study as helpful, in reducing the prevalence of the disease in the nation.

5.7 Socio-demographic characteristics associated with knowledge, attitude and perception towards SCD

The only socio-demographic characteristic found in this study to be significantly associated with knowledge of SCD was educational level, with participants who had acquired tertiary education being more likely to have good knowledge about SCD compared with those who had no formal education. The study however, did not find any significant association between attitude and perception towards SCD and socio-demographic factors.

This finding of an association between educational level and knowledge of SCD is consistent with findings of previous studies by Aboagye & Aboagye (2019) who also reported that high educational level was significantly associated with higher knowledge levels of SCD and also in a similar study by Boadu & Addoah, 2018 where postgraduate students had significantly higher knowledge scores as compared to undergraduates. This finding does not come as a surprise since participants with tertiary education are expected to be more knowledgeable about the disease as a result of their higher education, which gives them the advantage of being able to read about the disease and conduct research on it as opposed to those with no formal education, who might not even be able to read. Again, one of the major sources of information about the disease among participants in this study was the internet. It is obvious that participants with tertiary education are better able to use the internet for research and information acquisition than participants with no formal education.

This demonstrates unequivocally the importance of education in obtaining an in-depth knowledge of SCD. More awareness should be created especially in secondary cycle

institutions to ensure that those who do not make it to tertiary institutions, are still provided with adequate information to increase their knowledge of SCD in general, and help with making appropriate decisions that could help stop any rise in the incidence of SCD.

5.8 Socio-demographic factors associated with Sickle Cell Disease status of participants

It was discovered that ethnicity and whether or not participants had biological children were sociodemographic characteristics that were associated with SCD status in this study. The prevalence of SCD was observed to be higher among participants from other ethnic groups than among Akans, and among participants with biological children as opposed to those without biological offspring.

Although what may have influenced these results is unclear and these parameters, which were discovered in this study to be associated with SCD status have not been mentioned in any other studies, these associations could be attributed to the majority (49.3%) of the respondents in this study being Akans and minority (10.5%) coming from the other ethnic groups which could mean that the 54% of participants who knew their status mainly constituted Akans and less of the other ethnic groups. Also, it could be that the high prevalence found among participants with biological children is because health professionals suggest they take the test during pregnancy, as a result, they end up knowing their status.

It is recommended that, further studies be conducted to ascertain why participants belonging to ethnic groups other than Ewe, Ga, and Mole-Dagbon are more likely to have SCD compared to those who are Akan, and also, why participants with biological children have higher odds of getting SCD compared to their counterparts without biological children.

CHAPTER 6
CONCLUSION AND RECOMMENDATIONS

6.1 Introduction

The last chapter of this thesis provides a summary of the findings of the research obtained through the results and discussion. It also outlines the limitation of this study and recommendations for further studies.

6.2 Conclusion

The aim of this thesis was to determine the knowledge, perception and practices of young adults in Tema toward sickle cell disease. Using a quantitative sampling method, 400 individuals were asked to fill out a structured questionnaire and the data obtained were analysed. Findings showed that there was a 9% prevalence of SCD among individuals who took part in the study. 73.5% of the participants had a good knowledge of SCD, indicating a good overall knowledge of SCD among young adults in Tema. The overall attitude of most of the young adults in Tema (86.3%) toward the disease and the people living with it was found to be poor. Similarly, there was a poor perception observed among young adults in Tema toward SCD. However, practices of young adults in Tema were found to be very good. The study also found significant associations between SCD status and two socio-demographic characteristics (ethnicity and whether or not the participants had biological children) and an association between knowledge of SCD and educational level (tertiary education).

6.3 Limitation

The limitation of this study is in its small sample size, which makes it difficult to generalize the findings because it might not accurately reflect the total population of Tema.

6.4Recommendations

6.4.1 Institutional

I. The government and private sectors, as well as religious organizations, should intensify the dissemination or spread of information about the disease. This will encourage prospective couples to get premarital genetic testing so they may make better-informed decisions based on the outcome of the test.

II. To clear up misconceptions, raise awareness of the risks of having a child with SCD, and influence individual reproductive choices, there should be effective public health education for SCT and SCD by schools, the media (radio, television and the internet), health centres, and churches and also in certain rural communities where cultural and societal sensitivities act as a barrier.

III. The government, in collaboration with the Ghana Health Service should enact policies to ensure that community-wide sickle cell screening and premarital genetic counselling services are easily accessible in both rural and urban communities.

6.4.2 Research

More studies on this topic should be conducted using a larger sample size to help find the association between socio-demographic characteristics and SCD status.

REFERENCES

Abioye-Kuteyi, E. A., Osakwe, C., Oyegbade, O., & Bello, I. (2009). Sickle cell knowledge, premarital screening and marital decisions among local government workers in Ile-Ife, Nigeria. *African Journal of Primary Health Care and Family Medicine*, *1*(1), 1-5.

Aboagye, J. A. F., & Aboagye, A. Q. (2019). Sickle Cell Disease Awareness, Depth of Knowledge and Attitude towards Premarital Screening among Students in Ghana. *African Journal of Management Research, 26,* 107-119.

Adigwe, O.P. (2022). Knowledge and awareness of sickle cell disease: a cross-sectional study amongst unmarried adults in Nigeria's capital city. *J Community Genet*. https://doi.org/10.1007/s12687-022-00607-x

Agrawal, R. K., Patel, R. K., Shah, V., Nainiwal, L., & Trivedi, B. (2014). Hydroxyurea in sickle cell disease: drug review. *Indian journal of hematology & blood transfusion: an official journal of Indian Society of Hematology and Blood Transfusion*, *30*(2), 91–96. https://doi.org/10.1007/s12288-013-0261-4

Ajinkpang, S., Anim-Boamah, O., Bimpong, K. A., Kanton, F. J., Pwavra, J. B. P., Abdul-Mumin, A. (2022). "Sickle Cell Disease in Children: Knowledge and Home-Based Management Strategies among Caregivers at a Tertiary Facility in Northern Ghana", *BioMed Research International*, vol. 2022, Article ID 3384813, 6 pages. https://doi.org/10.1155/2022/3384813.

Alghamdi, A. A. M., Alamri, A. M. A., Alghamdi, A. H. A., Alghamdi, S. Y. S, Alzahrani, F. A. M., Alzahrani, S. A. S. & Albishi, M. A. (2018). Perceptions about Sickle Cell Disease among Adults in Albaha Region: A Cross-sectional Study. *The Egyptian Journal of Hospital Medicine, Vol. 70 (2),* Pages 357-363 357. DOI: 10.12816/0043105.

Ameade, E. P. K., Mohammed, B. S., Helegbe, G. K., & Yakubu, S. (2015). Sickle cell gene transmission: Do public servants in Tamale, Ghana have the right knowledge and attitude to curb it?

Andrade, C. (2020). Sample Size and its Importance in Research. *Indian journal of psychological medicine. 42(1), 102-103.* https://doi.org/10.4103/IJPSYM.IJPSYM_504_19

Anie, K. A., Egunjobi, F. E., & Akinyanju, O. O. (2010). Psychosocial impact of sickle cell disorder: perspectives from a Nigerian setting. *Globalization and health*, *6*, 1-6.

Asare, E. V., Wilson, I., Kuma, A. A., Dei-Adomakoh, Y., Sey, F. & Olayemi, E. (2018). "Burden of Sickle Cell Disease in Ghana: The Korle-Bu Experience", *Advances in Hematology*, vol. 2018, Article ID 6161270, 5 pages, https://doi.org/10.1155/2018/6161270

Attia, M., Kripalani, S., Darbari, I., & Nickel, R. S. (2020). Parents of children with sickle cell disease are interested in preimplantation genetic testing. *The Journal of Pediatrics*, *223*, 178-182.

Aygun, B., & Odame, I. (2012). A global perspective on sickle cell disease. *Pediatric Blood & Cancer. 59(2), pp. 386–390.* DOI: 10.1002/pbc.24175/PubMed2011585449.

Balogun, R. A., Obalum, D. C., Giwa, S. O., Adekoya-Cole, T. O., Ogo, C. N., The spectrumzo, G. O. (2010). The spectrum of musculoskeletal disorders in sickle cell disease in Lagos, Nigeria. *Journal of orthopedic surgery and research*, *5*(1), 1-6.

Battersby, A. J., Knox-Macaulay, H. H., & Carrol, E. D. (2010). Susceptibility to invasive bacterial infections in children with sickle cell disease. *Pediatric blood & cancer*, *55*(3), 401-406.

Boadu,I., & Addoah, T. (2018). Knowledge, Beliefs and Attitude towards Sickle Cell Disease among University Students. *Journal of Community Medicine & Health Education. 8(1). pp. 593.* DOI: 10.4172/2161-0711.1000593.

Booth, C., Inusa, B., & Obaro, S. K. (2010). Infection in sickle cell disease: a review. *International Journal of Infectious Diseases*, *14*(1), e2-e12.

Buser, J. M., Bakari, A., Seidu, A. A., Osei-Akoto, A., Paintsil, V., Amoah, R., Otoo, B., & Moyer, C. A. (2021). Caregiver Perception of Sickle Cell Disease Stigma in Ghana: An Ecological Approach. *Journal of pediatric health care: official publication of National Association of Pediatric Nurse Associates & Practitioners*, *35*(1), 84–90. https://doi.org/10.1016/j.pedhc.2020.08.002

Campbell, S. T., Curtis, S. & Shajani-Yi, Z. (2022). *Managing Sickle Cell Disease.* Retrieved from: https://www.aacc.org/cln/articles/2022/julyaugust/managing-sickle-cell-disease. on 12-04-2022.

Centers for Disease Control and Prevention. (2022). Sickle Cell Disease (SCD). Retrieved from: https://www.cdc.gov/ncbddd/sicklecell/facts.html on 11-05-2022.

Centers for Disease Control and Prevention. (2022). Sickle Cell Disease (SCD); what is Sickle Cell Trait? Retrieved from: https://www.cdc.gov/ncbddd/sicklecell/traits.html on 11-05-2022.

Chakravorty, S. & Williams, T. N. (2015). Sickle cell disease: a neglected chronic disease of increasing global health importance. *Archives of Disease in Childhood 100***:**48-53.

City Population. (2021). *Tema Metropolitan – Ghana*. Retrieved from https://citypopulation.de/en/ghana/admin/greater_accra/0308__tema_metropolitan/ on 12-05-2022.

David, A. N., Jinadu, M. Y., Wapmuk, A. E., Gbajabiamila, T. A., Okwuzu, J. O., Herbertson, E. C, & Ezechi, O. C. (2018). Prevalence and impact of sickle cell trait on the clinical and laboratory parameters of HIV infected children in Lagos, Nigeria. *Pan Afr Med J. 2018 Oct 15; 31:113*. DOI: 10.11604/pamj.2018.31.113.15097. PMID: 31037173; PMCID: PMC6462387.

DeBaun, M. R., & Galadanci, N. A. (2022). *Sickle cell disease in sub-Saharan Africa*. Retrieved from https://www.uptodate.com/contents/sickle-cell-disease-in-sub-saharan-africa on 16/08/22.

Djan, G., & Mensah, K. A. (2020). *Knowledge, Attitude and Practice towards Sickle Cell Disease Among Senior High School Students in the Sunyani Municipality in the Brong Ahafo Region, Ghana* (Doctoral dissertation).

Edwin, A. K., Edwin, F., & Etwire, V. (2011). Controlling sickle cell disease in Ghana - ethics and options. *Pan African Medical Journal. 10(14)*. DOI: 10.4314/pamj.v10i0.72223.

Ephraim, R. K., Adu, P., Ake, E., Agbodzakey, H., Adoba, P., Cudjoe, O., & Agoni, C. (2016). Normal non-HDL cholesterol, low total cholesterol, and HDL cholesterol levels in sickle cell disease patients in the steady state: a case-control study of Tema Metropolis. *Journal of lipids, 2016*.

Ephraim, R. K. D., Osakunor, D. N. M., Cudjoe, O., Oduro, E. A., Asante-Asamani, L., Mitchell, J., ... & Adoba, P. (2015). Chronic kidney disease is common in sickle cell disease: a cross-sectional study in the Tema Metropolis, Ghana. *BMC nephrology*, *16*(1), 1-7.

Fattoum S. (2009). Evolution of hemoglobinopathy prevention in Africa: results, problems, and prospect. *Mediterranean journal of hematology and infectious diseases*, *1*(1), e2009005. https://doi.org/10.4084/MJHID.2009.005.

Fonseca, S. F. D., Amorim, T., Purificação, A., Gonçalves, M., & Boa-Sorte, N. (2015). Hemoglobin A2 values in sickle cell disease patients quantified by high-performance liquid chromatography and the influence of alpha thalassemia. *Revista brasileira de hematologia e hemoterapia*, *37*, 296-301.

Gardner, R. V. (2018). Sickle Cell Disease: Advances in Treatment. *The Ochsner journal*, *18*(4), 377–389. https://doi.org/10.31486/toj.18.0076

Ghana Statistical Service. (2021). Ghana 2021 Population and Housing Census. *General Report. (3c)*. Retrieved from: https://statsghana.gov.gh/gssmain/fileUpload/pressrelease/2021%20PHC%20General%20Report%203C_revised%20print_281121a.pdf on 15-05-2022.

Gibson J. S & Rees D. C. (2016). How benign is sickle cell trait? *EBioMedicine*. doi: 10.1016/j.ebiom.2016.08.023. Epub 2016 Aug 21. PMID: 27580691; PMCID: PMC5049987.

Grosse, S. D., Odame, I., Atrash, H. K., Amendah, D. D., Piel, F. B., & Williams, T. N. (2011). Sickle cell disease in Africa: a neglected cause of early childhood mortality. *American journal of preventive medicine*, *41*(6 Suppl 4), S398–S405. https://doi.org/10.1016/j.amepre.2011.09.013.

Holdford, D., Vendetti, N., Sop, D. M., Johnson, S., & Smith, W. R. (2021). Indirect Economic Burden of Sickle Cell Disease. *Value in Health. 24(8). pp. 1095-1101*. DOI: 10.1016/j.jval.2021.02.014.

Isah, B. A., Musa, Y., Mohammed, U. K., Ibrahim, M. T. O., Awosan, K. J., & Yunusa, E. U. (2016). Knowledge and attitude regarding premarital screening for sickle cell disease among students of State school of nursing Sokoto. *Ann Int Med Dent Res*, *2*(3), 29-34.

Jackson, I., & Oppong, R. A. (2014). The planning of late colonial village housing in the tropics: Tema Manhean, Ghana. *Planning Perspectives*, *29*(4), 475-499.

John Hopkins Medicine. (2022). *Sickle Cell Disease.* Retrieved from: https://www.hopkinsmedicine.org/health/conditions-and-diseases/sickle-cell-disease on 20-05-22.

Kato, G. J., Piel, F. B., Reid, C. D., Gaston, M. H., Ohene-Frempong, K., Krishnamurti, L., … & Vichinsky, E. P. (2018). Sickle cell disease. *Nature Reviews Disease Primers*, *4*(1), 1-22.

Keshvar, Y., Sabeghi, S., Sharifi, Z. *et al.* A decade of molecular preimplantation genetic diagnosis of 350 blastomeres for beta-thalassemia combined with HLA typing, aneuploidy screening and sex selection in Iran. *BMC Pregnancy Childbirth* **22**, 330 (2022). https://doi.org/10.1186/s12884-022-04660-9

Kilonzi, M., Mwakawanga, D. L., Felician, F. F., Mlyuka, H. J., Chirande, L., Myemba, D. T., Sambayi, G., Mutagonda, R. F., Mikomangwa, W. P., Ndunguru, J., Jonathan, A., Ruggajo, P., Minja, I. K., Balandya, E., Makani, J., & Sirili, N. (2022). The Effects of Sickle Cell Disease on the Quality of Life: A Focus on the Untold Experiences of Parents in Tanzania. *International journal of environmental research and public health*, *19*(11), 6871. https://doi.org/10.3390/ijerph19116871

Kolapo, K. O., & Vento, S. (2011). Stroke: a realistic approach to a growing problem in sub-Saharan Africa is urgently needed. *Tropical Medicine & International Health*, *16*(6), 707-710.

Lanzkron, S., Carroll, C. P., & Haywood, C., Jr (2013). Mortality rates and age at death from sickle cell disease: U.S., 1979-2005. *Public health reports (Washington, D.C.: 1974)*, *128*(2), 110–116. https://doi.org/10.1177/003335491312800206

Lubeck, D., Agodoa, I., Bhakta, N., et al. (2019). Estimated Life Expectancy and Income of Patients with Sickle Cell Disease Compared with Those Without Sickle Cell Disease. *JAMA Netw Open*; 2(11): e1915374. doi:10.1001/jamanetworkopen.2019.15374.

McGann, P. T., & Ware, R. E. (2015). Hydroxyurea therapy for sickle cell anemia. *Expert opinion on drug safety*, *14*(11), 1749–1758. https://doi.org/10.1517/14740338.2015.1088827

Memish, Z. A., & Saeedi, M. Y. (2011). Six-year outcome of the national premarital screening and genetic counseling program for sickle cell disease and β-thalassemia in Saudi Arabia. *Annals of Saudi medicine*, *31*(3), 229-235. Modell, B. & Darlison, M. (2008). Global epidemiology of hemoglobin disorders and derived service indicators. *Bulletin of the World Health Organization.* 2008; 86:480–487.

Modell, B., & Darlison, M. (2008). Global epidemiology of haemoglobin disorders and derived service indicators. *Bulletin of the World Health Organization*, *86*(6), 480-487.

Mulumba, L. L & Wilson, L. (2015). Sickle cell disease among children in Africa: An integrative literature review and global recommendations. *International Journal of Africa Nursing Sciences, (3),* 56-64. https://doi.org/10.1016/j.ijans.2015.08.002.

Murphy, R. A. (2010). Preventable deaths in sickle-cell anemia in African children. *The Lancet*, *375*(9713), 460-461.

Nimako, B. A. (2012). *Concurrent Chronic Conditions in Adult Patients of the Medical Out-Patient Clinic of the Tema General Hospital* [Master's thesis, University of Ghana].

Novartis. (2019). *Novartis media release - Ghana MOU - November 2019*. Retrieved from: https://www.moh.gov.gh/wp-content/uploads/2019/11/Novartis-media-release-Ghana-MOU-November-2019-v7.pdf on 11-07-2022.

Novartis. (2022). *Novartis announces partnership with the American Society of Hematology to fight sickle cell disease in Sub-Saharan Africa*. Retrieved from: https://www.novartis.com/news/media-releases/novartis-announces-partnership-american-society-hematology-fight-sickle-cell-disease-sub-saharan-africa on 11-07-2022.

Nwabuko, O. C., Onwuchekwa, U., & Iheji, O. (2022). An overview of sickle cell disease from the socio-demographic triangle - a Nigerian single-institution retrospective study. *The Pan African medical journal*, *41*, 161. https://doi.org/10.11604/pamj.2022.41.161.27117

Ohene-Frempong, K., Segbefia, C., Spector, J., Amoah, E., Asubonteng, A., Hammond-Addo, R., Odame, I., & Odame, I. (2022). S129: Implementation of Hydroxyurea Therapy for Sickle Cell Disease on a Large Scale in Ghana. *HemaSphere*, *6*(Suppl). 16. https://doi.org/10.1097/01.HS9.0000821484.39112.40

Olakunle, O. S., Kenneth, E., Olakekan, A. W., & Adenike, O. B. (2013). Knowledge and attitude of secondary school students in Jos, Nigeria on sickle cell disease. *Pan African Medical Journal*, *15*(1).

Olatona, F. A., Odeyemi, K. A., Onajole, A. T., & Asuzu, M. C. (2012). Effects of health education on knowledge and attitude of youth corps members to sickle cell disease and its screening in Lagos State. *J Community Med Health Educ*, *2*(7), 163.

Oppong, M., Lamptey, H., Kyei-Baafour, E., Aculley, B., Ofori, E. A., Tornyigah, B., ... & Ofori, M. F. (2020). Prevalence of sickle cell disorders and malaria infection in children aged 1–12 years in the Volta Region, Ghana: a community-based study. *Malaria Journal*, *19*(1), 1-11.

Orish, V. N., Onyeabor, O. S., Sanyaolu, A. O., & Iriemenam, N. C. (2014). Evaluating the knowledge of sickle cell disease and hemoglobin electrophoretic pattern among people living in Sekondi-Takoradi Metropolis, Ghana. *Journal of Medicine in the Tropics*, *16*(2), 56.

Osunkwo, I., Andemariam, B., Minniti, C. P., Inusa, B. P. D., El Rassi, F., Francis-Gibson, B., Nero, A., Trimnell, C., Abboud, M. R., Arlet, J. B., Colombatti, R., de Montalembert, M., Jain, S., Jastaniah, W., Nur, E., Pita, M., DeBonnett, L., Ramscar, N., Bailey, T., Rajkovic-Hooley, O., … James, J. (2021). Impact of sickle cell disease on patients' daily lives, symptoms reported, and disease management strategies: Results from the international Sickle Cell World Assessment Survey (SWAY). *American journal of hematology*, *96*(4), 404–417. https://doi.org/10.1002/ajh.26063

Parikh, F. R., Athalye, A. S., Naik, N. J., Naik, D. J., Sanap, R. R., & Madon, P. F. (2018). Preimplantation Genetic Testing: Its Evolution, Where Are We Today?. *Journal of human reproductive sciences*, *11*(4), 306–314. https://doi.org/10.4103/jhrs.JHRS_132_18

Piel, F. B, Hay, S. I., Gupta, S., Weatherall, D. J., Williams, T. N. (2013). Global burden of sickle cell anemia in children under five, 2010–2050: modeling based on demographics, excess mortality, and interventions. *PLoS Med. 2013;10:e1001484. Medline:23874164* DOI:10.1371/journal.pmed.1001484

Piel, F. B., Patil, A. P., Howes, R. E., Nyangiri, O. A., Gething, P. W., Williams, T. N., ... & Hay, S. I. (2010). Global distribution of the sickle cell gene and geographical confirmation of the malaria hypothesis. *Nature communications*, *1*(1), 1-7.

Piel, F. B., Steinberg, M. H., & Rees, D. C. (2017). Sickle cell disease. *New England Journal of Medicine*, *376*(16), 1561-1573.

Rahimy, M. C., Gangbo, A., Ahouignan, G., Adjou, R., Deguenon, C., Goussanou, S., & Alihonou, E. (2012). Effect of a comprehensive clinical care program on disease course in severely ill children with sickle cell anemia in a sub-Saharan African setting. *Blood*, *102*(3), 834-838.

Rahman, M. M., Naznin, L., Giti, S., Islam, M. S., & Khatun, N. (2014). Premarital health screening a review and update. *Journal of Armed Forces Medical College, Bangladesh*, *10*(1), 103-109.

Rankine-Mullings, A. E., & Owusu-Ofori, S. (2021). Prophylactic antibiotics for preventing pneumococcal infection in children with sickle cell disease. *Cochrane Database of Systematic Reviews*, (3).

Rees, D. C., Williams, T. N., & Gladwin, M. T. (2010). Sickle-cell disease. *The Lancet*, *376*(9757), 2018-2031.

Sedrak A. & Kondamudi N. P. (2021). Sickle Cell Disease. *Treasure Island (FL): StatPearls Publishing*. Retrieved from: https://www.ncbi.nlm.nih.gov/books/NBK482384/

Segbefia, C. I., Goka, B., Welbeck, J., Amegan-Aho, K., Dwuma-Badu, D., Rao, S., ... & Odame, I. (2021). Implementing newborn screening for sickle cell disease in Korle Bu Teaching Hospital, Accra: Results and lessons learned. *Pediatric Blood & Cancer*, *68*(7), e29068.

Shiel, W. C. (2021). Sickle Cell Disease (Anemia). Retrieved from: https://www.medicinenet.com/sickle_cell/article.htm.

Sims, A. M., Bonsu, K. O., Urbonya, R., *et al.* (2021). Diagnosis patterns of sickle cell disease in Ghana: a secondary analysis. *BMC Public Health* **21,** 1719. https://doi.org/10.1186/s12889-021-11794-6

Tanabe, P., Spratling, R., Smith, D., Grissom, P., & Hulihan, M. (2019). CE: Understanding the Complications of Sickle Cell Disease. *The American journal of nursing*, *119*(6), 26–35. https://doi.org/10.1097/01.NAJ.0000559779.40570.2c

Tema Metropolitan Assembly. (2021). *Tema City*. Retrieved from: https://www.temametro.org/about-the-tema-city on 11-07-2022.

. *The Indian journal of medical research*, *134*(4), 538.

Tusuubira, S. K., Nakayinga, R., Mwambi, B., Odda, J., Kiconco, S., & Komuhangi, A. (2018). Knowledge, perception and practices towards sickle cell disease: a community survey among adults in Lubaga division, Kampala Uganda. *BMC Public Health*, *18*(1), 1-5.

Uche, E., Olowoselu, O., Augustine, B., Ismail, A., Akinbami, A., Dosunmu, A., & Balogun, A. (2017). An Assessment of Knowledge, Awareness, and Attitude of Undergraduates toward Sickle Cell Disease in Lagos, Nigeria. *Nigerian medical journal: journal of the Nigeria Medical Association*, *58*(6), 167–172. https://doi.org/10.4103/nmj.NMJ_111_18

Umar, A. M., & Wachiko, B. (2021). TARA YAMANE (1967), TARO YAMANE METHOD FOR SAMPLE SIZE CALCULATION. THE SURVEY CAUSES OF MATHEMATICS ANXIETY AMONG SECONDARY SCHOOL STUDENTS IN MINNA METROPOLIS. *MATHEMATICAL ASSOCIATION OF NIGERIA (MAN)*, *46*(1), 188.

Wajcman, H., & Moradkhani, K. (2011). Abnormal haemoglobins: detection & characterization. *The Indian journal of medical research*, *134*(4), 538.

Wastnedge, E., Waters, D., Patel, S., Morrison, K., Goh, M. Y., Adeloye, D., & Rudan, I. (2018). The global burden of sickle cell disease in children under five years of age: a systematic review and meta-analysis. *Journal of global health*, *8*(2).

Weatherall, D. J., & Clegg, J. B. (2001). Inherited haemoglobin disorders: an increasing global health problem. *Bulletin of the World Health Organization*, *79*(8), 704-712.

Williams, T. N., Uyoga, S., Macharia, A., Ndila, C., McAuley, C. F., Opi, D. H. ... & Scott, J. A. G. (2009). Bacteraemia in Kenyan children with sickle-cell anemia: a retrospective cohort and case-control study. *The Lancet*, *374*(9698), 1364-1370.

World Health Organisation (2006). Sickle-Cell Anaemia Report by the Secretariat. *Fifty-ninth World Health Assembly*. http://apps.who.int/gb/ebwha/pdf_files/WHA59/A59_9-en.pdf

Zounon, O., Anani, L., Latoundji, S., Sorum, P. C., & Mullet, E. (2012). Misconceptions about sickle cell disease (SCD) among lay people in Benin. *Preventive medicine*, *55*(3), 251-253.

APPENDICES

APPENDIX A: PARTICIPANT'S CONSENT FORM

NOGUCHI MEMORIAL INSTITUTE FOR MEDICAL RESEARCH (NMIMR)
COLLEGE OF HEALTH SCIENCES, UNIVERSITY OF GHANA, LEGON
INSTITUTIONAL REVIEW BOARD

CONSENT FORM

Title: Knowledge, Perception, and Practices of Young Adults in Tema toward Sickle Cell Disease.

Principal Investigator:

Adwoa Ayewa Ayimadu

Address:

University of Ghana,

School of Public Health,

P.O. Box LG 13,

Legon, Accra.

General Information about Research

The above-mentioned study is a research project with the goal of acquiring information on the knowledge, perception, and practices of young adults in Tema toward sickle cell disease. The main objective of the study is to determine the knowledge, perception, and practices of young adults in Tema toward sickle cell disease. This study will be conducted using a Quantitative research design with a cross-sectional approach employing a structured electronic questionnaire. There is no risk associated with the study. The study will produce results to inform decision-making on an individual's knowledge about sickle cell disease which will aid in creating pertinent public health initiatives to raise awareness and prevent the disease.

Participants must respond to the questions stated below in the questionnaire. Filling out the form will take about 5 to 10 minutes.

Possible Risks and Discomforts

NMIMR INSTITUTIONAL REVIEW BOARD
VALID UNTIL
0 8 DEC 2023
APPROVED DOCUMENT

1

For participants who have sickle cell disease, filling out the questionnaire may cause them to recall uncomfortable or stressful memories.

Possible Benefits

The study will produce results to inform decision-making on an individual's knowledge about sickle cell disease which will aid in creating pertinent public health initiatives to raise awareness and prevent the disease.

Confidentiality

Confidentiality and privacy will also be assured to the participants. All data gathered would be made anonymous. Both the identity of the research participants and the confidentiality of the research data will be guaranteed

Compensation

There will not be any compensation or payment to participants.

Voluntary Participation and Right to Leave the Research

Participants have the option to withdraw from the study even after providing the initial consent. Participants can also withdraw from the study if the study will have any negative consequences.

Contacts for Additional Information

Name: Adwoa Ayewa Ayimadu

Email: aayimadu002@st.ug.edu.gh

Contact: 0244786858

Academic supervisor

Name: Dr. Prudence Tettey

Email: narhtsay@gmail.com

Contact: 0550424815

NOGUCHI MEMORIAL INSTITUTE FOR MEDICAL RESEARCH (NMIMR)
COLLEGE OF HEALTH SCIENCES, UNIVERSITY OF GHANA, LEGON

INSTITUTIONAL REVIEW BOARD

Your rights as a Participant

This research has been reviewed and approved by the Institutional Review Board of Noguchi Memorial Institute for Medical Research (NMIMR-IRB). If you have any questions about your rights as a research participant you can contact the IRB Office between the hours of 8am-5pm through the landline 0302916438 or email addresses: nirb@noguchi.ug.edu.gh

VOLUNTEER AGREEMENT

The above document describing the benefits, risks and procedures for the research title ***(name of research)*** has been read and explained me. I have been given an opportunity to have any questions about the research answered to my satisfaction. I agree to participate as a volunteer.

Date _____ Name and signature or mark of volunteer _____

If volunteers cannot read the form themselves, a witness must sign here:

I was present while the benefits, risks and procedures were read to the volunteer. All questions were answered and the volunteer has agreed to take part in the research.

Date _____ Name and signature of witness _____

I certify that the nature and purpose, the potential benefits, and possible risks associated with participating in this research have been explained to the above individual.

Date _____ Name Signature of Person Who Obtained Consent _____

NMIMR INSTITUTIONAL REVIEW BOARD
VALID UNTIL
0 8 DEC 2023
APPROVED DOCUMENT

3

APPENDIX B: PARTICIPANT'S INFORMATION SHEET

NOGUCHI MEMORIAL INSTITUTE FOR MEDICAL RESEARCH (NMIMR)
COLLEGE OF HEALTH SCIENCES, UNIVERSITY OF GHANA, LEGON

INSTITUTIONAL REVIEW BOARD

QUESTIONNAIRE

TITLE OF STUDY: KNOWLEDGE, PERCEPTION, AND PRACTICES OF YOUNG ADULTS IN TEMA TOWARD SICKLE CELL DISEASE.

Dear Sir/Madam

My name is Adwoa Ayewa Ayimadu. I am a Master of Public Health student at the University of Ghana. As part of the university's requirement, I am undertaking a research project in partial fulfilment of my Master's degree in Public Health. This questionnaire was created to gather information for the above-mentioned research project. Young adults (18 – 40 years) in Tema have been chosen as the unit of analysis. I respectfully implore your participation in achieving my objectives for this study by answering the following questions in the questionnaire. Participation in this study is completely voluntary and all potential participants have the right to partake in the study. Any information shared remains confidential and private. Information provided will be used solely for the purpose of research and will not trace back to participants in any way. Kindly spare me 5 to 10 minutes of your time.

I acknowledge that I have read the contents and understood the information about the project. I acknowledge that my participation is voluntary and that I am free to withdraw from the study at any time without any consequences.

Kindly check in box to confirm participation. I voluntary agree to partake in the study.

☐ YES

☐ NO

Thank you!

1

APPENDIX C: QUESTIONNAIRE

1. SOCIO-DEMOGRAPHIC CHARACTERISTICS

Tick the correct one

Sex	Male { } Female { }
Age	
Marital Status	Single { } Married { }
Religion	Christian { } Muslim { } Other { }
Ethnicity	Akan { } Ewe { } Ga { } Dagbani{ } Other { }
Educational Level	Basic school { } JHS { } SHS { } Tertiary { } None { }
Occupation	Employed { } Unemployed { }
Do you have biological children?	Yes { } No { }

2. PREVALENCE OF SCD

Do you have sickle cell disease?	Yes { } No { } Don't know { }

3. AWARENESS OF SICKLE CELL DISEASE

Tick all applicable ones

Have you heard of sickle cell disease?	Yes { } No{ }
Have you heard of sickle cell trait?	Yes { } No { }
If you have, what was your source of information?	TV/ radio { } Internet { } Friends /family { } Health professional { } Other { }

4. KNOWLEDGE OF SICKLE CELL DISEASE

Tick the correct one

What is the cause of SCD?	Acquired { } Family curse { } Spiritual attack { } Genetically inherited { } Don't know { }
What are the signs and symptoms of SCD?	Skinny body { } Frequent sickness { } Yellow eyes { } Don't know { }
How is it diagnosed?	Blood test { } Urine test { } Don't know { }
Can SCD be prevented?	Yes { } No { } Don't know { }
How do you prevent SCD?	Genetic counselling / Pre-marital screening { } Abortion { } Don't know { }
What are the chances of having a healthy baby when both parents have SCD?	100% { } 50% { } 25% { } No chance { } Don't Know { }

5. ATTITUDE TOWARD SCD

I feel sympathetic for people with SCD	Agree { }	Disagree { }
We should worry less about people with SCD since they may die soon	Agree { }	Disagree { }
I will end my relationship if I find out that I and my partner's genotype puts us at risk of having children with SCD	Agree { }	Disagree { }
I will choose not to have a child than give birth to a child with SCD	Agree { }	Disagree { }

6. PERCEPTION OF SICKLE CELL DISEASE

Tick the correct one

Someone with SCD can work	Agree { }	Disagree { }
Someone with SCD can school	Agree { }	Disagree { }
Someone with SCD can live a normal life	Agree { }	Disagree { }
People living with SCD cannot live long	Agree { }	Disagree { }
People living with SCD are disabled	Agree { }	Disagree { }
People living with SCD are abnormal	Agree { }	Disagree { }
People living with SCD should not be treated as normal people	Agree { }	Disagree { }

7. PRACTICES TOWARD SCD

Have you ever tested for SCD?	Yes { }	No { }
Did/Would knowing your partner's status influence your decision to marry?	Yes { }	No { }
Are you willing to continue a relationship despite the risk of having children with SCD?	Yes { }	No { }

APPENDIX D: ETHICAL CLEARANCE

UNIVERSITY OF GHANA

NOGUCHI MEMORIAL INSTITUTE FOR MEDICAL RESEARCH (NMIMR)
COLLEGE OF HEALTH SCIENCES
INSTITUTIONAL REVIEW BOARD

9th December, 2022.

ETHICAL CLEARANCE

FEDERALWIDE ASSURANCE FWA 00001824 **IRB 00001276**

NMIMR-IRB CPN 030/22-23 **IORG 0000908**

On 9th December 2022, the Noguchi Memorial Institute for Medical Research (NMIMR) Institutional Review Board (IRB) conducted an expedited review and approved your protocol titled:

TITLE OF PROTOCOL : **Knowledge, Perception and Practices of Young Adults in Tema Toward Sickle Cell Disease.**

PRINCIPAL INVESTIGATOR : **Ayimadu Adwoa Ayewa, Mphil Cand.**

Please note that a final review report must be submitted to the Board at the completion of the study. Your research records may be audited at any time during or after the implementation.

Any modification of this research project must be submitted to the IRB for review and approval prior to implementation.

Please report all serious adverse events related to this study to NMIMR-IRB within seven days verbally and fourteen days in writing.

This certificate is valid till 8th December, 2023. You are to submit annual reports for continuing review.

Signature of Chair: .....
Dr. Abraham Hodgson
(NMIMR – IRB CHAIR)

P. O. Box LG 581, Legon, Accra, Ghana | Tel: +233 (0) 302-2916438
Email: nirb@noguchi.ug.edu.gh | www.noguchimedres.org | www.ug.edu.gh

UG