FACTORS INFLUENCING KNOWLEDGE, PERCEPTION AND ATTITUDE TOWARDS PREMARITAL SICKLE CELL DISEASE SCREENING AMONG PREGNANT WOMEN ATTENDING ANTENATAL CLINIC AT MUHIMBILI NATIONAL HOSPITAL

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By

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A Dissertation Submitted in (Partial) Fulfilment of the Requirements for the Degree of Master of Medicine (Obstetrics and Gynaecology) of

Muhimbili University of Health and Allied Sciences
October, 2024

CERTIFICATION

The undersigned certifies that they have read and hereby recommends for acceptance by the Muhimbili University of Health and Allied Sciences a dissertation entitled **"Factors Influencing Knowledge, Perception and Attitude Towards Premarital Sickle Cell Disease Screening Among Pregnant Women Attending Antenatal Clinic at Muhimbili National Hospital"** in partial fulfilment of the requirements for the Degree Award of Master of Medicine in Obstetrics and Gynaecology of Muhimbili University of Health and Allied Sciences.

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Date

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Dr. Brian Abraham

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Date

DECLARATION AND COPYRIGHT

I, **Asma Zain Ali**, declare that this **dissertation** is my original work and it has not been presented and will not be presented to any other University for a similar or any other degree award.

Signature…… **Date**……...….....

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DEDICATIONS

I dedicate this dissertation first and foremost to Almighty God who granted me the strength to complete this project. Secondly, I wish to extend much gratitude to my family and partner for accepting and respecting the times when I could not avail myself of my academic responsibility.

ABSTRACT

Background: Tanzania has a high burden of Sickle Cell Disease, with approximately 11,000 babies born with Sickle Cell Disease (SCD) each year, ranking 5th in the world. This calls for effective premarital screening to reduce this burden. However, limited data exist on factors influencing pregnant women's knowledge, attitudes, and perceptions toward premarital screening (PMS) for sickle cell disease.

Objective: The study aimed to assess factors influencing knowledge, perception, and attitude toward premarital sickle cell disease screening among pregnant women attending the antenatal clinic (ANC) at Muhimbili National Hospital (MNH).

Material and Methods: This was a cross sectional study whereby 400 pregnant women were recruited from December 2023 to January 2024. Structured questionnaire was used to collect socio demographic, obstetric characteristics associated with knowledge, attitude and perception reagarding premarital SCD screening. Multivariable logistic regression was conducted to identify independent factors associated with knowledge, perception and attitude towards premarital screening for sickle cell disease. Results were reported using Odds Ratio (OD). A p-value of less than 0.05 was considered significant.

Result: The mean age of participants was 29 years (SD ± 6.2) and 48% of pregnant women were aged 26-35. The proportion of women with adequate knowledge was 6.5%, positive perception 68.7% and positive attitude 68.0% towards premarital screening for sickle cell disease. The multivariate regression analysis shows, college education (OR=3.0, 95% CI=1.46-6.19), secondary education (OR=2.26, 95% CI=1.10-4.64), are associated with a positive attitude towards PMS. Positive perceptions of PMS are associated with being employed (OR=2.42, 95% CI=1.21-4.86).

Conclusion: The study identified a significant knowledge gap of PMS for SCD screening among pregnant women. Education and employment status influenced attitude and perception. Improving education and opportunities for work will enhance knowledge, perception and attitude for PMS.

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LIST OF ABBREVIATIONS

ART	Assistive Reproductive Technologies
CKD	Chronic Kidney Disease
CVS	Chorionic Villus Sampling
Hb	Haemoglobin
Hb A	Normal Haemoglobin
Hb S	Sickle Haemoglobin
MNH	Muhimbili National Hospital
PGD	Preimplantation Genetic Diagnosis
PMS	Premarital screening program
PND	Prenatal Diagnosis
SCD	Sickle Cell Disease
SD	Standard Deviation
SPSS	Statistical Package for Social Sciences
VF	Vitro Fertilization

OPERATIONAL DEFINITIONS

Knowledge: refers to understanding, information, and experience that a person has acquired through learning or studying (1). In this study, knowledge referred to information about premarital screening for sickle cell disease acquired by someone through experience and studying. Then, twelve questions were used to assess the level of knowledge, and 80% was cut- off point for adequate knowledge score (2).

Attitude: It can be defined as how someone thinks, feels, and behaves in response to a particular stimulus, based on their beliefs, values, experiences, and emotions. In this study, attitude refers to how someone feels about premarital screening for sickle cell disease. There were eight (8) domains used to assess the level of attitude towards premarital screening whereby a cut-off point of 80% represented a positive attitude regarding PMS for screening SCD (3).

Perception: is the process by which individuals organize, interpret, and give meaning to sensory information in order to understand and interact with their environment. In this study, the perception was referred to as the way participants interpreted the practices of taking premarital screening for sickle cell disease before marriage. There were nine “9” item on the perception of premarital screening, a cut-off point of 80% represent positive perception of PMS (4).

CHAPTER ONE

1.0 INTRODUCTION

1.1 Background

Sickle Cell Disease (SCD) is a hereditary condition that typically passes from one parent to their children via genetic inheritance **(5)**. SCD is an inherited blood disorder that is caused by a mutation in the genes that codes for hemoglobin, a protein in the red blood cell designed to deliver oxygenated blood via small blood vessels throughout the body (6). Sickle cell patients have defective hemoglobin resulting in a C-shaped farm tool known as a "sickle", which causes red blood cells to cling together and impede the blood flow in small blood vessels (7). Usually, the life span for healthy red blood cells is 120 days while abnormal Sickle cells die within 10–17 days which leads to a shortage of red blood cells (5). Therefore, this might result in discomfort and even severe health problems, and increase the risk of infections.

There are different types of SCD manifest when an individual receives two abnormal Hb genes, which are responsible for producing sickle haemoglobin (HbS), from both parents. Inheritance of two abnormal HbS genes led to SS disease with clinical phenotype, HbSS also known as sickle cell anemia is the most severe disease compared to other types of sickle cell disease (2). Moreover, in combination with other abnormal haemoglobins such as sickle cell haemoglobin C disease led to Haemoglobin SC disease (HbSC), sickle cell β-thalassemia (HbSβ-Thal), Haemoglobin SB 0 (Beta-Zero) thalassemia, Haemoglobin SD, Haemoglobin SE, Haemoglobin SO. However, the SCD type that is most prevalent and associated with high morbidity and mortality is HbSS, known as sickle cell anaemia. (8,9). Some of the common causes of death are acute chest syndrome, inter-current infections, pulmonary emboli, infarction of a vital organ, and chronic kidney disease (CKD). Therefore, it is very important to maintain regular or routine check-ups and adherence to medical prescriptions from the medical team.

Acute aplastic, infection, spleen sequestration, chronic haemolytic anaemia, and vaso-occlusion were the most common complications affecting patients with SCD (10). Others include stroke, cognitive dysfunction, priapism, leg ulcers, avascular necrosis (of the femoral head or humeral head), chronic pain, retinopathy, pulmonary hypertension, acute kidney injury, chronic kidney disease, thromboembolic events, and hepatic sequestration (11). Therefore, the consequences of SCD and continuous treatment effects quality of life including the psychological, social, and cultural attitudes of the patient.

SCD patients may feel severe discomfort at an early age in infancy, childhood, and maturity. Microvascular blockage causes pain as a result of activated nociceptive nerve fiber, then microcirculation is clogged by sRBCs which restrict blood circulation to the organ leading to ischemia, edema, pain, necrosis, and organ damage (10). The 'hand-foot syndrome' is distinguished by tissue edema and extremity pain caused by vaso-occlusion of the post-capillary vasculature. Others include infections, fever, dehydration, acidosis, and rapid changes in weather including wind speed, cold, rain, and air pollution are well-known triggers (12).

The most prominent clinical feature among SCD patients with SCA (Homozygous S) is anaemia. With regards to the phenotype, the steady state of haemoglobin of healthy individuals ranged from 60–80 g/L for homozygous S and /Sβo to 100–110 g/L in double heterozygous SC and Sβ+ forms however the rate of fall of the steady state of haemoglobin level stimulate the symptoms of hypoxia (aplastic crises) or a shock-like state (e.g., acute splenic sequestration) (10). Moreover, the acute aplastic crisis is the result of viruses called Parvovirus B19, interfering with erythrocytes in the creation of new red blood cells in bone marrow progenitors (11).

Prospective couples should be screened for inherited diseases to reduce the chances of having a child with a genetic disorder or disease. Knowledge, perception, and attitude toward premarital screening play a pivotal role in the decision-making process of couples. A study conducted in Jordan found that teenagers believed it was important to undergo premarital genetic testing before getting married, as it would reduce the likelihood of having genetic diseases passed to their offspring (13). The knowledge that genetic disorders like sickle cell disease can be inherited has been shown to positively influence couples' decision to seek

screening. Furthermore, couples who perceive the screening as a preventive measure often feel more secure in their marriage decisions, especially when they are aware of options such as in vitro fertilization (IVF), which offers the possibility of selecting embryos free of genetic disorders. For example, Chinese couples undergoing IVF treatment reported an improved psychological status and stronger marital relationships (14).

In contrast, in Tanzania, the prevalence of sickle cell carriers is currently estimated at 26%, with SCD affecting 6 children out of every 1,000 live births (15). Without interventions such as premarital screening (PMS), the burden of SCD is likely to increase significantly (5). The lack of awareness or negative attitudes toward PMS could hinder its adoption, exacerbating the public health challenge posed by SCD. The belief that premarital screening is mainly a barrier to marriage, rather than a helpful tool for informed decision-making and reproductive planning, may discourage its use (16).

Premarital screening enhances parents' understanding of the odds of transmitting abnormal hemoglobin genes responsible for SCD to their offspring. Those with higher levels of knowledge and positive attitudes toward genetic testing are more likely to seek out PMS services. Conversely, misconceptions or negative attitudes may deter couples from participating, leading to a higher prevalence of children born with SCD. Given this context, it is imperative to assess the level of knowledge, attitudes, and perceptions of women regarding premarital screening for sickle cell disease in Tanzania (5,15,17). Such research is critical to identifying barriers and enablers to the acceptance of PMS, which can inform the development of effective interventions to minimize the occurrence of SCD in the country.

1.2 Problem Statement

Sickle cell disorder poses a significant public health challenge for individuals and communities. It is associated with a range of health complications, including chronic pain, anaemia, and organ damage. It can also lead to early mortality, particularly in children. Approximately 90% of the world's SCD patients are found in Sub-Saharan Africa and Tanzania is one of the countries in the world with the highest prevalence of SCD (18,19). The prevalence of SCD is still increasing, despite the effort to reduce the burden of SCD in Tanzania. There may be several causes for this, including limited access to healthcare, inadequate education, and awareness about the disease, and limited resources for screening, diagnosis, and treatment.

Premarital screening for sickle cell disease was an effective method of reducing the spread of SCD to future generations. Studies done elsewhere from Iran and Lebanon show the incidence of SCD was reduced by 70% and 75% respectively (20). Also, the Jordan PGS program lowers the incidence, psychosocial problems, and economic burden of a caring patient with SDC (13). This identifies, carriers of the sickle cell gene before marriage or plans to have children and helps them to opt for various assistive reproductive technologies (ART) for the prevention of the gene passing to offspring (21). This includes in vitro fertilization (IVF) with preimplantation genetic diagnosis (PGD) or prenatal diagnosis (PND) through amniocentesis or chorionic villus sampling (CVS). Therefore, PMS can raise awareness about the disease and encourage individuals to be screened and seek appropriate medical care.

In our local context, studies revealed, that misinformation, health belief, and, limited resources available for diagnosis of SCD were among the leading factors impairing the efforts to reduce the SCD burden in Tanzania (5,22,23) As a result, 90% of children who were born with SCD died before reaching 18 years of age (18,24). Although there is an opportunity to prevent the complication through premarital screening, little has been done to determine the factors influencing pregnant women’s level of knowledge, attitude, and perception of premarital screening for premarital sickle cell disease screening.

1.3 Conceptual framework

This study was guided by the conceptual framework developed by a researcher through the knowledge gained from reading literature on the factors influencing pregnant women's knowledge, perception, and attitude toward premarital sickle cell disease screening (25,26) (figure 1 below)**.**

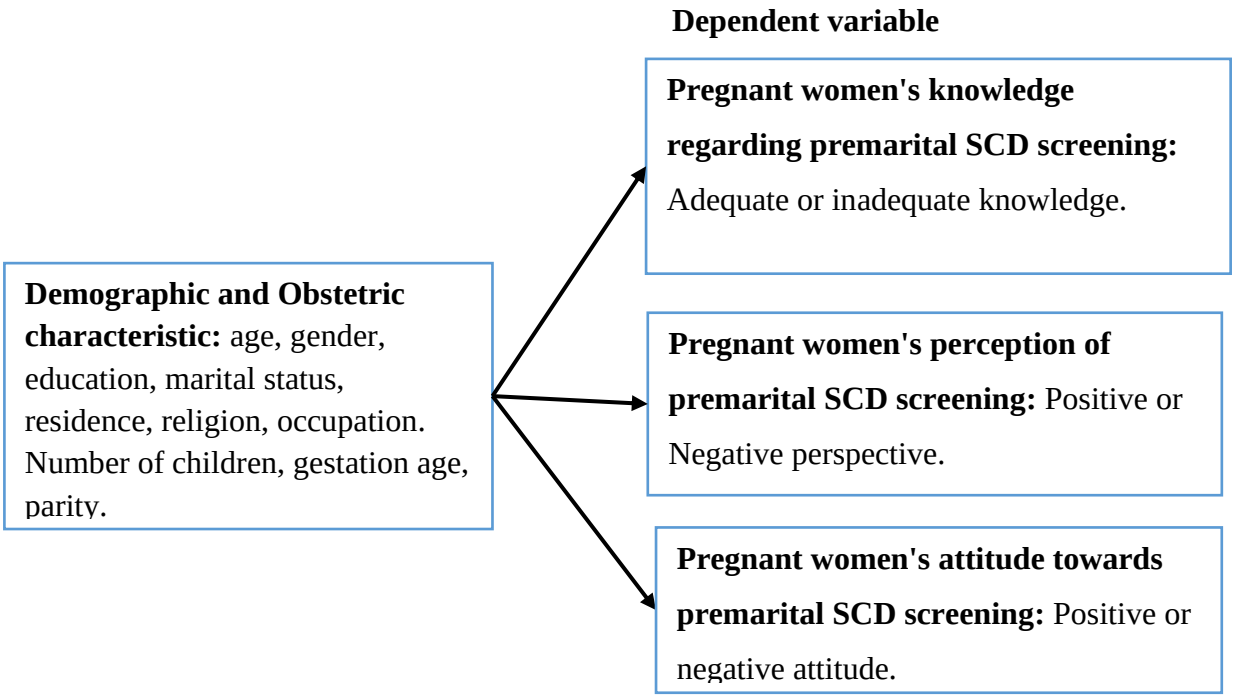


Figure 1: Conceptual framework on factors influencing pregnant women's knowledge, perception, and attitude towards premarital sickle cell disease screening at Muhimbili National Hospital.

1.3.1 Description of the conceptual framework.

Inadequate or limited utilization of PMS for SCD affects spreading and increases the burden of genetic blood diseases like sickle cell anaemia and thalassemia. Knowledge, attitude, and perception of premarital screening for sickle cell disease are primarily predisposed by the social demographic of pregnant women such as age, religion, number of children, residence, and family history of SCD. On the contrary, independent variables have a direct influence on the dependent variable. This, suggests that pregnant women's knowledge, attitude, and perception towards premarital screening for sickle cell disease can influence their decision

to undergo the screening or not. For example, if a pregnant woman has a good understanding of the benefits of premarital screening, a positive attitude towards it, and perceives it as important for the health of their future child, they may be more likely to undergo the screening. On the other hand, if they lack knowledge or have negative perceptions and attitudes toward premarital screening, they may be less likely to undergo it.

1.4 Rationale of the Study

This study intended to bridge the gap of knowledge, attitude, and perception of premarital screening disease among pregnant women at the Muhimbili National Hospital (MNH). The findings of the study are expected to provide information about premarital screening which will reveal the current situation regarding the level of knowledge, attitude, and perception toward premarital screening for SCD and factors influencing it. The information obtained will be added to the body of knowledge and lay down the foundation for the improving health education provided to pregnant women attending antenatal clinics (ANC) at MNH.

1.5 Research questions

What are the factors influencing knowledge, perception, and attitude toward premarital sickle cell disease screening among pregnant women attending ANC at MNH?

1.5.1 Specific research question

i. What is the level of knowledge of premarital sickle cell disease screening among pregnant women attending ANC at MNH?

ii. What is the attitude towards premarital sickle cell disease screening among pregnant women attending ANC at MNH?

iii. What are the perceptions of premarital sickle cell disease screening among pregnant women attending ANC at MNH?

iv. What are the factors associated with knowledge, perception, and attitude toward premarital sickle cell disease screening among pregnant women attending ANC at MNH?

1.6 Objectives

1.6.1 Broad objective

To assess factors influencing knowledge, perception, and attitude towards premarital sickle cell disease screening among pregnant women attending ANC at MNH**.**

1.6.2 Specific objectives

i. To identify the level of knowledge of premarital sickle cell disease screening to pregnant women visiting ANC at MNH

ii. To assess attitudes towards the premarital sickle cell disease screening among pregnant women attending ANC at MNH

iii. To determine the perception of premarital sickle cell disease screening among pregnant women attending ANC at MNH

iv. To determine factors associated with knowledge, perception, and attitude towards premarital sickle cell disease screening among pregnant women attending ANC at MNH.

CHAPTER TWO

2.0 LITERATURE REVIEW

2.1 Burden, complication of Sickle Cell Disease and Role of Premarital Screening in Prevention

Sickle cell disease (SCD) poses a significant global health burden, particularly in sub-Saharan Africa, where it is most prevalent. SCD is a hereditary blood disorder caused by a mutation in the hemoglobin gene, leading to the production of abnormal hemoglobin (HbS) and resulting in distorted, sickle-shaped red blood cells (16). These abnormal cells can block blood flow, causing painful crises, organ damage, stroke, and increased susceptibility to infections (27).

Complications of SCD include chronic anemia, acute chest syndrome, kidney dysfunction, and early mortality, particularly in children (28). Premarital screening is highly relevant in the context of SCD prevention, as it helps identify carriers of the sickle cell trait and informs couples of their risk of having children with the disease (29). Promoting informed reproductive choices, premarital screening can play a crucial role in reducing the incidence of SCD in high-prevalence regions. Such screening programs provide an opportunity for early intervention, counseling, and consideration of reproductive options, ultimately helping to lower the burden of SCD (12,30).

2.1 Knowledge of premarital screening for SCD among pregnant women.

World Health Organisation and American Society of Haematology prompted the provision of educational programs to improve the level of understanding about sickle cell disease worldwide (6,19).

However, a survey study conducted in Kampala Uganda, reported, 50% were not aware of methods of diagnosing SCD (1). On the contrary, another study conducted in the Democratic Republic of Congo revealed that 53.6% knew diagnosis of SCD can be done by blood test and 85.6% did not understand the risk to children (22). The provision of an education program helped to improve the understanding of SCD. Therefore, to bridge the gap in the

knowledge domain and to improve awareness of SCD, it is important to incorporate sickle cell campaigns into the community's health education.

PMS is an effective measure for reducing the occurrence of genetic disorders, particularly SCD. A study conducted in Oman revealed that 89.3% of adults in the general population were knowledgeable about pre-marital carrier screening (26). Healthcare workers, periodical notes, and friends were identified main sources of knowledge regarding PMS. In addition to that, a study conducted in Saudi Arabia among the Al-Madinah community revealed, that 61% and 50.2% of the study participants knew Sickle Cell Anaemia (SCA) and thalassemia can be diagnosed during premarital screening respectively (29). Similarly, another study done in the same country by Khan *et al.*, (2022) revealed, 92.6% of the adult Saudi community is aware of the premarital screening program (PMS), however, 47.4% and 36.3% understood SCA and Thalassemia can be detected by PMS respectively (31). The finding of these studies shows the level of knowledge among study participants varies across different domains, emphasizing the provision of health education to promote community understanding of premarital screening.

An effective and efficient process of promoting and preventing disease through education is needed in various African countries. For example in Nigeria, 26.9% of women receiving care at a tertiary health centre did not know about PMS while 85% of women were aware of SCD (32). The finding of this study exposed that awareness of sickle cell disease did not correspond with an adequate understanding of premarital screening due to a lack of health education about PMS. The findings contrasted with a study conducted in the same country among youth selected from Yaba Local Council Development Area reported, that 80% of respondents were knowledgeable about PMS for SCD (33). Furthermore, it's stated that awareness regarding SCD and genetic premarital counselling adults lived in metropolitan areas, where there is a higher level of literacy compared to rural areas. Also in Nigeria, 55% of unmarried adults from the urban community had adequate knowledge of PMS (16). This is because most single adults understood the importance of PMS to lower the likelihood of having children affected with SCD. Therefore, public health education should be provided to individuals and communities to equip them with the knowledge, skills, and resources needed to make informed decisions about their health.

In Tanzania, there has been a minimal number of studies, conducted to address knowledge of sickle cell among pregnant women. Although a study conducted by Lumbe and Kibusi, (2022) in Dodoma revealed considerable gaps in knowledge on screening and preventive measures and benefits of SCD screening (5). Moreover, another study conducted in Dar es Salaam shows, 14.7% of pregnant women who attended the ANC understood about SCD (15). Despite the prevalence of haemoglobin-S being reported to be higher at 15.7% of pregnant women, there is a limited study on assessing the knowledge about premarital screening. Then this necessitates the importance of conducting this study to bridge this gap.

2.2 Attitude towards PMS for SCD among pregnant women.

Several steps or precautions have been taken to prevent the spread of genetic diseases worldwide. World Health Organization (WHO), recommended the following steps which included the provision of health education, screening of couples at risk, genetic counselling, and prenatal diagnosis (34).

PMS programs established in several countries worldwide reduce the occurrence of genetic disorders and other diseases. In Oman, 30.5% of the adults from the general population accessing the health centre had a negative attitude toward a blood test for premarital carrier screening (35). The finding of the study identifies certain demographic characteristics like gender, age, and marital status are associated with negative attitudes towards premarital testing. Targeted intervention may be necessary to address negative attitudes toward premarital testing. However, in Muscat, about 87.2% of the students had a positive attitude toward PMS and 55.3% agreed that it should be required before marriage. Additionally, 38.3% of the students advised setting up rules and guidelines for preventing cohabitating marriage (20). Therefore, studies suggest there is a need to employ appropriate interventions like health education campaigns to raise awareness about the importance of premarital testing and its potential benefits, as well as efforts to address cultural or social barriers that may be contributing to negative attitudes towards testing.

Several studies have been conducted in Africa regarding attitudes toward premarital screening. For example, recent research that focused on the attitude of premarital screening in a general population from Odisha reported that the majority of families with SCD patients

58% had a positive attitude towards sickle cell screening influenced by frequent hospitalization and uneven health insurance (25). As the author noted, despite a positive attitude toward premarital screening still there is a high prevalence of SCD. This was reinforced by a shred of evidence from a study conducted in Oman, which found that freely available premarital screening was less useful, despite 91.8% of the study participants agreeing to take the test in the future and 89.3% understanding the importance of screening for SCD before marriage (26).

The incorporation of an education program in a school curriculum aided in developing new experiences to lower the burden of SCD in the community. For example, Gwagwalada Abuja, Nigeria shows, the majority of students have a good attitude toward PMS (3). On the contrary, a recent study from Nigeria concluded that women of childbearing age had insufficient knowledge and perception, which resulted in an unsatisfactory attitude toward premarital screening (8). But, when comparing males and females, a student from a high school in Muscat, Oman, the female was more likely to legalize genetic screening as a mandatory test to be undertaken before marriage (20).

In Tanzania, studies are limited regarding attitudes towards PMS for SCD among pregnant women, although an experimental study conducted by Tutuba, et al 2023 among pregnant women attending ANC at the three hospitals in Dar es Salaam region demonstrated maternal education is important in improving women knowledge about utilization of infant diagnosis for SCD (36). This indicates little has been done regarding attitudes towards premarital screening in Tanzania, among women of childbearing age, hence necessitating conducting this study to fill the gap

2.3 Perception of pregnant women on premarital screening.

According to WHO, recommends population-wide screening tests for certain diseases that have serious consequences, whereby the benefits of screening outweigh the potential harms (37). Several countries both developed and developing countries accepted premarital screening as a method that facilitated the process of making decision-making to reduce the incidence of genetic diseases to future generations like sickle cell disease (7).

Most developed countries, implement premarital screening programs as an approach to reducing birth defects and avoiding genetic disorders. A study cross-section study conducted in Jordan shows that 87.8% of women believe PMS can lower the burden of SCD (13). Even though a significant portion of young individuals in Jourdan believed that premarital screening (PMS) decreases the transmission of genetic diseases, they also recognized that it could contribute to family disintegration due to the financial strain of caring for a child with a genetic disorder. Then, a study done in Qatar, shows that 90% of adults in the general population were more likely to conceal their marriage plan when premarital genetic results are mismatched and do not interfere with their religious beliefs (38).

In Africa, perspectives regarding PMS for SCD are reported in several pieces of literature. For example, a study conducted in Gombe state Nigeria, highlighted, that 57.10% of the women of childbearing age had a negative perception of premarital genetic screening (8). The study noted that individuals with a history of having a patient with SCD in their family were significantly connected with information that influenced their perspectives of premarital genetic screening. On the other hand, in Nigeria, 79.5% of university students have a positive perception and are accepted to undertake the premarital screening if it is available (39). It is therefore important to initiate education programs about the benefit of premarital genetic screening among women to lower the prevalence of SCD in developing countries (25).

In Tanzania, studies are scarce regarding the perception of women of childbearing age on premarital screening although a qualitative study conducted by Kisanga *et al.*, (2021) explored parents' experiences of caring for children with SCD and premarital genetic screening (PGS). A recent study done in Tanzania shows financial barriers and humiliation have affected the quality of care and management of children with SCD children (17). However, there is no known study that assessed the perception of pregnant women on premarital screening. This necessitates conducting this study to bridge this gap regarding the perception of women towards PMS.

2.4 Factors associated with pregnant women's knowledge, attitude, and perception towards premarital screening for sickle cell disease.

Knowledge, attitude, and perception towards premarital screening for sickle cell diseases can be associated with obstetric and demographic characteristics of pregnant women. A study done by Al-Farsi *et al.*, (2018) reported certain social demographic features like age, and marital status had an association with the negative attitude toward premarital screening for sickle cell disease among pregnant women (35). Similarly, in Saudi Arabia, marital status, age, education level, and family income were the factors associated with a good attitude toward premarital screening (40). It is important to provide educational programs regarding premarital screening in media like TV, radio, and newspapers for community outreach.

Moreover, in the United States of America (USA), it was found that knowledge of premarital genetic counselling, awareness options, and knowledge of premarital genetic testing was significantly improved after having been exposed to education and a clinical vignette (41). The studies concluded that clinical vignettes are a useful teaching tool for encouraging community attitudes about premarital screening for sickle cell disease.

In Tanzania, being a homemaker, having a lower level of education, and hearing SCD from street or peers, were highly associated with having a lower level of knowledge about SCD among pregnant women attending ANC in Dar es Salaam (41). The full package for possible health promotion at prenatal clinics should include maternal screening and health education on SCD. Understanding the variables influencing pregnant women who attend the antenatal clinic at MNH's knowledge, attitude, and perspective about premarital screening for sickle cell disease is therefore necessary.

In a study conducted in Tanzania, being a homemaker, having a lower level of education, and hearing an SCD from street or peers, were highly associated with having a lower level of knowledge about SCD among pregnant women attending clinics in Dar es Salaam (41). The study suggested maternal screening and health education on SCD should be included as part of the comprehensive package for potential health promotion at antenatal clinics. Therefore, this necessitates understanding the factors associated with knowledge, attitude,

and perception toward premarital screening among pregnant women attending antenatal clinics at MNH.

2.5 Research Gap

The section reviews several studies conducted from higher income countries and low-middle-income countries to understand factors associated with knowledge, attitude, and perception towards premarital screening for Sickle Cell Disease (SCD) (12,15,31,38). The knowledge gap identified for each specific study objective shows there is limited information regarding factors that influence pregnant women's knowledge, attitude, and perception in this context. The study aims to fill this gap by providing valuable insights into the specific factors associated with pregnant women’s knowledge, attitude, and perception toward premarital SCD screening for MNH in Tanzania.

CHAPTER THREE

3.0 MATERIALS AND METHODS

3.1 Study Design

A descriptive cross-sectional study design with a quantitative approach was employed to study factors influencing premarital sickle cell disease screening among pregnant women attending ANC at MNH. The approaches guided the provision of important information regarding factors associated with pregnant women's level of knowledge, attitude, and perception toward premarital SCD screening (42).

3.2 Study Area

Muhimbili National Hospital (MNH) is located in the Ilala District within the Dar es Salaam region. The National referral hospital received cases from different parts of the country through referral systems. This hospital was selected to be a study area since it is the largest national referral hospital and primary hospital for SCD patients in Dar es Salaam. The hospital received almost 2,000 outpatients per day and had a capacity of 1500 beds. MNH provided healthcare to SCD patients, with normal outpatient visits scheduled at three-month intervals for routine check-ups.

The study setting for this study was the Department of Obstetrics and Gynaecology of MHN. The department was comprised of six units, namely general obstetrics, general gynaecology, acute care or fatal maternal medicine, gynaecology-oncology, urogynaecology, and reproductive endocrinology and infertility unit. Moreover, the department received about 154 pregnant women who attended ANC per day. The ANC clinic at the hospital was carried out from Monday to Friday and each firm had a specific day of the week to run the ANC. A follow-up ANC appointment could be scheduled for Tuesday, Wednesday, or Thursday for women who had scheduled their first ANC visit during pregnancy.

Every woman who was scheduled to receive care at the clinic had to first register. An ANC nurse then educated the women on general prenatal care of pregnancy before seeing each woman individually. Every pregnant woman who attended the ANC clinic had to first register before being provided with health education regarding general antenatal care of pregnancy by the ANC nurse on duty.

Moreover, the Obstetrics and Gynaecology Department of MHN provides a specialized clinic for pregnancy care for SCD patients. Normally, the clinic is held on Friday from 12 p.m. to 4.30 p.m. at the MNH maternity block ground floor. The Pregnant women with SCD visited the ANC for the first time to receive a comprehensive assessment including hemoglobinopathy screening. The blood pressure, urinalysis, and midstream urine for culture were done monthly during a follow-up ANC visit. Additionally, to reduce the risk of pre-eclampsia, women with SCD were advised to begin receiving low-dose aspirin 75 mg once a day at 12 weeks of pregnancy. SCD-affected women are also advised avoid things like exposure to extreme heat or cold, dehydration, and strenuous activity that might precipitate sickle cell crises.

3.3 Study Population

The study population comprised pregnant women aged 18 to 45 years who attended antenatal care at Muhimbili National Hospital. Women in this age range were included because they were considered capable of making informed decisions about premarital sickle cell disease screening, due to their adult status, engagement with healthcare, and increased awareness of genetic health risks related to their pregnancies.

3.4 Sample size estimation

Yamane (1967) has recommended the proportional formula for sample size from a known population(43).

The formula is;

$$\mathbf{n} = \frac{\boldsymbol{z^2 p(1-p)}}{\boldsymbol{e^2}}$$

Where **n**= expected minimum sample size

z= standard, corresponding to 95% confidence, 1.96

e= maximum likely error, taken as 5%

p**=** The prevalence of attitude toward premarital screening was 63.20% (0.632) among women of childbearing age in Gombe state, Nigeria (8).

$$\mathbf{n} = \frac{\mathbf{1.96^2 * 0.632 * (1 - 0.632)}}{\mathbf{0.05^2}}$$

The minimum sample size is **357 of** pregnant women were included in the study. Then, the minimum sample size was adjusted for 10% of the non-response rate.

$$\textbf{Sample size} = \frac{\boldsymbol{n}}{\mathbf{1 - 0.1}}$$

=357/ (1- 0.1)

=400

Therefore, **400** pregnant women made up to study's sample size after adjusting a non-responsive.

3.5 Variables

The following were the dependent and independent variables for the study

i. **Independent variable:** Demographic and obstetric characteristics: including continuous variables like Age, gestational age, parity, and Number of children while categorical variables were Sex, Level of education, Religion, Occupation, Family history of sickle cell disease, and Residence.

ii. **Dependent variables:** Knowledge, Perception, and Attitude toward premarital SCD screening.

3.6 Sampling Procedure

A sampling frame containing details of patients who attended ANC on a particular day was obtained from the nurses at the registry desk to facilitate the selection of study participants. A piece of paper with a number written on it was prepared. In this study, a lottery system was used in the selection of participants who were willing to participate when attending ANC on a particular day (44). Pregnant women were requested to draw a piece of paper from a box after it had been mixed. Those who drew an even number (like 2, 4, 6, etc.) from the

box were selected to participate in the study until the required sample size was obtained. Moreover, the card number of pregnant women was used during data collection to avoid repetition and redundancy, and after data collection, the number was coded. Therefore, the technique provided a chance for recruiting a sample of the study from the population since participants in the population had an equal chance of being selected.

3.7 Inclusion and Exclusion Criteria

3.7.1 Inclusion criteria

All pregnant women who provided their consent of participation were included in this study.

3.7.2 Exclusion Criteria

i. Pregnant women who had obstetrics emergency were unable to participate were excluded.
ii. All pregnant women who were mentally handicapped were excluded from the study.

3.8 Data collection procedure

Data were collected for a period of one and a half month on working days from Monday to Friday except public holidays from December 2023 to January 2024 by the researcher and research assistant. Participants were visited by the researcher at the waiting area of the ANC at the Department of Obstetrics and Gynaecology of MNH hospital. Before initiating data collection, the Chief in charge, who was acquainted with the surroundings, introduced the Researcher to the participants of the study. Purpose, benefits, and risks including the eligibility criteria for participating in the study were explained by the researcher to the study participants, and their consent for participation was sought. A simple random method involving a lottery method was used to recruit study respondents who agreed to participate in the study. Pregnant women were requested to draw a piece of paper from a box after it had been mixed. Those who drew an even number (like 2, 4, 6, etc.) from the box were selected to participate in the study until the required sample size was obtained. Then, the selected respondent was given a written consent form upon voluntary consent to participate in the study.

A self-administered questionnaire was provided to the study participants for data collection, which was estimated to take about 30 minutes. The researcher and the researcher assistant had the responsibility of collecting the questionnaire, once it had been filled out by the respondent. Anonymity, privacy, and politeness were highly encouraged by the researcher and trained research assistants during data collection to maximize the response rate from the participants.

3.9 Data Collection Tools

The questionnaire consisted of closed-ended questions to assess factors influencing the level of knowledge, perception, and attitude toward premarital SCD screening among pregnant women (16,38). To encourage maximum participation, the Baraza la Kiswahili Tanzania (BAKITA) translated the questionnaire from English to Swahili, the predominant language spoken by the majority of the study participants. Moreover, data collection tools were segmented into four parts to meet the study objectives. The first section covered questions regarding the demographic characteristics of pregnant women, including age, sex, level of education, etc. The second section included all questions on the knowledge of sickle cell disease and premarital screening among pregnant women. Knowledge about premarital sickle cell disease was assessed by selecting the right response, which was marked as “1” from the wrong response, marked as “0”. The third section was covered with a question regarding attitudes toward premarital screening for sickle cell disease, which was assessed using a five-point Likert scale ranging from strongly disagree to strongly agree. The fourth section covered questions to determine perceptions of premarital screening for sickle cell disease among pregnant women, which were assessed using a five-point Likert scale ranging from strongly disagree to strongly agree.

3.10 Training of Research Assistants.

There were two research assistants, each holding a diploma or degree in health-related fields such as clinical medicine. They underwent a training program conducted by the principal investigator, lasting three to four days. The training covered essential research methods for recruiting eligible participants and emphasized the importance of respecting and treating participants with dignity throughout the study. Additionally, the research assistants were trained in administering questionnaires, including providing clear explanations to ensure that

participants understood the questions. This comprehensive training aimed to equip them with the skills necessary to conduct the research ethically and effectively.

3.11 Pre-testing of data collection tool

The data collection tools were pretested on forty (40) pregnant women attending the Department of Obstetrics and Gynaecology of MNH Mloganzila branch. Conducting a pretest, allowed modifications to be made to the data collection tools, such as rephrasing questions, to address any misconceptions or misunderstandings related to specific topics and align with the participants' understanding and local context during data collection (45).

3.12 Data management

The completeness of the questionnaire was checked before entering it into the IBM Statistical Package for Social Sciences (SPSS) version 23. The softcopy of the data collected was deposited in a computer protected by a password under the supervision of the researcher. Likewise, the hard copy of completed questionnaires was securely managed in a locked file cabinet accessible exclusively to the researcher.

3.13 Data analysis

The researcher performed data entry and data analysis using the IBM Statistical Package for the Social Science (SPSS) version 23. Data were analysed using descriptive and inferential statistics; measures of central tendency like mean and standard deviation were performed for continuous data. The independent variables such as age, sex, religion, and education status were analysed in terms of frequency and percentage. Knowledge about premarital SCD screening was measured by selecting the Right response, which was marked as “1”, and the Wrong choice was marked as “0”. Moreover, participants’ Knowledge about premarital SCD screening was analysed by totalling scores from the correct responses from the questionnaire. According to Bloom’s taxonomy, the knowledge scores were categorized into two groups. Then, 80% was cut- off point for adequate knowledge score which is the sum of the correct answer regarding knowledge of PMS. (16)

Attitude towards premarital screening for SCD were measured by using a Likert scale ranging from 1 = strongly disagree, 2 = disagree, 3 = unsure, 4 = agree, and 5 = strongly

agree. Furthermore, each item on the attitude domain towards premarital screening was grouped into two categories. Strongly agree and agree were merged and coded as “1” while strongly disagree, disagree, and unsure were coded as “0”. The total scores were converted into percentages Then the cut-off point of 80% was used which is the sum of the correct answers to classify those with positive attitude towards PMS for SCD (3).

Also, perception of premarital screening was measured by a Likert scale ranging from 1= strongly disagree, 2 = disagree, 3 = no opinion, 4 = agree, and 5 = strongly agree. Furthermore, each item on the perception of premarital screening was grouped into two categories whereby strongly agree and agree were merged and coded as “1” and strongly disagree, disagree as well as unsure were merged and coded as “0”. The total scores were converted into percentages Then the cut-off point of 80% was used which is the sum of the correct answers to classify those with positive perception of PMS for SCD (4).

Logistic regression was employed to estimate the factors influencing the level of knowledge, attitude, and perception regarding premarital SCD screening among pregnant women. The odds ratio and their corresponding 95% confidence intervals were performed to determine the strength of association between variables. Statistically significant variables had a P-value below 0.05. For comparative purposes between univariate and multivariate logistic regression, crude and adjusted odds ratios were employed. The final logistic regression model took into account variables connected to premarital testing for sickle cell disease at a P value of 0.05.

3.14 Ethical consideration

Ethical clearance letter with Ref No DA 282/298/01 C/1860 for conducting the study was granted by Muhimbili University of Health and Allied Sciences (MUHAS) Institutional Ethical Review Board. Before data collection, the researcher sought authorization to recruit study participants from the national hospital management of Muhimbili. Discretion was strictly upheld during and after the study. To ensure respondent anonymity, the questionnaire was designed without any personal identifiers or names. Additionally, detailed information regarding the aim of assessing factors influencing knowledge, perception, and attitude toward premarital sickle cell disease screening was provided to study participants. This

information provided enabled pregnant women to make an informed and voluntary decision regarding their participation. Participants had the right to withdraw from the study without facing any penalties. Before completing the questionnaire, respondents were requested to provide written consent.

3.15 Dissemination plan

After completion, the study will be submitted to the Muhimbili University of Health and Allied Science, Muhimbili School of Medicine, Publication in peer-reviewed journals, and the MUHAS library. Moreover, the findings of the study will be disseminated to the executive director of Muhimbili National Hospital and the findings will be disseminated at national and international scientific conferences.

CHAPTER FOUR

4.0 RESULTS

4.1 Presentation and analysis of the result

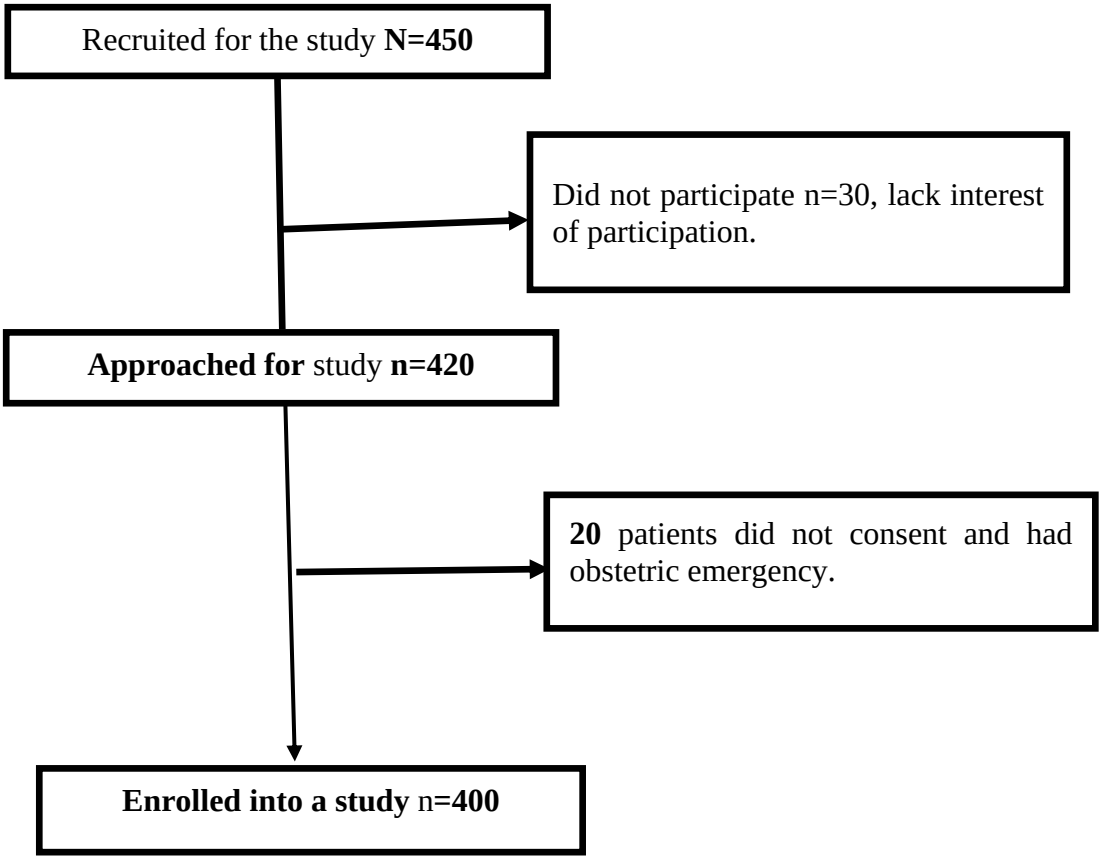


Figure 2: Schematic flow of enrolled study participants

4.2 Socio-demographic and Obstetrics characteristics of the study participants

Throughout the study period, 450 women attended antenatal care (ANC), out of which 400 were chosen through simple random sampling. Fifty of the women were not included in the study for reasons like having an obstetric emergency and not having enough time to participate.

The mean age of participants was 29 years (SD ± 6.2) and less than half 48.0% (192/400) were aged between 26 and 35 years, and 43.5% (174/400) had college level of education. Moreover, 39.3% (157/400) of study participants were married, and more than one-third of 36.5% (146/400) of study participants were self-employed.

More than two third of 70.8% (283/400) of study participants were in the third trimester of pregnancy at the time of collecting data. Also, 42.3% (169/400) had more than two pregnancies, and majority of study participants 71.5% (286/400) did not have an abortion.

Table 1: Socio-demographic and obstetrics characteristics of the study participants, N=400

Variable	Frequency (n)	Percent (%)
Age group (years)		
18 – 25	122	30.5
26 – 35	192	48.0
>35	86	21.5
Level of education		
No formal education	45	11.2
Primary education	59	14.8
Secondary education	122	30.5
College and university	174	43.5
Marital status		
Single	132	33.0
Married	157	39.3
Cohabiting	58	14.5
Separated and divorced	41	10.2
Widowed	12	3.0
Occupation		
Self-employed	146	36.5
Unemployed	80	20.0
Employed	130	32.5
House wife	44	11.0
Gestational age (weeks)		
First trimester	47	11.7
Second trimester	70	17.5
Third trimester	283	70.8
Gravidity		
1	121	30.2
2	110	27.5
>2	169	42.3
Parity		
0 - 1	235	58.8
2	83	20.7
>2	82	20.5
Number of abortions		
0	286	71.5
1	58	14.5
>1	56	14.0

4.3 Knowledge about premarital sickle cell disease screening for pregnant women

In this study, a significant majority of participants, at 93.5%, exhibited inadequate knowledge about premarital screening (PMS) for sickle cell disease (SCD). Most participants were unaware that there is a 50% chance of having a child with SCD if both parents carry the sickle cell gene, and they did not recognize that an individual without SCD can still be a carrier of the sickle cell gene. Furthermore, many were not informed about the benefits of PMS in reducing the burden of having a child with SCD.

Conversely, the proportion of participants with adequate knowledge about premarital sickle cell disease screening was 6.50% of which they understood blood test is used for diagnosis of SCD as well as PMS should be done before marriage **(figure 3)**.

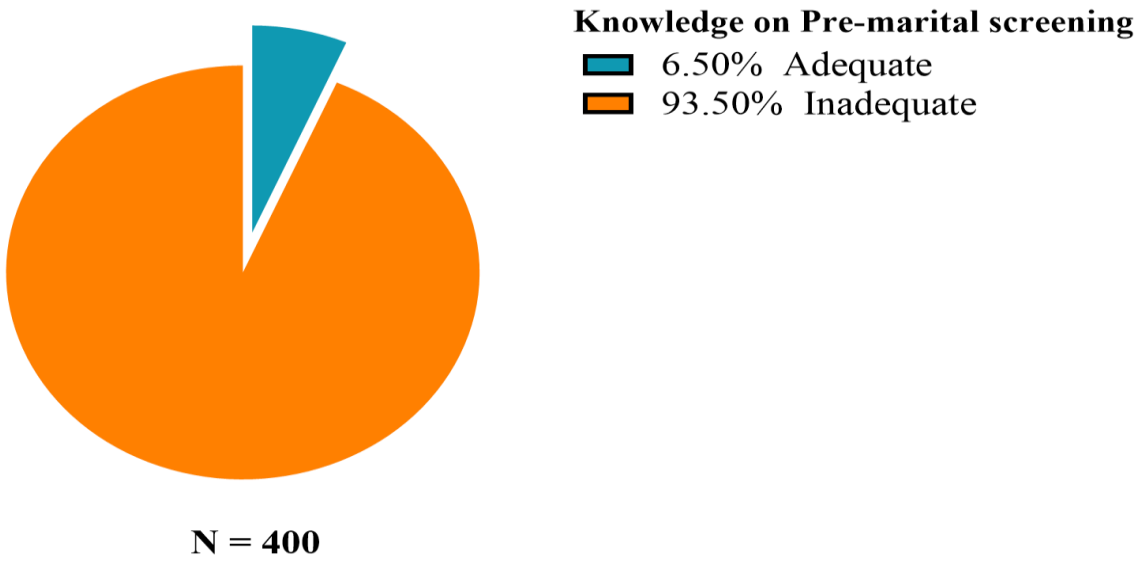


Figure 3: Knowledge about premarital sickle cell disease screening to pregnant women

4.3.1 Knowledge about premarital sickle cell disease screening to pregnant women

In the survey, several aspects of sickle cell disease (SCD) knowledge 65.3% of respondents demonstrated understanding of the timing importance of premarital screening, knowing that it should ideally occur before marriage or courtship. This is followed by 64.3% correctly identified that SCD can be diagnosed through a blood test. Substantial majority (58.8%) comprehended those carriers of the sickle cell gene can pass it on to their children. Nearly half of the respondents 47.3% correctly understood that SCD is inherited from parents.

Conversely, the majority of 90.3% of respondent misunderstood the transmission risk, incorrectly believing that carriers of the sickle cell gene have a 50% chance of passing on SCD. Also, considerable proportion 85.5% of respondents erroneously believed that there is treatment available for SCD. Also 81.5% of respondents incorrectly believed that individuals without SCD cannot be carriers for the sickle cell gene. Also, two-third of 69.5% of responded incorrectly believed that two parents without SCD cannot have a child with the disease.

Table 2: Knowledge about premarital sickle cell disease screening to pregnant women N=400

Questions on knowledge	Yes	No
Know a person gets Sickle cell disease from the inheritance by parents	47.3	52.7
Know two parents without SCD can give birth to a child with SCD	30.5	69.5
Know sickle cell carriers have 50% chance of SCD transmission	9.7	90.3
Know that there is no cure for sickle cell disease	46.0	54.0
Know there is no treatment for SCD	14.5	85.5
Know Both males and females are more likely to get SCD	37.7	62.3
SCD diagnosed by a blood test	64.3	35.7
A person without SCD can be a carrier for the sickle cell gene	18.5	81.5
Carrier of sickle cell gene can pass the gene to a child	58.8	41.2
Understand premarital screening for SCD	40.0	60.0
Know PMS should be done before marriage or courtship	65.3	34.7
Know benefit of PMS is preventing having a child with Sickle cell disease	22.2	77.8

4.4 Attitude towards premarital sickle cell disease screening among pregnant women

The study observed that most of 68.0% of the study participants in this study showed a positive attitude towards PMS for screening SCD before marriage aids in informed decision-making about their future together (figure 4).

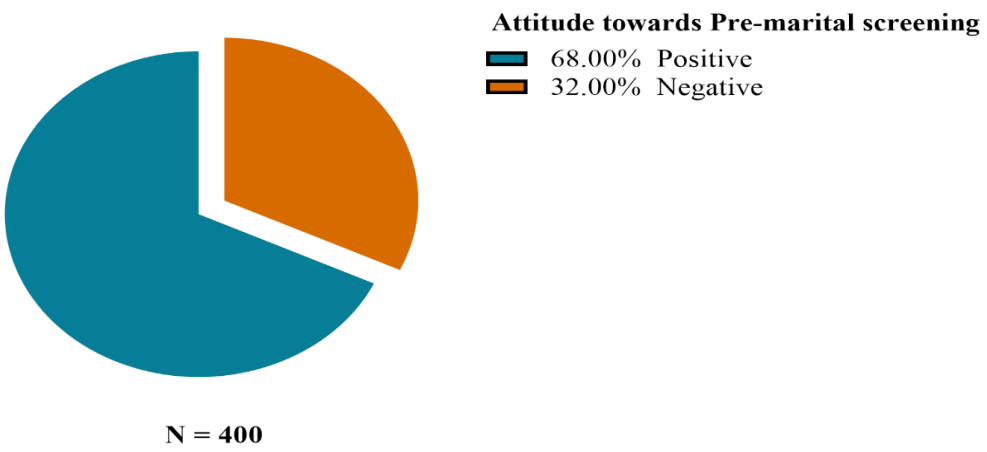


Figure 4: Attitude toward premarital sickle cell disease screening among pregnant women

4.4.1 Attitude toward premarital sickle cell disease screening among pregnant women

The data on attitudes toward premarital screening awareness for sickle cell disease (SCD) reveals 66.8% believe it is beneficial for everyone to know their genotype before marriage, highlighting a widespread acknowledgment of genetic awareness's importance. Similarly, 48.0% support the idea that awareness of premarital SCD screening is crucial, although the intensity of agreement is somewhat lower. Counselling and screening for couples are viewed as vital by 47.0%, underlining their role in informed decision-making.

Table 3: Attitude toward premarital sickle cell disease screening among pregnant women N=400

Questions on attitude	Strongly disagree (%)	Disagree (%)	Uncertain (%)	Agree (%)	Strongly agree (%)
Good for everyone to know his genotype (SCD carrier status) before marriage	3.0	1.2	8.5	20.5	66.8
Awareness about premarital sickle cell disease screening	3.2	5.3	13.7	42.5	35.3
Importance for two lovers to undergo counselling and screening before marriage	1.5	3.0	14.0	33.5	48.0
Believe premarital screening for SCD contributes to healthier family planning	3.3	6.7	17.0	31.3	41.7
I will go for PMS before marriage	3.0	3.8	16.0	37.5	39.7
PMS is not a waste of time and money	6.8	4.6	18.8	31.0	38.8
PMS influences the couple to decide on their future	1.8	2.2	15.0	35.0	46.0
PMS necessary before agreement to marry	1.0	6.0	11.8	34.2	47.0

4.5 Perception of premarital sickle cell disease screening among pregnant women

Interestingly, despite most of the study participants having insufficient knowledge about PMS for screening of SCD, more than two-third of 68.75% had positive perceptions towards its benefits, importance of screening SCD willingness to undergo genetic counselling, in reducing the burden of SCD, both psychologically and economically, for families and society at large (figure **5**).

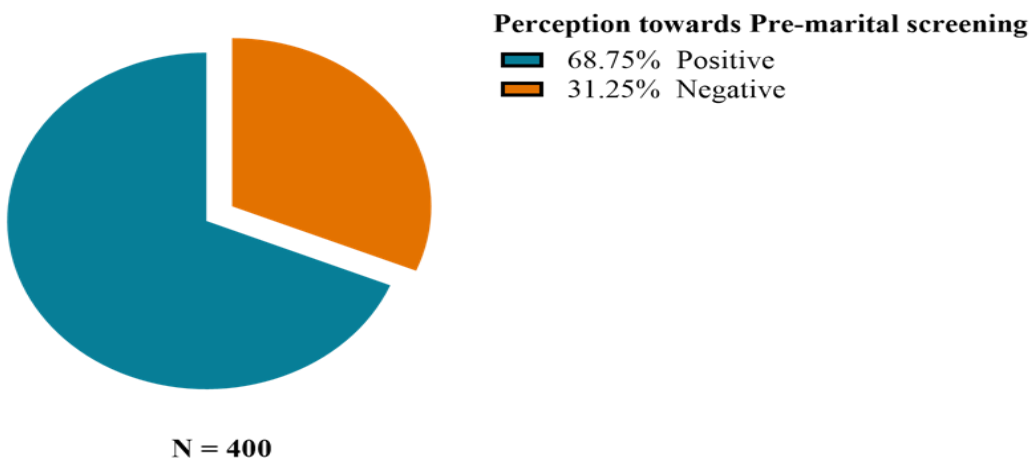


Figure 5: Perception of premarital sickle cell disease screening among pregnant women

4.5.1 Perception of premarital sickle cell disease screening among pregnant women

The analysis of the result shows a majority 64% believe that PMS is important for reducing the burden of SCD, indicating strong support for the role of PMS in addressing the impact of the disease. This is followed by 57.5% also agree or strongly agree that PMS helps reduce the psychological burden on families affected by sickle cell disease (SCD), suggesting recognition of its potential benefits in this aspect. A substantial majority 48.5% are willing to undergo genetic counselling as part of PMS, highlighting openness to receiving professional guidance in genetic matters.

Table 4: Perception of premarital sickle cell disease screening among pregnant women N=400

Questions on perception	Strongly disagree (%)	Disagree (%)	Uncertain (%)	Agree (%)	Strongly agree (%)
PMS is an important step for reducing the burden of SCD	1.5	3.3	12.2	25.5	57.5
PMS reduces the psychological burden on the family	0.4	4	12.3	39	44.3
PMS reduces the economic burden on the family	2.2	3.7	14.5	35.8	43.8
PMS will do better than harm to society	1.8	3	13.7	42	39.5
PMS should be a standard practice for SCD among couples before marriage	2.5	2.7	16	34.8	43.8
I will undergo genetic counselling as part of PMS	3	2.8	11.2	34.5	48.5
Awareness about PMS, important to the community	1	1.2	9	24.8	64
PMS does not interfere with a belief in destiny	3	3	15	40	39
PMS could lead to denial of marriage for couple	7.5	5	22	33.5	32

4.6 Factors associated with knowledge, perception, and attitude towards premarital sickle cell disease screening among pregnant women

Various factors influence knowledge, perception, and attitude toward premarital sickle cell disease screening among pregnant women. Understanding these factors will shed light on the multifaceted aspects of the healthcare practice within prenatal care settings.

4.6.1 Factors associated with knowledge about premarital screening for sickle cell disease

The multivariate regression analysis **revealed** that age, marital status, level of education, gestation age, occupation, gravidity, and parity were not independent factors for knowing about premarital screening for sickle cell disease (**Table 5**).

Table 5: Univariable and multivariable analysis of the factors associated with knowledge of PMS, N=400

		Univariable analysis			Multivariable analysis		
Variable	**Category**	**cOR**	**95% CI**	**p-value**	**aOR**	**95% CI**	**p-value**
Age group (years)	18 – 25	Ref					
	26 – 35	0.99	0.38 – 2.65	0.997			
	>35	1.69	0.59 – 4.84	0.332			
Marital status	Living together	0.72	0.33 – 1.60	0.423			
	Not living together	Ref					
Education	No formal	Ref					
	Primary	1.15	0.18 – 7.20	0.880			
	Secondary	1.71	0.36 – 8.25	0.502			
	College	1.59	0.34 – 7.39	0.552			
Gestational age	First trimester	Ref					
	Second trimester	0.38	0.09 – 1.66	0.196	0.35	0.08 – 1.55	0.166
	Third trimester	0.57	0.20 – 1.62	0.292	0.53	0.19 – 1.53	0.242
Occupation	Self-employed	1.10	0.36 – 3.35	0.863			
	Employed	1.25	0.41 – 3.80	0.694			
	House wife	0.35	0.04 – 3.08	0.344			
	Unemployed	Ref					
Gravity	1	Ref					
	2	0.64	0.22 – 1.82	0.404			
	>2	0.70	0.28 – 1.73	0.439			
Parity	0 – 2	Ref					
	2	0.32	0.07 – 1.40	0.130	0.31	0.07 – 1.37	0.122
	>2	1.20	0.48 – 3.00	0.701	1.24	0.49 – 3.13	0.645

Key: cOR: Crude Odds Ratio, aOR: adjusted Odds Ratio, Ref: Reference Category

4.6.2 Factors associated with attitude towards premarital screening for sickle cell disease

The multivariate regression analysis identified level of education as independent factor influencing attitude towards premarital screening for SCD **(Table 6)**. The finding of the study revealed pregnant women with college and secondary level were 3.0 and 2.3 times more likely to have a positive attitude toward PMS, (OR=3.0, 95% CI=1.46-6.19) and (OR=2.3, 95% CI=1.10-4.64) compared to those with lower level of education respectively.

Table 6: Univariable and multivariable analysis of the factors associated with attitude on PMS, N=400

		Univariable analysis			Multivariable analysis		
Variable	**Category**	**cOR**	**95% CI**	**p-value**	**aOR**	**95% CI**	**p-value**
Age group (years)	18 – 25	Ref					
	26 – 35	1.00	0.62 – 1.62	0.993	0.81	0.48 – 1.37	0.431
	>35	1.73	0.93 – 3.23	0.084	1.51	0.77 – 2.95	0.227
Marital status	Living together	1.09	0.71 – 1.66	0.699			
	Not living together	Ref					
Education	No formal	Ref					
	Primary	0.70	0.32 – 1.53	0.376	0.68	0.30 – 1.51	0.342
	Secondary	2.38	1.18 – 4.81	**0.016**	2.26	1.10 – 4.64	**0.027**
	College	3.54	1.78 – 7.05	**< 0.001**	3.00	1.46 – 6.19	**0.003**
Gestational age	First trimester	Ref					
	Second trimester	1.17	0.53 – 2.62	0.699			
	Third trimester	0.96	0.49 – 1.86	0.898			
Occupation	Self-employed	1.49	0.85 – 2.61	0.159	1.19	0.66 – 2.16	0.566
	Employed	3.11	1.68 – 5.76	**< 0.001**	1.91	0.97 – 3.74	0.060
	House wife	1.24	0.58 – 2.62	0.581	1.17	0.53 – 2.58	0.702
	Unemployed	Ref					
Gravity	1	Ref					
	2	1.02	0.59 – 1.76	0.957			
	>2	1.11	0.67 – 1.83	0.680			
Parity	0 – 2	Ref					
	2	1.03	0.61 – 1.75	0.904	0.95	0.53 – 1.67	0.845
	>2	1.74	0.98 – 3.11	0.060	1.58	0.85 – 2.95	0.151

Key: cOR: Crude Odds Ratio, aOR: adjusted Odds Ratio, Ref: Reference Category

4.6.3 Factors associated with perception towards premarital screening for sickle cell disease

The multivariate regression analysis revealed employment status is the only independent factor associated with positive perception toward premarital screening for sickle cell disease **(Table 7)**. Pregnant women who were employed were 2.4 times more likely to have a positive perception towards PMS for screening SCD (OR=2.4, 95% CI=1.21-4.86) compared to those who were self-employed, unemployed, and housewife as p-value of 0.013.

Table 7: Univariable and multivariable analysis of the factors associated with the perception of PMS, N=400

		Univariable analysis			Multivariable analysis		
Variable	**Category**	**cOR**	**95% CI**	**p-value**	**aOR**	**95% CI**	**p-value**
Age group (years)	18 – 25	Ref					
	26 – 35	1.16	0.70 – 1.90	0.566			
	>35	0.73	0.41 – 1.30	0.280			
Marital status	Living together	1.22	0.80 – 1.86	0.365			
	Not living together	Ref					
Education	No formal	Ref					
	Primary	0.77	0.35 – 1.70	0.519	0.77	0.34 – 1.73	0.523
	Secondary	1.34	0.66 – 2.74	0.419	1.15	0.55 – 2.40	0.716
	College	1.79	0.90 – 3.59	0.098	1.26	0.61 – 2.62	0.533
Gestational age	First trimester	Ref					
	Second trimester	1.42	0.64 – 3.12	0.387			
	Third trimester	1.26	0.66 – 2.40	0.490			
Occupation	Self-employed	0.80	0.45 – 1.41	0.432	0.74	0.42 – 1.33	0.315
	Employed	2.80	1.44 – 5.45	**0.002**	2.42	1.21 – 4.86	**0.013**
	House wife	0.56	0.26 – 1.18	0.128	0.55	0.26 – 1.17	0.120
	Unemployed	Ref					
Gravity	1	Ref					
	2	0.83	0.48 – 1.44	0.515			
	>2	1.15	0.69 – 1.92	0.581			
Parity	0 – 2	Ref					
	2	1.24	0.72 – 2.15	0.432			
	>2	1.38	0.79 – 2.41	0.257			

Key: cOR: Crude Odds Ratio, aOR: adjusted Odds Ratio, Ref: Reference Category

CHAPTER FIVE

5.0 DISCUSSION

This study underscores the vital role of premarital screening (PMS) in identifying carriers of sickle cell disease (SCD) and providing genetic counselling to at-risk couples. Many participants showed inadequate knowledge about PMS, highlighting the need for targeted educational interventions to enhance public health efforts. Despite this knowledge gap, a significant number of pregnant women had positive attitudes toward PMS, reflecting their willingness to prioritize preventive healthcare. Additionally, higher education levels were associated with more favourable attitudes towards screening. These findings emphasize the importance of empowering women through education to make informed reproductive health decision.

5.1 Discussion of the main findings

Premarital screening program plays a vital role in identifying carriers and offering genetic counselling and reproductive options to couples at risk of having children with SCD. The findings of this study revealed about 93.5% of participant's demonstrated inadequate knowledge regarding premarital screening for sickle cell disease (SCD). This finding is similar to a previous study that demonstrated about 75% of pregnant women had limited knowledge about PMS for SCD in Saudi Arabia (46). Inadequate knowledge can act as a significant barrier to public health initiatives aimed at preventing SCD transmission (15). The high proportion of individuals lacking adequate knowledge underscores the critical need for targeted educational interventions. These interventions could include workshops, educational materials, and community outreach programs.

Moreover, the finding of this study revealed a positive trend, whereby over two-third of pregnant women had a positive attitude towards premarital SCD screening. Furthermore, a positive attitude towards PMS may influence the use of SCD screening techniques before marriage. This is a proactive method that could enable couples to make informed decisions about their marital future by ensuring they are aware of their genetic compatibility and the possibility of SCD in their offspring. Likewise, a positive attitude signifies a willingness to engage with healthcare and prioritize PMS for screening for SCD to prevent genetic disease

(35). The similarity between these studies could be due to the reasons that pregnant women often receive information about genetic screening during prenatal visits, which contributes to their openness toward SCD screening.

This study found more than two-thirds of pregnant women held positive perceptions of premarital sickle cell disease (SCD) screening, with 68.8% of participants having positive perceptions toward PMS. Despite a lack of comprehensive understanding of Premarital Screening (PMS), pregnant women's willingness to undergo PMS was significantly influenced by the observed psychological and economic impacts of SCD within their communities. Many women were motivated by the desire to prevent the emotional distress and financial burdens associated with SCD, which they had witnessed in affected families. This awareness of the severe consequences of SCD, despite limited knowledge about PMS itself, underscored the importance they placed on preventive measures to ensure healthier future generations and to alleviate the socio-economic challenges linked to the disease. Their willingness to participate in PMS reflects a proactive approach to mitigating the impact of SCD on their families and society at large. Likewise, positive perceptions of screening among pregnant women can lead to increased awareness and utilization of prenatal screening programs in healthcare settings (39). Ultimately, positive perceptions signal a willingness to engage with healthcare and prioritize both maternal and child health.

5.2 Factors associated with knowledge, attitude, and perceptions towards PMS

The study revealed that age, marital status, level of education, gestation age, occupation, gravidity, and parity were not significant factors that influence the level of knowledge about PMS among pregnant women. The findings of this study concurred with the done by Tutuba et al. (2022) who reported there parity and gravidity were not significantly associated with knowledge about PMS for screening of SCD among pregnant women in Dar es Salam, Tanzania (15). The finding of the study was inconsistent with a study conducted in Nigeria (9) and Oman (20) which reported higher levels of education are the most significant factors for having adequate knowledge about PMS for SCD. This discrepancy suggests that other factors, such as cultural beliefs, awareness campaigns, or access to healthcare information, might play a more crucial role in influencing knowledge about PMS in our study population.

This found pregnant women with higher levels of education are more likely to have a positive attitude toward prenatal maternal screening (PMS) for screening SCD. Similar findings have been reported in Nigeria whereby educational qualification has a significant influence on health literacy and health-related behaviour toward SCD and premarital counselling (33). This could be because, having higher education levels is often associated with greater socioeconomic resources and access to healthcare services (47) (38), which may further enhance awareness and engagement with preventive health measures such as PMS

In this study, we found that who were employed pregnant women were more likely to have a positive perception toward PMS for screening SCD. The findings of this study were similar to other studies conducted in Nigeria (48) and the United States of America (41). The consistent positive perception across different cultural and geographical contexts suggests that women recognize the value of PMS in preventing hereditary diseases like SCD and ensuring healthier offspring. This shared understanding signifies women's roles as primary caregivers and their awareness of the implications of genetic diseases on family health and well-being (46). The alignment of our findings with those from diverse settings underscores the universal importance of educational and health interventions targeting women to promote the benefits of PMS. This could lead to more informed decision-making and greater acceptance of PMS as a preventive health measure.

5.3 Study limitation and mitigation.

Social desirability bias was identified as a potential limitation in the study, as self-administered questionnaires may lead respondents to provide answers they believe align with the researcher's expectations. To mitigate this bias and promote accurate responses, respondents received thorough explanations during data collection, emphasizing that there are no right or wrong answers.

CHAPTER SIX

6.0 CONCLUSION AND RECOMMENDATION

6.1 Conclusion

In conclusion, the majority had an inadequate knowledge about the genetic risks and benefits of PMS, however, considerable number demonstrated a positive attitude toward it. Specifically, 68.0% of participants had positive attitudes, and 68.75% had a positive perception of PMS. This study revealed employment status is associated with positive perception, however education is a single factor associated with having a positive attitude towards PMS among pregnant women.

6.2 Recommendation

The following could be recommended

i. **Educational Program Development**: Create targeted educational programs aimed at pregnant women to address knowledge gaps regarding premarital sickle cell disease (SCD) screening. These programs should clearly explain the importance and benefits of screening in language that is accessible and appropriate for the audience's literacy level.

ii. **Awareness Campaigns**: Utilize various channels, such as the internet, social media, and family networks, to promote awareness of premarital SCD screening beyond hospital settings. Collaborate with community leaders to ensure that information reaches a broader audience effectively.

iii. **Support for Multiparous Women**: Offer specialized support and counselling for women who have had multiple pregnancies, ensuring they understand the benefits of premarital SCD screening. Address their concerns and emphasize how screening can positively impact their health and that of their children.

iv. **Healthcare Provider Training**: Train healthcare providers in effective communication and counselling techniques specifically for discussing premarital SCD screening with pregnant women. Equip them with skills to sensitively address questions and concerns that may arise.

v. **Encouragement for Genetic Counselling**: Promote the importance of genetic counselling services for pregnant women and their partners to learn more about premarital SCD screening and its implications for their family's health. Highlight the value of personalized information and support in facilitating informed decision-making.

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APPENDECES

Appendix 1: Data collection tools (English version)

Title: Factors Influencing Pregnant Women's Knowledge, Attitude and Perception towards Premarital Sickle Cell Screening at Muhimbili National Hospital.

Date: _ ID no_

Section A: Demographic and general characteristics

i. Date of birth(date/month/year)_
ii. Gestational age (weeks)_
iii. Gravidity_
iv. Parity___
v. Abortions_____
vi. What is your highest level of education?
    1. No formal education []
    2. Primary education[]
    3. Secondary education []
    4. College level of education []
vii. Marital status
    1. Single [ ]
    2. Married
    3. Cohabiting(living with partner) []
    4. Divorced [ ]
    5. Separated [ ]
    6. Widowed [ ]
viii. Employment status
    1. Self-employed [ ]
    2. Employed [ ]
    3. Unemployed [ ]
    4. House wife [ ]

ix. Religion

1. Christian []
2. Muslim []
3. Others (specify)__.

x. Which region of Tanzania are you originating from? __?

xi. Which region of Tanzania does your current partner originate from? _?

xii. Do you know Premarital screening of any diseases??

1. Yes []
2. No []

If yes to above, which diseases do you think may undergo premarital screening

1.____
2.____
3.____
4.____
5.____
6.____

xiii. Have you ever done Premarital Screening for any disease?

1. Yes[]
2. No []

If Yes to the above, which disease(s) did you screen?_____

xiv. Do you have Sickle Cell disease (SCD)?

1. Yes[]
2. No []
3. Do not know []

xv. Are you aware of Sickle Cell disease(SCD)?

1. Yes []
2. No []
3. Do not know []

Section B: Knowledge on Premarital screening and Sickle Cell Disease among pregnant women.

PART ONE: Knowledge on Sickle Cell Disease among pregnant women (Circle the most correct response from the multiple choices)

i. How does a person get sickle cell disease?

1. Infection of the mother during pregnancy []
2. Infection of the child after birth []
3. Contact with the infection person []
4. Punishment for sin/wrong doing []
5. Inherited from parents []
6. I don't know []

ii. Do you have a relative with Sickle cell disease?

1. Yes []
2. No []
3. Do not know []

iii. Does your partner have a relative with SCD?

1. Yes []
2. No []
3. Do not know []

iv. What are complications of Sickle cell disease?

1. Stroke []
2. Lung tissue/kidney damage []
3. Pain episode []
4. All of the above – []
5. Anemia []
6. Do not know []
7. Early death []

v. Which body parts may be affected by SCD?

1. Heart []
2. Kidney []
3 Liver []
4 .Eyes []
5. Bone []
6. Do not know []

vi. Can two parents without Sickle Cell Disease give birth to a child with SCD.

1.Yes []
2. No []
3. Do not know []

vii. What are the percentages of two normal patients carrying genes for SCD giving birth to a child with Sickle Cell Disease?

1. 100%[]
2. 75% []
3. 50% []
4. 25% []
5. 0% []
6. Do not know []

viii. Is ther any treatment for Sickle Cell Disease?

1. Yes [ ]
2. No []
3. Do not know []

ix. Is there cure for Sickle Cell Disease?

1. Yes [ ]
2. No []
3. Do not know []

x. Which gender is more likely to get Sickle Cell Disease?

1. Male []
2. Equally likely in male and female []
3. Female []
4. Do not know []

xi. How is Sickle Cell Disease diagnosed?

1. Blood Test[ ]
2. Physical examination [ ]
3. X –ray examination [ ]
4. Eye examination [ ]
5. I don't know- []

xii. Can a person without SCD be a carier for sickle cell gene?

1. Yes []
2. No []
3. Do not know []

xiii. Can a carrier of Sickle Cell gene pass the gene to a child?

1. Yes []
2. No []
3. Do not know []

xiv. What is the source of your information about sickle cell disease?

1. Healthcare professionals []
2. Internet/Mass media []
3. Family []
4. Friends []
5. Other (specify)___
6. None. []

PART TWO: Knowledge on Premarital Screening for SCD among pregnant women. (Circle the most correct response from the multiple choices).

xv. What do you understand by Premarital Sickle Cell screening?

1. Test done after marriage to rule out any abnormality in the blood []
2. A test that reveals the level of malaria parasite in an individual []
3. Test done before marriage to rule out Sickle Cell disorder []
4. None of the above. []
5. I don't know. []

xvi. Have you ever done Premarital screening for SCD?

1. Yes []
2. No []
3. Do not know []

xvii. Have you ever heard of Premarital screening for SCD?

1. Yes []
2. No []
3. Do not know []

xviii. In your opinion,which disease should be screened for before marriage(can choose more than one choice)

1. Genetic disorders eg Sickle cell Disease []
2. Infectious diseases eg HIV []
3. Chronic illness []
4. Other (specify)___
5. I don't know. []

xix. When do you think should Premarital Sickle Cell screening be done?

1. Just before marriage or during courtship [ ]
2. After marriage [ ]
3. Immediately after delivery [ ]
4. When a couple find out they have a child with SCD []

xx. What is the benefit of Premarital Sickle Cell screening?

1. Helps to detect abnormalities in couples early before marriage. [ ]
2. It helps to prevent having a child with Sickle cell disease [ ]
3. It helps to expose the genetic status of an individual to the public before marriage [ ]
4. It has no benefits [ ]
5. Do not know [ ]

xxi. What are the major consequences of not adhering to Premarital Sickle Cell screening?

1. Giving birth to a child living with Sickle cell disease. [ ]
2. Separation / divorce from couples [ ]
3. Spend family economy for treatment [ ]
4. Spend a lot of time for treating a Sickle cell child [ ]
5. All of the above. [ ]
6. Do not know. [ ]

Section C: Attitude toward the Premarital Sickle cell disease screening among pregnant women.

Premarital screening for sickle cell disease informs couples about genetic compatibility, aiding in family planning decisions and potentially lowering the risk of passing the disease to their children. ***What is the level of agreement regarding attitude toward the Premarital Sickle cell disease screening among pregnant women.***

Variable -	5	4	3	2	1
i. Is it good for everyone to know their genotype(sickle cell carrier status) before marriage?					
ii. Is there awareness and education about Premarital sickle cell disease screening.					
iii. Is it important for two people in relationship to undergo genetic counselling and screening before marriage.					
iv. I believe that premarital sickle cell disease screening contributes to healthier family planning.					
v. I will go for PMS before marriage					
vi. PMS is not a wastage of time and money					
vii. PMS influence the couple to decide for the future.					
viii. PMS is necessary before agreement to marry.					

Key: 1=strongly disagree, 2=disagree, 3=no opinion, 4=agree, 5=strongly agree.

Section D: The Perception of Premarital sickle cell disease screening among pregnant women

Premarital screening for sickle cell disease informs couples about genetic compatibility, aiding in family planning decisions and potentially lowering the risk of passing the disease to their children, *What is the level of agreement regarding perception toward the Premarital Sickle cell disease screening among pregnant women.*

Variable: Kigezo	Response				
	5	4	3	2	1
i. Premarital sickle cell disease screening is an important step to reduce sickle cell disease burden in a country.					
ii. Premarital screening reduces psychological burden on family.					
iii. Premarital screening reduces economic burden on family.					
iv. Premarital screening will do good than harm for society.					
v. Do you believe that premarital sickle cell disease screening should be a standard practice for couples before marriage?					
vi. Are you willing to undergo genetic counselling as part of premarital sickle cell screening?					
vii. Do you think that raising awareness about premarital sickle cell disease screening is important for the community					
viii. Premarital screening does not interfere with a belief in destiny.					
ix. PMS could lead to denial of marriage for a couple.					

Key: 1=strongly disagree, 2=disagree, 3=unsure, 4=agree, 5=strongly agree.

.

Appendix 2: Data collection tools (Swahili version)

VISABABISHI VILIVYOSABABISHA WAJAWAZITO KUPATA ELIMU, UELEWA NA MTAZAMO DHIDI YA UCHUNGUZI WA SELI MUNDU KABLA YA KUOLEWA KATIKA HOSPITALI YA MUHIMBILI

TAREHE..... NAMBA YA UTAMBULISHO.....

Sehemu A: Idadiyawatunasifazaokwaujumla.

i. Umri wa mama (miaka)_____
ii. Umri wa ujauzito (wiki)_____
iii. Je,ulishawahi kushika mimba mara ngapi_____
iv. Je,ulishawahi kujifungua/kuzaa mara ngapi_____
v. _____Je, ulishawahi kuharibikiwa/ kutoa mimba mara ngapi?
vi. Kiwango chako cha juu cha elimu ni kipi?
   1. Elimu isiyo rasmi []
   2. Elimu ya msingi []
   3. Elimu ya sekondari []
   4. Elimu ya chuo. []
vii. Hali ya ndoa
   1. Sijaolewa [ ]3. Nimeolewa [ ]5.Ninaishi na mtu []
   2. Nimeachika [ ]4. Tumetengana [ ]6. Mjane [ ]
viii. Hali ya ajira
   1. Nimejiajiri mwenyewe [ ] 3. Nimeajiriwa [ ]
   2. Sina ajira [ ] 4. Mama wa nyumbani [ ]
ix. Dini
   1. Mkristo [] 3. Muislamu []
   2. Dini nyingine (itaje)_____ .

x. Umezaliwa mkoa gani hapa Tanzania_____?
xi. Mwenza wako ni mzaliwa wa wapi_____?

xii. Unafahamu uchunguzi wowote wa magonjwa kabla ya ndoa?
   1. Ndiyo []
   2. Hapana []

Kama ndiyo ugonjwa gani ambao unafikiri unahitaj iufanyiwe uchunguzi kabla ya ndoa?
1._____
2._____
3._____
4._____
5._____
6._____

xiii. Umeshawahi kufanya uchunguzi wa ungonjwa wowote kabla ya ndoa?
1. Ndiyo []



2. Hapana []
Kama jibu lako ni ndio, ugonjwa gani ambao ulishawahi kuchunguza?

xiv. Una ugonjwa wa selimundu?
1. Ndiyo [] 2. Hapana [] 3. Sijui []

xv. Unafahamu chochote kuhusu ugonjwa wa SeliMundu(Sickle Cell)?
1.Ndiyo[] 2.Hapana[]

Sehemu B: Elimu kuhusu uchunguzi kabla ya ndoa na ugonjwa wa SeliMundu kwa wajawazito

Kipengele cha kwanza: *Elimu kuhusu ugonjwa wa SeliMundu miongoni mwa wajawazito (zungushia duara jibu sahihi Zaidi katika orodha ya majibu ya kuchagua)*

i. Ni kwa namna gani mtu hupata ugonjwa wa SeliMundu?
1. Huambukizwa na mama wakati wa ujauzito []
2. Huambukizwa baadaya kuzaliwa []
3. Kuguswa na mtu mwenye ugojwa huo []
4. Adhabu ya zambi tunazozifanya []
5. Kurithi kutoka kwa wazazi wetu []
6. Sijui []

ii. Una ndugu yeyote ambaye anaugojwa huu wa SeliMundu?
1. Ndiyo [] 2. Hapana[] 3. Sijui []

iii. Mwenza wako ana ndugu ambaye ana ungojwa wa SeliMundu?
1. Ndiyo[] 2.Hapana [] 3. Sijui []

iv. Ugojwa huu wa SeliMundu una matatizo gani?
1. Kiharusi []
2. Matatizo ya mapafu /kuharibika kwa figo []
3. Maumivu ya muda []
4. Upungufu wa damu []
5. Sijui []
6. Vifo vya mapema []
7. Yote ni majibu []

v. Viungo gani vya mwili ambavyo vinaweza kuathirika na ugonjwa wa SeliMundu
1.Moyo []
2.Mapafu []
3.Ini []
4.Macho []
5.Mifupa []
6.Sijui []



vi. Je, kuna uwezekano wa wazazi wawili waslokuwa na ugonjwa wa selimundu kuzaa mtoto mwenye ugonjwa huu?
1.Ndiyo [] 2. Hapana [] 3.Sijui []

vii. Asilimia ngapi ya wagonjwa wa kawaida wenye vinasaba vya selimundu huzaa watoto wenye ugonjwa huu?

1.100% [] 2. 75% [] 3. 50% []
4. 25% [] 5. 0% [] 6. Sijui []

viii. Je, kunatiba yoyote ya ugonjwa huu wa SeliMundu?
1.Ndiyo [ ] 2. Hapana [] 3. Sijui []

ix. Je, kuna kinga ya ugonjwa wa SeliMundu?
1.Ndiyo [ ] 2. Hapana [] 3. Sijui []

x. Jinsi ipi yenye uwezekano mkubwa wa kupata ugonjwa wa SeliMundu?
1.Wanaume []
1. 3. Hutokea sawa kwa wanawake nawanaume []
2. 2.Wanawake []
3. 4. Sijui []

xi. Je,ni kwa namna gani ugonjwa wa SeliMundu hupimwa?
1. Kipimo cha damu [ ]
2. Kwa kumwangalia mtu [ ]
3. Kwa njia ya mionzi[ ]
4. Kwa njia ya macho
5. Sijui []

xii. Je, kuna uwezekano wa mtu asiye na ugonjwa wa selimundu kueneza vinasaba vya ugonjwa huu?
1. Ndiyo [ ] 2. Hapana [] 3. Sijui []

xiii. Je, mtu mwenyevinasaba vya selimundu anaweza akavisambaza kwa mtoto?
1. Ndiyo [ ] 2. Hapana [] 3. Sijui []

xiv. Je, taarifa za ugonjwa wa selimundu umezipata katika chanzo kipi?
1. Wataalamu wa afya []
2. Mtandao/vyombo vya habari []
3. Kupitia familia []
4. Kupitia marafiki []
5. Chanzo kingine (fafanua) []
6. Hakuna []



Kipengele cha Pili: Elimu kuhusu uchunguzi wa ugonjwa wa selimundu kwa wajawazito (zungushia duara jibu sahihi katika orodha ya kuchagua)

xv. Unaelewa nini kuhusu uchunguzi wa ugonjwa wa selimundu kabla ya ndoa?
1. Kipimo hufanyika baadaya ndoa ili kuondoa tatizololote katika damu
2. Kipimo kinachoonesha wa dudu wa malaria kwa binadamu.
3. Kipimo hufanyika kabla ya ndoa kuondoa ugonjwa wa selimundu
4. Hakuna jibu sahihi
5. Sijui

xvi. Je, umehawahi kufanya uchunguzi wa ugonjwa wa Selimundu kabla ya ndoa?
1. Ndiyo [ ] 2. Hapana [] 3. Sijui []

xvii. Je, umeshawahi kusikia uchunguzi wa ugonjwa wa selimundu kabla ya ndoa?
1. Ndiyo [ ] 2. Hapana [] 3. Sijui []

xviii. Yapi ni maoni yako kuhusu ugonjwa gani unaopaswa kuchunguzwa kabla ya ndoa (unaweza kuchagua jibu Zaidi ya moja)
1. Matatizo ya kinasaba mfano ugonjwa wa selimundu []
2. Magonjwa ambukizi mfano ugojwa wa ukimwi []
3. Magonjwa sugu []
4. Magonjwa mengine-fafanua []
5. Sijui []

xix. Je, unadhani ni wakati gani uchunguzi wa selimundu kabla ya ndoa ufanyike?
1. Kabla ya ndoa/ kipindi cha uchumba
2. Baada ya ndoa
3. Punde tu baada yakujifungua
4. Baada ya wenza kugundua kuwa mtoto wao anaugonjwa wa selimundu

xx. Kuna umuhimu gani wa kufanya uchunguzi wa ugonjwa wa selimundu kabla ya ndoa?
1. Husadia kugundua matatizo yote kwa wenza kabla ya ndoa
2. Husaidia kuzuia kuwa na mtoto mwenye ugonjwa wa selimundu
3. Husaidia kuonesha hali ya vinasaba vya kila mmoja kwa umma kabla ya ndoa.
4. Haina umuhimu wowote
5. Sijui

xxi. Ni madhara gani makubwa yakutofanya uchunguzi wa ugonjwa wa selimundu kabla ya ndoa?
1. Kuzaa mtoto mwenye ugonjwa wa selimundu []
2. Kutengana/ kuachana kwa wanandoa []
3. Kutumia uchumi wa familia kwa matibabu []
4. Kutumia muda mwingi kumtibu mtoto mwenye ugonjwa wa selimundu []
5. Yote ni majibu[]
6. Sijui []



SehemuC: Uchunguzi kabla ya ndoa kwa ugonjwa wa seli hujulisha wanandoa kuhusu uwiano wa jeni, ukiwasaidia katika maamuzi ya kupanga uzazi na kwa uwezekano wa kupunguza hatari ya kuambukiza ugonjwa kwa watoto wao.

Je unamtazamo juu ya uchunguzi wa ugonjwa wa selimundu kabla ya ndoa kwa Wajawazito

Kigezo	5	4	3	2	1
1. Je, ni vizuri kwa kila mmoja kujua kinasaba chake kabla ya ndoa?					
2. Kuna utambuzi na elimu yoyote juu ya uchunguzi wa ugonjwa wa selimundu?					
3. Je, kuna umuhimu wowote wa watu wenye uhusiano wa kimapenzi kupata ushauri wa vinasaba kabla yandoa?					
4. Ninaamini kuwa uchunguzi waugonjwa wa selimundu kabla ya ndoa unachangia katika mpango mzuri wa uzazi wa mpango.					
5. Nitafanya uchunguzi wa Selimundu kabla ya ndoa.					
6. Uchunguzi wa selimundu haupotezi muda wala pesa.					
7. Uchunguzi wa Seli Mundu huwasaidia wenza kuamua maisha yao ya baadae.					
8. Uchunguzi wa selimundu ni muhimuk ufanyika kabla ya makubaliano ya ndoa.					

Maelekezo: 1=Sikubalikabisa, 2=Sikubali, 3= Sinamaoni, 4=Ninakubali, 5=Ninakubalikabisa

Sehemu D: Uchunguzi kabla ya ndoa kwa ugonjwa wa seli hujulisha wanandoa kuhusu uwiano wa jeni, ukiwasaidia katika kufanya uamuzi wa kupanga uzazi na kwauwezekano wa kupunguza hatari ya kuambukiza ugonjwa kwa watoto wao.

Je, unaweza kubainisha upi ni Utambuzi wa uchunguzi wa ugonjwa wa selimundu kabla ya ndoa kwa wajawazito?

Kigezo	Majibu				
	5	4	3	2	1
1. Uchunguzi wa ugonjwa wa selimundu kabla ya ndoa ni hatua muhimu ya kupunguza mzigo katika nchi.					
2. Uchunguzi wa ugonjwa wa selimundu kabla ya ndoa hupunguza matatizo ya kisaikolojia katika familia.					
3. Uchunguzi wa ugonjwa wa selimundu kabla ya ndoa hupunguza matatizo ya kiuchumi katika familia.					
4. Uchunguzi wa ugonjwa wa selimundu kabla ya ndoa hauna madhara yoyote katika jamii.					
5. Je, unaamini kuwa uchunguzi wa ugonjwa wa selimundu kabla ya ndoa kwawenza unatakiwa kuwa ni zoezi la kawaida?					
6. Je, uko tayari kupata ushauri wavinasaba kama sehemu ya uchunguzi wa ugonjwa wa selimundu kabla ya ndoa?					

TAASISI YA LUGHA IMETHIBITISHWA NA BARAZA LA KISWAHILI LA TAIFA
CHETI NA. —
TAREHE 8.12.2023

wa ugonjwa wa selimundu kabla ya ndoa?					
7. Je, unafikiri ni muhimu kuongeza ufahamu kwa jamii kuhusu uchunguzi wa ugonjwa wa selimundu kabla ya ndoa?					
8. Uchunguzi wa selimundu hauhusiani na Imani kuhusu hatma.					
9. Uchunguzi wa selimundu unaweza kusababisha wenza kukataa kuoana.					

Maelekezo: 1=Sikubalikabisa, 2=Sikubali, 3= Sinauhakika, 4=Ninakubali, 5=Ninakubalikabisa

Appendix 3: Consent form (English version)

MUHIMBILI UNIVERSITY OF HEALTH AND ALLIED HEALTH SCIENCES

DIRECTORATE OF RESEARCH AND PUBLICATIONS

ID No. | | | | |

Hello…!, My name is, **Dr Asma Zain Ali,** a postgraduate student from MUHAS, conducting a study on knowledge, attitude, and perception of women towards premarital screening for sickle cell disease.

Purpose of study: To assess the level of knowledge, attitude, and perception of women towards premarital screening for sickle cell disease at Muhimbili National Hospital.

What participation involves: Your participation in the study will be your own choice and you are free to decide without any adverse reactions. You will be required to answer questions knowledge, attitude, and perception of women towards premarital screening for sickle cell disease which will consume not more than 20 minutes to fill out the questionnaire.

Confidentiality: All information collected will be confidential and this will be maintained by use of codes, no names will be asked or required. Information collected from the questionnaire will be entered into computers with only the study identification number and if the results of the current study will be published or presented in a scientific meeting, names and other information that might identify you will not be used.

Benefits: There will be no direct benefit for your participation; however, the study findings will create awareness about the premarital screening for sickle cell diseaseamong women with childbearing age to reduce the burden of Sickle cell diseases.

Compensation: There will be no compensation of any kind for participation.

Risk: The study will not harm you physically, psychologically, or emotionally.

Rights to withdraw and Alternatives: Participation in this study is voluntary and you have the right to refuse to participate and at any time you may withdraw from the study even if you have already given your consent. Refusal to participate or withdraw from the study will not involve penalty or loss of any benefits to which you are otherwise entitled.

Who to Contact: If you ever have questions about this study, you should contact the principal investigator, Dr Asma Zain Ali, Phone number 0712786005, P.O. Box 6000, Dar es Salaam. If you ever have questions about your rights as a participant, you may contact or call the Director of Research Innovation and Publication (DRPI), Dr. Nahya Salim, P.O. Box 65001, Telelephone: 2150302-6, Dar es Salaam-Tanzania.

Signature:

Do you agree to participate?

Participant agrees …… Participant does NOT agree ……..

I, _____ have read the contents in this form. My questions have been answered. I agree to participate in this study.

Signature of participant _____

Signature of the researcher _____Date_____

Appendix 4: Consent form (Swahili version)

CHUO KIKUU CHA AFYA MUHIMBILI NA SAYANSI VINGINE VYA AFYA

KURUGENZI YA UTAFITI NA MACHAPISHO

ID No.

Habari...! Jina langu ni, **Dk Asma Zain Ali, mwanafunzi wa shahada** ya uzamili kutoka MUHAS, akifanya utafiti kuhusu maarifa, mtazamo, na mtazamo wa wanawake kuelekea uchunguzi wa jeni kabla ya ndoa kwa anemia ya seli mundu .

Madhumuni ya Utafiti: Kutathmini kiwango cha maarifa, mtazamo, na mtazamo wa wanawake kuhusu uchunguzi wa jeni kabla ya ndoa kwa anemia ya seli mundu katika Hospitali ya Taifa ya Muhimbili .

Ushiriki unahusisha nini: Kushiriki kwako katika utafiti kutakuwa chaguo lako mwenyewe na uko huru kuamua bila athari zozote mbaya. Utahitajika kujibu maswali maarifa, mtazamo, na mtazamo wa wanawake kuhusu uchunguzi wa jenotipu kabla ya ndoa kwa anemia ya seli mundu ambayo itatumia si zaidi ya dakika 20 kujaza dodoso.

Usiri: Taarifa zote zitakazokusanywa zitakuwa siri na hii itatunzwa kwa kutumia misimbo, hakuna majina yatakayoulizwa au kuhitajika. Taarifa zitakazokusanywa kutoka kwenye dodoso zitaingizwa kwenye kompyuta na nambari ya utambulisho wa utafiti pekee na ikiwa matokeo ya utafiti wa sasa yatachapishwa au kuwasilishwa katika mkutano wa kisayansi, majina na taarifa nyingine ambazo zinaweza kukutambulisha hazitatumika.

Manufaa: Hakutakuwa na manufaa ya moja kwa moja kwa ushiriki wako; hata hivyo, matokeo ya utafiti yatajenga ufahamu kuhusu uchunguzi wa jeni kabla ya ndoa miongoni mwa wanawake walio na umri wa kuzaa ili kupunguza mzigo wa magonjwa ya Sickle cell.

Fidia: Hakutakuwa na fidia ya aina yoyote kwa ushiriki.

Hatari: Utafiti hautakudhuru kimwili, kisaikolojia, au kihisia.

Haki za kujiondoa na Njia Mbadala: Kushiriki katika utafiti huu ni kwa hiari na una haki ya kukataa kushiriki na wakati wowote unaweza kujiondoa kwenye utafiti hata kama tayari umetoa kibali chako. Kukataa kushiriki au kujiondoa kwenye utafiti hakutahusisha adhabu au hasara ya manufaa yoyote ambayo unastahiki kuyapata.

Nani wa Kuwasiliana naye: Iwapo utakuwa na maswali kuhusu utafiti huu, unapaswa na Dk Asma Zain Ali , Nambari ya simu 0712786005, PO . Box 6000, Dar es Salaam. Ukiwa na maswali kuhusu haki zako kama mshiriki, unaweza kuwasiliana au kumpigia kwa Dk. Nahya Masoud, Mkurugenzi Utafiti, Machapisho na Ubunifu, MUHAS. P.O.BOX 65001 Dar es Salaam. Simu 0221503026

Sahihi:

Je, unakubali kushiriki?

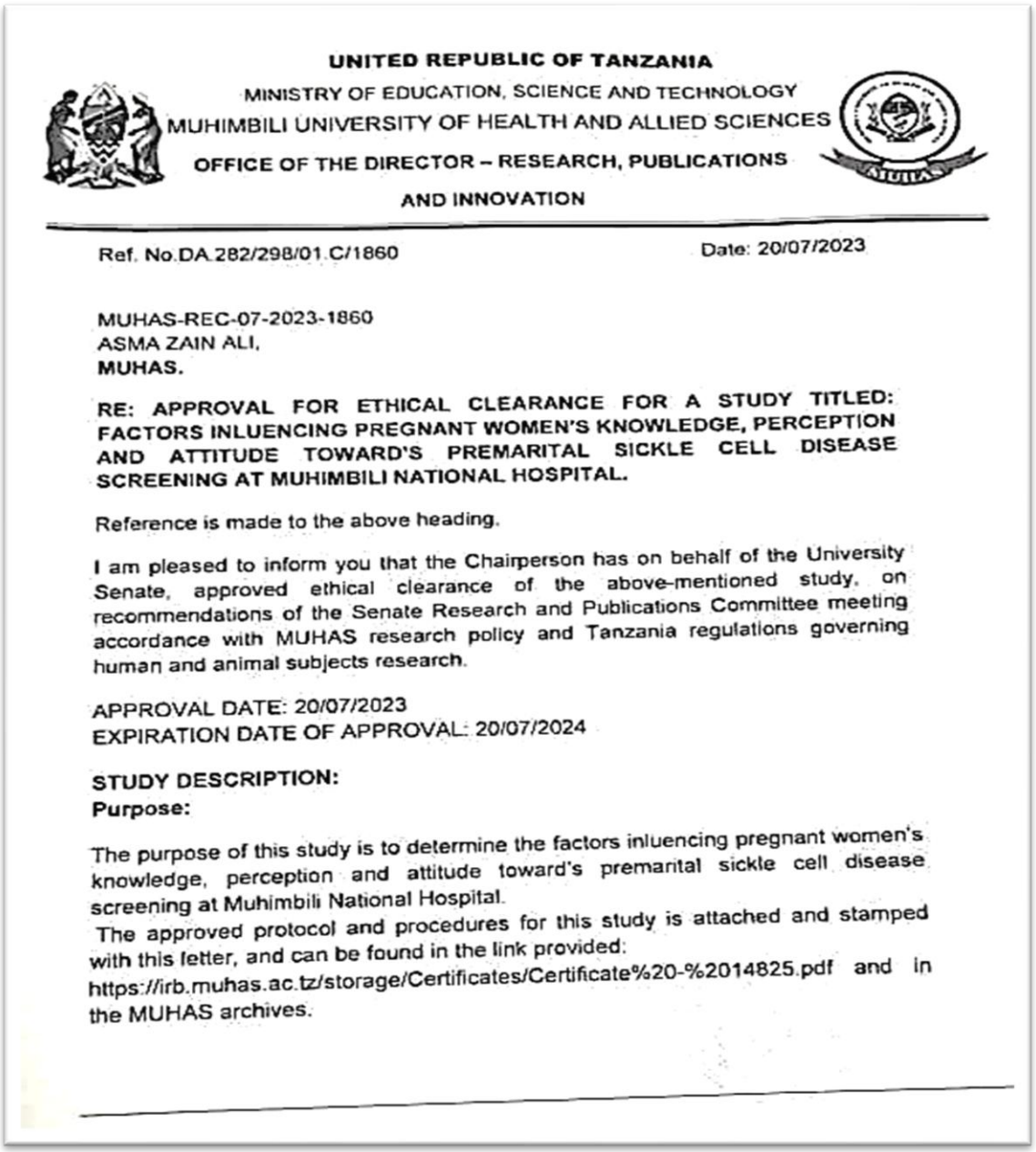
Mshiriki anakubali …… Mshiriki HAKUBALI ……..

Mimi, _____ nimesoma yaliyomo katika fomu hii. Maswali yangu yamejibiwa. Ninakubali kushiriki katika utafiti huu.

Sahihi ya mshiriki _____

Sahihi ya mtafiti _____Tarehe_____

Appendix 5: Ethical clearances letter



UNITED REPUBLIC OF TANZANIA
MINISTRY OF EDUCATION, SCIENCE AND TECHNOLOGY
MUHIMBILI UNIVERSITY OF HEALTH AND ALLIED SCIENCES
OFFICE OF THE DIRECTOR – RESEARCH, PUBLICATIONS AND INNOVATION

Ref. No.DA.282/298/01.C/1860 Date: 20/07/2023

MUHAS-REC-07-2023-1860
ASMA ZAIN ALI,
MUHAS.

RE: APPROVAL FOR ETHICAL CLEARANCE FOR A STUDY TITLED: FACTORS INLUENCING PREGNANT WOMEN'S KNOWLEDGE, PERCEPTION AND ATTITUDE TOWARD'S PREMARITAL SICKLE CELL DISEASE SCREENING AT MUHIMBILI NATIONAL HOSPITAL.

Reference is made to the above heading.

I am pleased to inform you that the Chairperson has on behalf of the University Senate, approved ethical clearance of the above-mentioned study, on recommendations of the Senate Research and Publications Committee meeting accordance with MUHAS research policy and Tanzania regulations governing human and animal subjects research.

APPROVAL DATE: 20/07/2023
EXPIRATION DATE OF APPROVAL: 20/07/2024

STUDY DESCRIPTION:
Purpose:

The purpose of this study is to determine the factors inluencing pregnant women's knowledge, perception and attitude toward's premarital sickle cell disease screening at Muhimbili National Hospital.
The approved protocol and procedures for this study is attached and stamped with this letter, and can be found in the link provided:
https://irb.muhas.ac.tz/storage/Certificates/Certificate%20-%2014825.pdf and in the MUHAS archives.

The PI is required to:

1. Submit bi-annual progress reports and final report upon completion of the study.
2. Report to the IRB any unanticipated problem involving risks to subjects or others including adverse events where applicable.
3. Apply for renewal of approval of ethical clearance one (1) month prior its expiration if the study is not completed at the end of this ethical approval. You may not continue with any research activity beyond the expiration date without the approval of the IRB. Failure to receive approval for continuation before the expiration date will result in automatic termination of the approval for this study on the expiration date.
4. Obtain IRB amendment (s) approval for any changes to any aspect of this study before they can be implemented.
5. Data security is ultimately the responsibility of the investigator.
6. Apply for and obtain data transfer agreement (DTA) from NIMR if data will be transferred to a foreign country.
7. Apply for and obtain material transfer agreement (MTA) from NIMR, if research materials (samples) will be shipped to a foreign country.
8. Any researcher, who contravenes or fail to comply with these conditions, shall be guilty of an offence and shall be liable on conviction to a fine as per NIMR Act No. 23 of 1979, PART III section 10 (2)
9. The PI is required to ensure that the findings of the study are disseminated to relevant stake holders.
10. PI is required to be versed with necessary laws and regulatory policies that govern research in Tanzania. Some guidance is available on our website https://drp.muhas.ac.tz

Muhimbili University of Health and Allied Sciences
DIRECTOR
Research, Publications & Innovations
Box 65001, Dar es Salaam

Dr. Nahya Salim Mussa

Chairperson, MUHAS Research and Ethics Committee

Appendix 6: Introduction letter to MNH

UNITED REPUBLIC OF TANZANIA
MINISTRY OF EDUCATION, SCIENCE AND TECHNOLOGY
MUHIMBILI UNIVERSITY OF HEALTH AND ALLIED SCIENCES
OFFICE OF THE DIRECTOR – POSTGRADUATE STUDIES

In reply quote;
Ref. No. HD/MUH/K.115/2021

05th October, 2023

MUHIMBILI NATIONAL HOSPITAL
RECEIVED
13 OCT 2023
REGISTRY
File No:

The Executive Director,
Muhimbili National Hospital,
P.O. Box 65000,
DAR ES SALAAM

Re: INTRODUCTION LETTER

We would like to inform you that the bearer of this letter is Asma Zain Ali with Reg. No. HD/MUH/K.115/2021 is a student at Muhimbili University of Health and Allied Sciences (MUHAS) "pursuing MMed. Obstetrics/Gynaecology.

As part of her studies, she will be doing an elective research titled: **"Factors Influencing Pregnant Women's Knowledge, Perception and Attitude Toward's Premarital Sickle Cell Disease Screening at Muhimbili National Hospital."** she is being supervised by Dr. Abraham Brian from MNH and Dr. Furaha August from MUHAS.

The research has been approved by the Chairman of University Senate.

Kindly provide her the necessary assistance to facilitate the conduct of her research.

We thank you for your cooperation.

Victoria Mwanilwa
For: DIRECTOR, POSTGRADUATE STUDIES

c.c Asma Zain Ali

9 Ur ations Road; Upanga West; P.O. Box 65001, Dar Es Salaam: Tel. G/Line: +255-22-2150302/6; Ext. 1015;
Direc +255-22-2151378;Telefax:+255-22-2150465;E-mail:dpgs@muhas.ac.tz;Web:https://www.muhas.ac.tz

Appendix 7: Permission letter to data collection.

12/10/2023
Please Incharge
PCH Asst
Dr Asma
to Collect
data at your
Place
Thankable
PCH MNH II

THE UNITED REPUBLIC OF TANZANIA

MINISTRY OF HEALTH

MUHIMBILI NATIONAL HOSPITAL

In reply please quote;

Ref No MNH/CRTCU/Perm/2023/524 Date 16th October, 2023

Head Department,
Obstetrics and Gynaecology
Muhimbili National Hospital

Report to Unit I
Aff. Dr. Helen Mtina
N. Mthiangi
23.10.2023

RE: PERMISSION TO COLLECT DATA AT MNH.

Akunkaweo
ANC PCMBI

Name of Student	**Asma Zain Ali**
Title	**"Factors Influencing Pregnant Women's Knowledge, Perception and Attitude Towards Premarital Sickle Cell Disease Screening at MNH"**
Institution	Muhimbili University of Health and Allied Sciences
Supervisor	Dr. Furaha August (MUHAS)
Co - Supervisor	Dr. Abraham Brian (MNH)
Period	16th October, 2023 to 15th January, 2024

Approval has been granted to the above mentioned student to collect data at MNH. **A final study report should be lodged with Clinical Research, Training and Consultancy Unit.** Dissemination of study findings to MNH stakeholders shall be overseen by Dr. Abraham Brian (MNH) Co – supervisor.

Kindly ensure that the student abide to the ethical principles and other conditions of the research approval.

Yours Sincerely,

HEAD, TEACHING, RESEARCH & CONSULTANCY UNIT
P. O. Box 65000
DAR ES SALAAM
MUHIMBILI NATIONAL HOSPITAL

Dr. Jessie Mbwambo
Head of Clinical Research, Training and Consultancy Unit

c.c DSS
c.c Dr. Abraham Brian
c.c **Asma Zain Ali**

Upanga West, Kalenga Street, Plot No. 10480/3, P.O. BOX 65000, Dar es Salaam, Tanzania
Telephone +255-22-2151367-9, Telephone +255-22-2151351-2
Email info@mnh.or.tz, Website www.mnh.or.tz

Appendix 8: Turnitin receipt

turnitin

Digital Receipt

This receipt acknowledges that Turnitin received your paper. Below you will find the receipt information regarding your submission.

The first page of your submissions is displayed below.

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Assignment title:	RESEARCH PROPOSAL
Submission title:	DISSERTATION_Asma
File name:	complete_DISSERTATION_DR.ASMA_ZAIN.docx
File size:	5.07M
Page count:	79
Word count:	14,542
Character count:	80,797
Submission date:	24-Jun-2024 11:46PM (UTC+0300)
Submission ID:	2408057986



FACTORS INFLUENCING KNOWLEDGE, PERCEPTION AND ATTITUDE TOWARDS PREMARITAL SICKLE CELL DISEASE SCREENING AMONG PREGNANT WOMEN ATTENDING ANTENATAL CLINIC AT MUHIMBILI NATIONAL HOSPITAL

Dr Asma Zain Ali (MBBS)

MMed (Obstetrics and Gynaecology) dissertation
Muhimbili University of Health and Allied Sciences
June 2024

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Appendix 9: Plagiarism Report

DISSERTATION_Asma

ORIGINALITY REPORT

26%	22%	16%	11%
SIMILARITY INDEX	INTERNET SOURCES	PUBLICATIONS	STUDENT PAPERS

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4	Solomon Kyakuha, Mbabazi G. Scovia, Nathan Mugenyi, Andrew Twineamatsiko. "Factors associated with utilization of preconception Sickle cell screening among women receiving antenatal care at Hoima regional referral hospital, Uganda.", Cold Spring Harbor Laboratory, 2024 Publication	1%
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